Implementation of the right of disabled people to independent living

Written Evidence

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Should the right to Independent Living continue to form the basis for Government Policy on Disability in the UK?

I believe that the right to independent living for disabled people should continue as the basis for Government Policy on Disability, however, it seems that this is under attack with changes to the Independent Living Fund, changes to the Disability Living Allowance and the cutbacks in funding to the NHS and local authorities. If a disabled person is to live independently they require both physical and financial support to do so. The Government Policy at the moment seems to forget that disabled people do not want to live in residential settings in the middle of nowhere. At the moment I think this indicates that the Government does not have a coherent policy regarding this matter. The fact that the Independent Living Fund is only assured until 2015 for existing clients only, this means that the fund which has made a huge difference to disabled people no longer has the ability to support new clients. This is a major attack on the right of disabled people to live independently. The changes in disability benefits will potentially make independent living harder for disabled people.

It seems that the Government is wholly focussed on the financial aspects of disability. It does not seem to view the issue in holistic terms. In order that disabled people have the same level of choice, control and freedom in their daily lives they require good access to services whether that service is their corner shop or someone aiding them to access services regarding their personal care, housing, work, educational opportunities or social activities. It seems that it is fairly easy for the Government to investigate disability benefits and services while it seems to drag its feet on tax evasion and avoidance.

The restrictions on local authority budgets will greatly affect independent living for disabled people as the eligibility criteria have been tightened in many local authorities so that people who have minor or moderate disabilities may not get any service from their local authority. This is not because local authorities do not want to help such people but they cannot afford to do so. In many ways, giving small amounts of help to such people may prevent the worsening of their disability.

I believe that disabled people’s right to independent living needs to be protected from various political ideologies and practices and would welcome that being enshrined in law. I would welcome the Government adopting Article 19 of the UN Disability Rights Convention. I do not believe that the Big Society will benefit disabled people, the Government does not understand that volunteers give their time voluntarily and can withdraw their help at a moment’s notice. Volunteering unlike paid work does not bring any obligation to engage in the care of vulnerable people, such people need to know that the person who is scheduled to give them assistance will come to do so at the agreed time.

It would be wonderful if one could take one’s care package and funding from one area to the other. It may seem that this is possible on paper but it does not seem to work in practice. I know of several disabled people who have tried to move to another area of the country only to find that they would not be allowed to take their existing care package and funding with them.
It seems that too many disabled people are not being involved in policy development and decision making whether this is due to them not being asked or not being interested in doing so is very hard to say. However, I do think that the media could have a role in notifying the public when policy development and decision making are about to take place. The Government could use the Census to have individuals indicate whether they would like to be involved in any consultation. In Newcastle upon Tyne the Local Authority has a citizens panel that it contacts from time to time to ask questions about local authority policy. Individuals can elect to take part in the consultations mostly this is to do with local authority future spending plans and services. The Government could use a similar method after all they do know who they pay disability benefits to. Monitoring could be done in a similar way.

2 March 2011
St Bridget’s is a LCD residential home for people who have severe and complex physical difficulties and are all in need of a high level of personal care. The majority are in their 30s to 40s.

The range of disabilities include those caused by cerebral palsy, genetic syndromes and Spina bifida from birth; degenerative illness e.g. MS; Stroke and brain damage from accidents.

As a group we have campaigned to get the government to understand our needs and aspirations through our M.P. and the home was visited in January by Maria Miller, Minister for the Disabled.

We have compiled this document so that as many people as possible who live in St Bridget’s home could express their opinions on how the proposed cut in the DLA mobility allowance would affect their everyday lives. Without exception the general feeling was one of fear and dread of the consequences of this cut.

We sincerely hope that the coalition government will come to appreciate the effect that the proposed change in mobility allowance will have on the freedom of people who live, not by choice but necessity, in residential homes.

As a result of their various disabilities the residents of these homes have already forfeited the pleasures of a “normal” family life and the basic right of access to their immediate neighbourhood and to the outside world. To deny them this access is surely a curtailment of their human rights in what we all hope should be a free, open and fair society.

March 2011
I am a 47 year old disabled woman with Spina Bifida, living in a bungalow attached to a care home run by Leonard Cheshire Disability and live fairly independently doing the necessary every day things shopping once a week going to meetings to represent my other service in the home I’ve been with the organisation 31 years Have been in my current home for 15 years. I was in another one for 17yrs also run by the same organisation. At the moment like many others as well as myself we not happy with the DLA decision to get rid of the component part of the benefit this is truly distressful getting rid of this would stop and take away the independence of thousand of disabled people and if this benefit is removed from people like myself.

Many people also put it towards buying things like powered wheelchairs I have just bought one myself after a lot of hard saving at a cost of many pounds witch many disabled people do these days and the hardest part is the saving and maintained and repairs if the chair goes wrong I would be very happy to give my evidence oral and to attend the hearing.

18 February 2011
I understand a clear right to independent living cannot be achieved currently because the main responses are institutionalised.

We are continuing to use and build "total institutions" and have policy proposals like the removal of DLA mobility from disabled people in residential care and nursing "homes" that are embedding institutionalisation.

I am a member of a working group of the ONS and ODI that has successfully launched the longitudinal study into the lives of disabled people and wish to see their work significantly developed to look at the lives of disabled people in care homes, hostels, nursing homes, prisons, hospitals and similar institutions.

I understand the real costs of institutions in creating and enforcing dependency has not been properly recognised, and as part of this, their huge economic cost is not properly recognised.

I propose a Kafka scale, like Richter and Beaufort, to measure how institutionalised someone's life is. Social network analysis does this to some extent.

My experience is that the default position of professionals is very often when faced with complexity is to prescribe a home and often to undermine other solutions.

The terms person centred are used but are they meant?

Mariella Frostrup The Young Ones showed alternatives.

I formally recommend the closing down of all long stay institutions.

The following expands my thinking.


2 March 2011
As a disabled person I face many challenges, in particular I have huge problems with Transport, there are no wheelchair accessible taxis where I live. I need to use a Taxi that can take my powered wheelchair, these taxis are more expensive to run and therefore no incentive exists for companies to have these. I would like the government to look at incentives for taxi and coach companies to run a wheelchair accessible service.

I have a grant from the ILF that enables me to pay for a personal assistant to take me to Schools and Libraries in the area to provide educational talks, thus enabling me to provide a meaningful service to society by employing my skills as a teacher. In my wheelchair I am unable to carry teaching aids to my talks thus help from my PA is also vital to my independence. Because of the nature of my disability I need a personal assistant to enable me to set up exhibitions of my photography and also learning displays. The grant also enables me to travel to a specialist physiotherapy centre every week for vital treatment of my condition. I am very concerned about the future, as the ILF which is vital to me is being wound down by the government, the loss of this help will be catastrophic for me.

I understand the need to save money but I do feel I have the right to expect society to help me to live a valuable and independent life. I do contribute to society in running a physiotherapy service for MS sufferers, backed by my local MS Society, this service cannot run without the support I get from several volunteers’ who provide magnificent support. I rent premises from my local authority paid for by my local charity and hope I can continue to make a valuable contribution to society. Official recognition for my tremendously valuable volunteers would be most welcome; perhaps some sort of award for volunteers could be arranged by the government.

Despite laws to make shops wheelchair accessible there are many shops that flout the law and local authorities do little or nothing to encourage shops to provide just a simple portable ramp, perhaps the local authorities should offer a rate reduction for making premises wheelchair accessible.

I would like to think I am involved and as such I already attend a Disability Focus Group through regular meetings run by my local authority, but finding transport to these meetings is expensive for me. I need some help in getting to these meetings and would like to think that I can attend these group meetings at least with help from a carer.

I am also a committee member of my local MS Society Branch, actively raising funds to enable us to help local MS Sufferers. I would welcome government help again to assist us in finding volunteers to enable us run our group meetings and outings, perhaps again some sort of award would be useful.

2 March 2011
I am the mother of a severely autistic 25 year old son who lives in Supported Living with 24/7 support. He loves his house and his life and I am worried about what is going to happen to him in the future with the cuts. He is slowly learning to grow away from us and to develop his skills and interests in a way we never thought would be possible. This is entirely due to the fact he can live in his own home and have activities suited to him.

Tom is able to buy his own home because of a Family–funded joint ownership scheme with Advance Housing, using a SME mortgage.

Tom’s step-father and I do a lot of work on a voluntary basis around the rights of the Learning Disabled.

The government is making it very difficult for disabled people to have the same rights as the rest of the population to live independently.

1. They intend stopping the Independent Living Fund from 2015. This means councils will need to administer this pot of money which comes from the DWP. The councils have administrative costs of 40%, whilst the ILF have admin costs of 4%- so 36% will not go the disabled anyway. Also the money will not be ring fenced so some disabled people will inevitably miss out.

2. SME mortgage rules have been changed. Already this means that some disabled people can not buy their own homes (Ref: Advance Housing in Witney)

3. As a direct result of the cuts in Council funding in Sheffield some Day Services have gone and are to be replaced by more costly private services, which will have to be paid for out of the Disabled person’s budget. Also Special Needs transport costs have rocketed. This means that some disabled people are effectively trapped in their homes and their independence much reduced.

**Benefit changes** will effect many—the Learning Disabled more especially as their disability is often “hidden”.

1. Changes to DLA may mean that autistic people lose their money. (Ref National Autistic Society). This isn’t because they no longer need it, it is because the questions are not phrased in such a way as to take account of their needs.

2. Changes in Incapacity Benefit may make it difficult for some disabled to prove their need. Again it’s the questions that are wrong, not that the disabled have suddenly become less needy.

**Eligibility**

SDS has been a disaster for some with a learning disability. Again, the questions do not allow the severity of the problems and needs be shown. Hence independence is badly compromised.
People with disabilities can be involved through local Disability Parliaments. However that advocacy service is being cut (or restructured as it is commonly called) and so many people with a learning disability especially will be excluded from the decision making process.

It must be recognised that there are many ways to communicate and it is up to the experts to ensure that all are included.

The “clients” of the services are already very poorly off and so shouldn’t be expected to take ANY cuts. The government should look at other ways of saving money (less defence, tax on bankers bonuses?) rather than attacking the most vulnerable

16 March 2011
I volunteer for the website http://benefits.tcell.org.uk/forum in which lists various information and topics on Benefits, Social Care, Rights, Responsibilities and Entitlements and more.

I would like to include within this submission some points of reference, information, data and analysis, these are:

2. ILF was introduced in 1988 to assist disabled people to continue living independently in the community rather than moving into residential care. Around 21,000 people across the UK benefit from ILF including 3,654 who live in Scotland. http://www.capability-scotland.org.uk/ilffundingchanges.aspx and http://www.scotland.gov.uk/Publications/2010/01/25130907/2

ILF eligibility—The ILF is permanently closed to new applications.

To continue to get funding from the ILF, in the majority of cases customers must:

- Get social services support worth at least £340 a week or £17,680 a year. This can include direct payments or services from your local council, like going to a day centre
- Be living in the UK for at least 26 weeks a year
- Have less than £23,000 in savings or capital. This includes any money their partner has, if they have a partner get or be entitled to the highest rate care component of Disability Living Allowance. http://www.dwp.gov.uk/ilf/


4. Cost of person in receipt of ILF (if averaged) £961 per week v £610 per week (Care Home) (N) (http://www.counselandcare.org.uk/category/policy/pdf/the-real-cost-of-quality)

5. Cost of an individual on Incapacity Benefit, Income Support and DLA per week £280.20 per week (rate of High Care and High Mobility used).

6. Job Seekers Allowance is set between £51.85 and £102.75 per week http://www.direct.gov.uk/en/MoneyTaxAndBenefits/BenefitsTaxCreditsAndOtherSupport/Employedorlookingforwork/DG_10018757

7. Average income earned in the UK for 2010 is £499 per week http://www.statistics.gov.uk/cc/i/nugget.asp?id=285


9. A Freedom of Information request was made to Wales for the analysis of Direct Payment, I was advised no such data was collected.
10. London analysis submitted by Main Disabling Condition. 30,000 people supported through Personnel Budgets (7.5 million population in London (estimated in 2005)).

11. London analysis of its budget and spend through the Area Based Grant. Includes Supporting People, Health, AIDS support, Children and Carers grants. Other income such as the Disabled Facility Grant are not shown within this submission, I do ask that these also be considered which are provided by the state to help support and address the needs of living with a disability (also the social care grant, budgeting loan etc.)

12. An analysis of the UK Population has been submitted including a breakdown of benefits. (Analysed from various resources)

13. An analysis of Disability Living Allowance, Attendance Allowance, Carers (Entitled and in Payment) and State Pension are provided by the DWP Tabulation Tool http://83.244.183.180/100pc/tabtool.html

14. A report by the Princess Trust / Crossroads http://benefits.tcell.org.uk/forums/no-breaks-carers-report-primary-care-trusts-and-carers-strategy-crossroadsp-trust found “Using Freedom of Information requests The Princess Royal Trust for Carers and Crossroads Care have found that only 23% of this year’s £50m has been used by PCTs to increase services for carers.”

It is estimated that some 10 million people in the UK and have a disability, 770,000 are Children, we know 3.2 million claim Disability Living Allowance http://www.cafamily.org.uk/professionals/research/statistics.html and http://odi.dwp.gov.uk/disability-statistics-and-research/disability-facts-and-figures.php

No of People supported by the Independent Living Fund by Main Disabling Condition at 18th June 2010

<table>
<thead>
<tr>
<th>Disability description</th>
<th>number of users</th>
</tr>
</thead>
<tbody>
<tr>
<td>Severe learning disability</td>
<td>6618</td>
</tr>
<tr>
<td>Cerebral Palsy</td>
<td>3130</td>
</tr>
<tr>
<td>Multiple Sclerosis</td>
<td>2224</td>
</tr>
<tr>
<td>Other</td>
<td>1604</td>
</tr>
<tr>
<td>Down's syndrome</td>
<td>1199</td>
</tr>
<tr>
<td>Spinal injury</td>
<td>1183</td>
</tr>
<tr>
<td>Brain damage (Inc. head injury)</td>
<td>902</td>
</tr>
<tr>
<td>Learning disability</td>
<td>667</td>
</tr>
<tr>
<td>Cerebro-vascular (Inc. stroke)</td>
<td>631</td>
</tr>
<tr>
<td>Arthritis (osteo-rheumatoid-still's dis)</td>
<td>535</td>
</tr>
<tr>
<td>Muscular Dystrophy or Atrophy</td>
<td>519</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>423</td>
</tr>
<tr>
<td>Spina bifida</td>
<td>351</td>
</tr>
<tr>
<td>Autism</td>
<td>171</td>
</tr>
<tr>
<td>Friedreich's ataxia</td>
<td>168</td>
</tr>
<tr>
<td>Mental illness</td>
<td>108</td>
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<tr>
<td>Learning disability with autism</td>
<td>98</td>
</tr>
<tr>
<td>Polio damage</td>
<td>92</td>
</tr>
<tr>
<td>Huntington's Disease</td>
<td>86</td>
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<tr>
<td>Aids related disease</td>
<td>86</td>
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<tr>
<td>Parkinson's disease</td>
<td>85</td>
</tr>
<tr>
<td>Dementia (Inc. Alzheimer’s)</td>
<td>84</td>
</tr>
<tr>
<td>Condition</td>
<td>No of People</td>
</tr>
<tr>
<td>-----------------------------------------------------</td>
<td>--------------</td>
</tr>
<tr>
<td>Cardio-vascular (Inc. heart disease)</td>
<td>76</td>
</tr>
<tr>
<td>Cancers-tumours</td>
<td>67</td>
</tr>
<tr>
<td>Motor Neurone Disease</td>
<td>65</td>
</tr>
<tr>
<td>Hydrocephalus</td>
<td>59</td>
</tr>
<tr>
<td>Osteoporosis</td>
<td>58</td>
</tr>
<tr>
<td>Lung or respiratory disease (Inc. asthma)</td>
<td>43</td>
</tr>
<tr>
<td>Physical malformation limbs-Thalidomide</td>
<td>31</td>
</tr>
<tr>
<td>Asperger’s</td>
<td>25</td>
</tr>
<tr>
<td>Quadriplegic</td>
<td>21</td>
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<tr>
<td>Paraplegic</td>
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<tr>
<td>ME</td>
<td>13</td>
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<tr>
<td>Diabetes</td>
<td>7</td>
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<tr>
<td>Blood disease (Inc. leukaemia)</td>
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<tr>
<td>Visual impairment</td>
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<tr>
<td>ADHD</td>
<td>5</td>
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<tr>
<td>Lupus</td>
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**21464**

**UK Population analysis including benefits in payment**

<table>
<thead>
<tr>
<th>August 2010</th>
<th>No of People</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population</td>
<td>61,838,154</td>
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<tr>
<td>Population</td>
<td>61,838,154</td>
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<tr>
<td>Benefit</td>
<td>Amount</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>----------</td>
</tr>
<tr>
<td>Bereavement Benefit</td>
<td>-64,700</td>
</tr>
<tr>
<td>Carers Allowance</td>
<td>-1,002,600</td>
</tr>
<tr>
<td>Carers Allowance Children</td>
<td>-12,553,000</td>
</tr>
<tr>
<td>Carers Allowance Children - Disabled</td>
<td>-770,000</td>
</tr>
<tr>
<td>ESA</td>
<td>-563,980</td>
</tr>
<tr>
<td>Incapacity Benefits</td>
<td>-1,851,010</td>
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<tr>
<td>Job Seeker Allowance</td>
<td>-1,349,710</td>
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<tr>
<td>State Pension</td>
<td>-12,561,260</td>
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<tr>
<td>Widows Benefit</td>
<td>-49,110</td>
</tr>
<tr>
<td>Working Population</td>
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<tr>
<td>Working Population F/Time</td>
<td>-21,124,000</td>
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<tr>
<td>Working Population P/time</td>
<td>-7,910,000</td>
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<tr>
<td></td>
<td></td>
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</tbody>
</table>
Disability Living Allowance - Cases in payment (5% sample) Caseload (Thousands) : Main Disabling Condition by Gender

<table>
<thead>
<tr>
<th>Main Disabling Condition</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>3,148.1</td>
<td>1,571.3</td>
</tr>
<tr>
<td>Arthritis</td>
<td>580.8</td>
<td>374.1</td>
</tr>
<tr>
<td>Muscle / Joint / Bone Disease</td>
<td>211.8</td>
<td>113.2</td>
</tr>
<tr>
<td>Blindness</td>
<td>69.4</td>
<td>33.5</td>
</tr>
<tr>
<td>Stroke Related</td>
<td>110.6</td>
<td>49.1</td>
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<tr>
<td>Learning Difficulty</td>
<td>364.2</td>
<td>128.0</td>
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<tr>
<td>Mental Health Causes</td>
<td>510.6</td>
<td>245.1</td>
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<tr>
<td>Epilepsy</td>
<td>72.9</td>
<td>38.3</td>
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<tr>
<td>Deafness</td>
<td>41.5</td>
<td>20.4</td>
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<tr>
<td>Malignant Disease</td>
<td>83.0</td>
<td>46.5</td>
</tr>
<tr>
<td></td>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>------------------------------</td>
<td>--------</td>
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</tr>
<tr>
<td></td>
<td>Total</td>
<td>Male</td>
</tr>
<tr>
<td></td>
<td>Caseload (Thousands)</td>
<td>Caseload (Thousands)</td>
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<tr>
<td>Chest Disease</td>
<td>93.5</td>
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<tr>
<td>Back Ailments</td>
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<tr>
<td>Heart Disease</td>
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<tr>
<td>Parkinson's Disease</td>
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<td>Diabetes Mellitus</td>
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<td>Renal Disorders</td>
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<td>Skin Disease</td>
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<tr>
<td>Frailty</td>
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<tr>
<td>Multiple Sclerosis</td>
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<td>20.4</td>
</tr>
<tr>
<td>Other</td>
<td>435.2</td>
<td>238.7</td>
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</tbody>
</table>

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**Notes:**

**Caseload (Thousands)** Totals show the number of people in receipt of an allowance, and excludes people with entitlement where the payment has been suspended, for example if they are in hospital.

**Main Disabling Condition** Where more than one disability is present only the main disabling condition is recorded. "Other" includes 25 medical conditions, including "Obesity" from February 2010 (for claims to benefit from October 2008 onwards). Previously, "Obesity" was included within "Mental Health Causes".

---

**Attendance Allowance - Cases in payment (5% sample) Caseload (Thousands) : Main Disabling Condition by Gender**

**Time Series=AUG10**

<table>
<thead>
<tr>
<th>Gender</th>
<th>Total</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Caseload (Thousands)</td>
<td>Caseload (Thousands)</td>
<td>Caseload (Thousands)</td>
</tr>
<tr>
<td>Total</td>
<td>1,577.2</td>
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<tr>
<td>Main Disabling Condition</td>
<td>513.7</td>
<td>120.0</td>
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<tr>
<td>Arthritis</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Muscle / Joint / Bone</td>
<td>95.8</td>
<td>22.7</td>
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<td>Disease</td>
<td>Total</td>
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<td>--------</td>
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<tr>
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<td>Caseload (Thousands)</td>
<td>Caseload (Thousands)</td>
<td>Caseload (Thousands)</td>
</tr>
<tr>
<td>Blindness</td>
<td>57.4</td>
<td>19.1</td>
<td>38.3</td>
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<tr>
<td>Stroke Related</td>
<td>101.2</td>
<td>47.0</td>
<td>54.2</td>
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<tr>
<td>Learning Difficulty</td>
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<td>1.2</td>
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<tr>
<td>Mental Health Causes</td>
<td>153.2</td>
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<td>103.5</td>
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<tr>
<td>Epilepsy</td>
<td>4.4</td>
<td>2.0</td>
<td>2.4</td>
</tr>
<tr>
<td>Deafness</td>
<td>8.1</td>
<td>3.1</td>
<td>5.0</td>
</tr>
<tr>
<td>Malignant Disease</td>
<td>37.8</td>
<td>20.4</td>
<td>17.4</td>
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<tr>
<td>Chest Disease</td>
<td>74.2</td>
<td>35.9</td>
<td>38.3</td>
</tr>
<tr>
<td>Back Ailments</td>
<td>42.1</td>
<td>13.7</td>
<td>28.4</td>
</tr>
<tr>
<td>Heart Disease</td>
<td>136.7</td>
<td>55.0</td>
<td>81.7</td>
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<tr>
<td>Parkinson's Disease</td>
<td>33.8</td>
<td>18.9</td>
<td>14.9</td>
</tr>
<tr>
<td>Diabetes Mellitus</td>
<td>33.7</td>
<td>15.7</td>
<td>18.0</td>
</tr>
<tr>
<td>Renal Disorders</td>
<td>9.8</td>
<td>5.3</td>
<td>4.5</td>
</tr>
<tr>
<td>AIDS</td>
<td>* 0.1</td>
<td>* 0.1</td>
<td>-</td>
</tr>
</tbody>
</table>
### Table

<table>
<thead>
<tr>
<th>Main Disabling Condition</th>
<th>Caseload (Thousands)</th>
<th>Caseload (Thousands)</th>
<th>Caseload (Thousands)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Skin Disease</td>
<td>2.3</td>
<td>0.7</td>
<td>1.6</td>
</tr>
<tr>
<td>Frailty</td>
<td>141.2</td>
<td>38.0</td>
<td>103.2</td>
</tr>
<tr>
<td>Multiple Sclerosis</td>
<td>2.3</td>
<td>0.7</td>
<td>1.6</td>
</tr>
<tr>
<td>Other</td>
<td>127.3</td>
<td>53.0</td>
<td>74.3</td>
</tr>
</tbody>
</table>

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**Notes:**

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- **Main Disabling Condition** Where more than one disability is present only the main disabling condition is recorded. "Other" includes 25 medical conditions, including "Obesity" from February 2010 (for claims to benefit from October 2008 onwards). Previously, "Obesity" was included within "Mental Health Causes".
Disability Living Allowance - Cases in payment (5% sample) Caseload (Thousands) : Main Disabling Condition by Care Rate

Time Series=AUG10

<table>
<thead>
<tr>
<th>Total</th>
<th>Higher Rate</th>
<th>Middle Rate</th>
<th>Lower Rate</th>
<th>Nil Rate</th>
</tr>
</thead>
<tbody>
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<td>Caseload (Thousands)</td>
<td>Caseload (Thousands)</td>
<td>Caseload (Thousands)</td>
</tr>
<tr>
<td>Total</td>
<td>3,148.1</td>
<td>735.8</td>
<td>1,050.4</td>
<td>874.1</td>
</tr>
<tr>
<td>Main Disabling Condition</td>
<td>580.8</td>
<td>109.2</td>
<td>141.9</td>
<td>215.6</td>
</tr>
</tbody>
</table>

Arthritis

Muscle / Joint / Bone Disease

<table>
<thead>
<tr>
<th>Blindness</th>
<th>Stroke Related</th>
<th>Learning Difficulty</th>
<th>Mental Health</th>
</tr>
</thead>
<tbody>
<tr>
<td>69.4</td>
<td>110.6</td>
<td>364.2</td>
<td>510.6</td>
</tr>
</tbody>
</table>

Disability Living Allowance - Cases in payment (5% sample) Caseload (Thousands) : Main Disabling Condition by Care Rate

Time Series=AUG10

<table>
<thead>
<tr>
<th>Total</th>
<th>Higher Rate</th>
<th>Middle Rate</th>
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<th>Nil Rate</th>
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<td>Caseload (Thousands)</td>
<td>Caseload (Thousands)</td>
<td>Caseload (Thousands)</td>
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<td>735.8</td>
<td>1,050.4</td>
<td>874.1</td>
</tr>
<tr>
<td>Main Disabling Condition</td>
<td>580.8</td>
<td>109.2</td>
<td>141.9</td>
<td>215.6</td>
</tr>
</tbody>
</table>

Arthritis

Muscle / Joint / Bone Disease

<table>
<thead>
<tr>
<th>Blindness</th>
<th>Stroke Related</th>
<th>Learning Difficulty</th>
<th>Mental Health</th>
</tr>
</thead>
<tbody>
<tr>
<td>69.4</td>
<td>110.6</td>
<td>364.2</td>
<td>510.6</td>
</tr>
</tbody>
</table>
### Care Rate

<table>
<thead>
<tr>
<th>Causes</th>
<th>Total Caseload (Thousands)</th>
<th>Higher Rate Caseload (Thousands)</th>
<th>Middle Rate Caseload (Thousands)</th>
<th>Lower Rate Caseload (Thousands)</th>
<th>Nil Rate Caseload (Thousands)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Epilepsy</strong></td>
<td>72.9</td>
<td>15.6</td>
<td>48.0</td>
<td>5.5</td>
<td>3.9</td>
</tr>
<tr>
<td><strong>Deafness</strong></td>
<td>41.5</td>
<td>1.5</td>
<td>26.8</td>
<td>10.1</td>
<td>3.2</td>
</tr>
<tr>
<td><strong>Malignant Disease</strong></td>
<td>83.0</td>
<td>50.5</td>
<td>12.1</td>
<td>15.0</td>
<td>5.4</td>
</tr>
<tr>
<td><strong>Chest Disease</strong></td>
<td>93.5</td>
<td>24.3</td>
<td>25.4</td>
<td>17.4</td>
<td>26.5</td>
</tr>
<tr>
<td><strong>Back Ailments</strong></td>
<td>246.5</td>
<td>38.0</td>
<td>52.6</td>
<td>104.9</td>
<td>51.1</td>
</tr>
<tr>
<td><strong>Heart Disease</strong></td>
<td>136.9</td>
<td>26.0</td>
<td>31.4</td>
<td>29.8</td>
<td>49.8</td>
</tr>
<tr>
<td><strong>Parkinson’s Disease</strong></td>
<td>18.8</td>
<td>9.5</td>
<td>5.0</td>
<td>3.3</td>
<td>1.0</td>
</tr>
<tr>
<td><strong>Diabetes Mellitus</strong></td>
<td>59.5</td>
<td>13.8</td>
<td>29.5</td>
<td>11.2</td>
<td>5.0</td>
</tr>
<tr>
<td><strong>Renal Disorders</strong></td>
<td>16.0</td>
<td>4.8</td>
<td>5.8</td>
<td>3.5</td>
<td>1.9</td>
</tr>
<tr>
<td><strong>AIDS</strong></td>
<td>8.7</td>
<td>4.8</td>
<td>1.6</td>
<td>1.7</td>
<td>0.5</td>
</tr>
</tbody>
</table>
### Care Rate

<table>
<thead>
<tr>
<th>Condition</th>
<th>Total Caseload (Thousands)</th>
<th>Higher Rate Caseload (Thousands)</th>
<th>Middle Rate Caseload (Thousands)</th>
<th>Lower Rate Caseload (Thousands)</th>
<th>Nil Rate Caseload (Thousands)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Skin Disease</td>
<td>16.6</td>
<td>4.0</td>
<td>3.8</td>
<td>7.5</td>
<td>1.4</td>
</tr>
<tr>
<td>Frailty</td>
<td>2.8</td>
<td>1.5</td>
<td>0.9</td>
<td>* 0.2</td>
<td>* 0.2</td>
</tr>
<tr>
<td>Multiple Sclerosis</td>
<td>68.7</td>
<td>29.1</td>
<td>21.3</td>
<td>11.7</td>
<td>6.6</td>
</tr>
<tr>
<td>Other</td>
<td>435.2</td>
<td>114.9</td>
<td>142.8</td>
<td>115.9</td>
<td>61.6</td>
</tr>
</tbody>
</table>

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Written Evidence submitted by Kevin Kelleher (IL 9)

2010 (for claims to benefit from October 2008 onwards). Previously, "Obesity" was included within "Mental Health Causes".

Carer’s Allowance - all entitled cases Caseload (Thousands) : Entitled/Receiving payment by Gender of claimant

Time Series=AUG10

<table>
<thead>
<tr>
<th>Gender of claimant</th>
<th>Total</th>
<th>Female</th>
<th>Male</th>
<th>Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Caseload (Thousands)</td>
<td>Caseload (Thousands)</td>
<td>Caseload (Thousands)</td>
<td>Caseload (Thousands)</td>
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<td>Total</td>
<td>1,002.60</td>
<td>667.24</td>
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<tr>
<td>Entitled/Receiving payment</td>
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<td>185.71</td>
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<tr>
<td>Entitlement only</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Claimant receiving benefit</td>
<td>550.86</td>
<td>401.21</td>
<td>149.65</td>
<td>-</td>
</tr>
<tr>
<td>Entitled, payment status unknown</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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**SOURCE:** DWP Information Directorate: Work and Pensions Longitudinal Study.

**STATE PENSION AGE:** The age at which women reach State Pension age will gradually increase from 60 to 65 between April 2010 and April 2020. This will introduce a small increase to the
number of working age benefit recipients and a small reduction to the number of pension age recipients. Figures from May 2010 onwards reflect this change. For more information see http://statistics.dwp.gov.uk/asd/espa.pdf

**Notes:**

**Caseload (Thousands)** Totals show the number of people who are entitled to receive CA, including those who receive no actual payment.

**Entitled/Receiving payment** Carers entitled to receive CA may be paid the benefit, or not paid it because they receive an overlapping benefit equal to or greater than their weekly rate of CA. 'Claimant receiving benefit' cases cannot be distinguished from 'Entitled' cases prior to August 2003.

State Pension Caseload (Thousands) : Category of pension by Gender of claimant

<table>
<thead>
<tr>
<th>Time Series=AUG10</th>
<th>Gender of claimant</th>
<th>Caseload (Thousands)</th>
<th>Caseload (Thousands)</th>
<th>Caseload (Thousands)</th>
<th>Caseload (Thousands)</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Total</td>
<td>Female</td>
<td>Male</td>
<td>Unknown</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>12,561.26</td>
<td>7,770.16</td>
<td>4,791.10</td>
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<tr>
<td>Category of pension</td>
<td>Cat A</td>
<td>8,020.27</td>
<td>3,391.41</td>
<td>4,628.87</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>Cat B</td>
<td>951.84</td>
<td>950.04</td>
<td>1.79</td>
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<tr>
<td></td>
<td>Cat ABL</td>
<td>1,145.46</td>
<td>1,145.37</td>
<td>0.08</td>
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<td>Cat BL</td>
<td>892.96</td>
<td>892.93</td>
<td>0.02</td>
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<td></td>
<td>Cat AB</td>
<td>1,455.61</td>
<td>1,322.77</td>
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<td></td>
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<td>46.00</td>
<td>20.10</td>
<td>-</td>
</tr>
<tr>
<td>Gender of claimant</td>
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<td>Male</td>
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</tr>
<tr>
<td>--------------------</td>
<td>-------</td>
<td>--------</td>
<td>------</td>
<td>---------</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Caseload (Thousands)</td>
<td>Caseload (Thousands)</td>
<td>Caseload (Thousands)</td>
<td>Caseload (Thousands)</td>
<td></td>
</tr>
<tr>
<td>Cat C</td>
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<td>0.03</td>
<td>-</td>
<td>-</td>
<td></td>
</tr>
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<td>Cat D</td>
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<td>21.61</td>
<td>7.39</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>Unknown</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td></td>
</tr>
</tbody>
</table>

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**Notes:**

*Category of pension* People receiving Additional Pension only are included in the "Cat A" group.

22 March 2011
I have sent the below but have added a few sections to show problem of independent living.

Prior findings showed that "income of disabled working-age men is substantially lower than non-disabled working-age men." However, the paper demonstrates that "the majority of this disadvantage is accounted for by the low economic status of the men who become disabled" (Bardasi and Jenkins 2000, 1).

Many reports offered regarding independent living shows complex sexual, racial and religious reasons for a complex set of data variance. This in addition to the above academic research; often quoted, would be considered racial or sexual discrimination if re-written. Women/Black peoples disadvantages is due to the majority are of low economic status resulting in their lack of independent living.

It would be easy to loose any argument on independent living based on academic research or data collected. It would therefore be nice to use a simple methodology which would move disability forward. Independent Living is an issue of education. If a census was carried out at each secondary school and the number of wheelchair users was recorded there should be about 3%. If this 3% is not achieved either; "the majority of this disadvantage is accounted for by the low economic status of the men who become disabled", wheelchair users are thick or incapable of Independent Living. As Independent Living allows wheelchair users to teach the students will learn about disability and disabilities.

These enlightened students will in time allow independent Living to occur. In the short term the changes needed to allow only one section of the disabled community to enter the education system would change society dramatically.

For the few like myself who is unable to work independent living will occur hopefully, but more importantly we might see the small light of change. A complex set of targets or research including sex and race will only result in confusion.

Additions

DWP Industrial Injury

I was injured in work twice. The first time it made no difference to my income how much was given to me as my employer recovered any benefit from my income or pension.

I was assessed from 1984 to 1999 5 times. I had to appeal 7 times. Only once did DWP attend and offered no evidence. In 2005 I was again injured in work. I had been 15 percent disabled or 1 to 22 percent disabled since 1984.

I was found to be not disabled. On appeal I became 60 percent. I am a wheelchair user with numerous medical reports. A criminal case and civil case. I still have to keep everything since 1984 as DWP still cause problems. These errors by DWP are either a method of policing The system or generating income for appeals whilst showing high workload. Although the DWP allow an appeal period and then do not recover overpayment all pension providers stop your pension immediately and you have no income.
Pensions

Me

Because I was able to get a job paying more than my salary once retired I lost 300 a month. Now unable to work this is not reinstated as the reason for stopping work was not the original injury. It is a disincentive to take up education or employment once injured.

Partner if they have to retire early to look after disabled partner their pension is reduced.

Access

Essex railway goes into Liverpool Street, London there is no disabled access at this mainline station. and therefore limits where a disabled person can work or travel. The railways will pay for a taxi from Liverpool to your address but you must ring a disabled line to get a ref number. When you get to Liverpool Street you go to the customer services and they must get the taxi; or you cannot get the taxi charge back. In a working environment your employer must except the possible delay. The bigger problem is when you are at another Station because they will not accept Liverpool Street has no disabled access so you wait 30 to 90 minutes for a taxi as they argue who pays for the cost. It in effect means you have to use a car or not enter London.

Law changes

The traffic law changes that allows controlled areas are not clear.

Firstly they were not meant to be 24 hr restrictions 6 days a week and secondly if you are disabled and park in one of these unmarked and often illogical bays you cannot see the signs be4cause you have parked outside the restaurant.

Chelmsford has become a town wanting bus routes and no cars and in effect has made it impossible for me to visit. If I am asked out to Chelmsford unless I have to have over 24 hours notice so I can arrange to use the train. My station is not always manned.

VAT

I am not eligible for grants and when I adapted my house; I live in a conservation area, I had to ramp through the garage creating doors and a wheelchair enabled kitchen. Although you can get VAT back the IR ask the electrician which lights are for his disability and which are not. The same with each, brick, door, kitchen unit etc. This makes the builders not apply for VAT reduction as the cost of completing the paperwork is too high. As a result VAT is paid on everything unless you employ an architect who charges 17.5% of the building cost. VAT only works on identifiable disabled items not on access or ramps.

Disability is become harder over the last 5 years for me because the Governments have said we are all scroungers and that is where all the tax goes. The DWP accuse everyone of 'playing the system' and now we have a government pledged to reduce red tape. Every report has shown Government, Councils and DWP the worst offenders and now they intend to remove all rights.

24 April 2011
ADKC (Action Disability Kensington & Chelsea) is a local disability organisation aiming to enhance opportunities for people with physical, sensory and hidden disabilities living or working in the Royal Borough of Kensington & Chelsea. This is achieved through providing services like information and advice, running a number of user groups, raising awareness of disability issues and championing the rights of disabled people.

This submission brings together the responses from 9 local disabled people who attended a focus group in April 2011 to answer 7 questions around Independent Living (drawn from the Easy Read version of the Independent Living Strategy, ODI) and our responses as a disability organisation.

The 10 focus group participants were 8 females and 2 males comprising a diverse range of impairments including physical, sensory and hidden impairments. The group were from a range of ethnic groups including West African, White British and Asian origin.

1. What is Independent Living?

Five members of the group had heard of the term Independent Living, 4 had not. The participants took turns defining what Independent Living means to them.

The group very much felt that Independent Living was having the choice, freedom and support to choose how and when they receive services but with the key understanding that it’s not about disabled people doing things on their own but having the correct support to make choices for themselves. They felt that dignity and respect are important components of Independent Living.

- “It’s about becoming more independent but not managing it all yourself - being independent but with access to support”
- “Empowerment to remain active”
- “With the right support- it’s about remaining physically and mentally active”
- “Doing whatever you want to do: being in charge”
- “Having control over your life and the people in it such as care workers”
- “Different services to get myself more able and get my life back”
- “Being able to live your life to its full potential”
- “Freedom of choice and control”
- “Support when we need, not when it’s imposed on us”
- “We don’t want to be stigmatised or discriminated against”
Written Evidence submitted by Action Disability Kensington and Chelsea (ADKC) (IL 20)

- Not being treated like a product: when service providers don’t look at a person and their needs.

Independent Living was not being respected when they didn’t receive the right support to overcome barriers.

2. Could the government do more to give disabled people the same rights as everyone else to live independently?

The group looked at the various key services and noted that barriers still exist that prevent disabled people from living independently through accessing mainstream services.

**Education**

- It was noted there was a lack of resources in Further Education to support students to get into Higher Education. “It shouldn’t be only in “special” colleges you get the help and support you need!”

- The group felt that information and support is not always openly available and more effort should be made to publicise support available that disabled people may be eligible for. “Sometimes there is support but people don’t always know about it”

- The group felt that attitude and awareness could be improved: there needs to be more training about support needs and identifying students needs

- Some colleges have a good choice of courses, but that physical access remains a barrier “If you can’t get into the building what’s the point of having this amazing course?”

- The group felt that the recent increase in tuition fees (through the removal of a cap on fees) meant that disabled people (who already receive lower incomes that their non-disabled counterparts) simply couldn’t afford to attend university.

“Already it’s a challenge for disabled people to be in education- we have to struggle to take out loans and get £ now the rules have changed. If fees go up to £9,000 disabled people will be completely excluded. It’s really hard to work if you’re disabled like I am, I can’t go out and earn more money to pay my fees”

**Health**

- Lack of understanding of BME groups and those with additional communication needs was seen as a barrier to Independent Living. One person spoke about his young son who was diagnosed with a learning difficulty but in reality his limited English made it difficult for him to respond to the GP’s questions.

- There is still a lack of co-ordination between services in a health setting such as GPs and other health professionals such as hospital specialists and physiotherapists. Departments frequently not communicating with each other was commonly sited and prevented people from accessing the care they need.
3. How have the cuts or changes to the services you receive affect your daily life
The Joint Committee would like to hear

- how people have been affected by:
- changes to benefits
- cuts in funding
- changes in services
- the way local councils decide whether you can get a service or not.

The Joint Committee would like to know if you think these things are making being independent more or less difficult.

- The group reported that ESA and DLA had increased but only in line with inflation but that Income Support had decreased. ESA and DLA which are supposed to reflect the additional cost of disability does not do this. There was a brief rundown of the changes to DLA (being reformed to Personal Independence Payment) and Income Support being moved to Employment Support Allowance. The group felt that changes were great in number, significant in the level of change and so sudden that they couldn’t process the information properly and needed more information in an accessible format in order to respond properly to government consultations.

- One member stated that her severely disabled sister was signed up in recent weeks to receive Housing Benefit but was told following the cuts she was not eligible.

- Members also expressed the unfairness of Job Seekers Allowance eligibility criteria for those who wished to pursue Higher and Further Education. One members said that she was eligible for JSA if she registered for a full time college course but not if she was on a part-time course. The part-time course fitted in with her care requirements associated with her disability so she felt that she was unfairly being discriminated against because she could not commit to full-time education.

- This was echoed at the recent ADKC Disability Network meeting (a discussion event which brings together a panel of service providers and local disabled people to discuss and debate key issues - this meeting was on Education) The group expressed the discrepancy between the levels of support available to disabled students in Higher Education but not in Further Education (the level below university) as without support at this critical level they cannot achieve the necessary qualifications in order to enter university and access a wide range of support. Members felt that without the necessary skills and qualifications gained at university they are being excluded from jobs and the ability to be financially independent and therefore live independently.

- The group said that cuts meant that they were taking on additional caring roles (in 2 cases for elderly relatives) and that this was causing stress. One ADKC member said her dad had lost the right to free transportation. This meant she had to take on the responsibility of driving him to and from his day centre where he has meals and also take on the task of looking after his finances. However the pressure of this role combined with the physical difficulty in driving for long periods was causing her additional stress and pain due to her physical disability.
Another member said the closure of Pembroke Day Centre in Kensington & Chelsea meant her severely disabled sister was now “stuck at home getting more depressed”. The member was “terrified” they would class her as fit for work as it was her paid work as a carer combined with the stress of looking after her sister that bought on her illness to start with, “How can I look after my sister and go to work? I have to get up and give her medication before 7am every day and I get so tired I wouldn’t be able to work”

Another ADKC member who classes himself as a disabled parent said the Personal Assistant who was assigned to his son has been removed, as a result he had to take on a lot of this role at the cost of his own health.

The group felt the Independent Living Strategy is not being implemented at Borough level. They wanted more monitoring evidence to increase accountability of the local authority’s monitoring and a more explicit commitment to the Strategy at Borough level.

With regard to the recent cuts, one member said “we feel demoralised. Currently ESA just isn’t enough to survive on. I wish I knew where to go to get more help support and advice. I don’t feel I’m getting all I’m entitled to and all the information. I’m currently living on cereal and deciding which days to have a proper meal on.”

Social inclusion featured in the discussion around the need to access leisure opportunities and the fact this was not taken into account in people’s Personal Budgets. “We want to remain active and have a social life but there is no support to do this. Pretty soon we will be faced with a being given just enough money for the food, drink, medication, practical care and cleaning, we’ll go back to the dark ages” This reflects ADKC’s view that the current DLA reform plans and changes to Incapacity Benefit are regressive and will cost more to implement at a detriment to the wellbeing of the people they are aimed at.

In ADKC’s view, the Independent Living Strategy does take some steps to addressing the need to access social and leisure opportunities just like non-disabled people do but in reality this does not take place at Borough level (more below)

Another member who is a carer for her sister stated that she had lost meals and community transport. She also said that previously she had been able to take a carer’s respite break but that now this had to be paid for by her Personal Budget. She and other members of the group said they felt that the government was simply “juggling pots of cash around but that in actual fact services had been cut and the money being given to disabled people was being reduced” with these negative consequences.

There was a lot of concern around the back to work agenda and people who weren’t ready to go back to work being forced into employment. One member said “Our jobs should be suited to our needs not simply pushed into doing tokenistic jobs” Another member said “I’m worried every day because of the stress of the thought of going back to work. Even if I minimise my physical activity, if I get stressed I could end up spending two days in bed [...]”
4a) Do you think the government needs to change any laws or the way it does things? If so, what needs to change?

Changes to the Benefits and the Equalities Act

Threats to Participation and Consultation

The group received a brief account of the changes to DLA, Incapacity Benefit and the changes to the Equality Act. They found the changes to the Equality Act “appalling” as they minimise the amount of involvement public bodies are legally bound to carry out, remove the legally binding necessity of carrying out Equality Impact Assessments and mean that public bodies are only bound to make equalities targets for a small number of „protected” groups. This means in theory public bodies could quite legally focus just on gender and BME groups and bypass disability altogether and still meet their targets. The group view this as „unreasonable” and a threat to Independent Living.

ADKC is a small organisation. We aim to respond to key public consultations but this is not always possible due to limited resources. Here we briefly point out what we view as key impacts of recent changes to benefits and legislation, specifically focusing on how these may impact on Independent Living.

Overall, we view the Independent Living Strategy as an important document containing as it does a cross departmental Strategy to improve the life chances of disabled people by highlighting the importance of choice and freedom.

As one disabled person said, the Strategy does not always filter down to Borough level. Below we summarise key examples of this whilst also referring to national legislative changes.

DLA Reform

DLA is an essential benefit as it recognises the extra costs associated with disability. It means that disabled people can move closer to living independently just like their non-disabled counterparts.

ADKC believes that DLA should not be replaced with Personal Independence Payment (PIP). Our research and consultation with local disabled people has led us to the conclusion that PIP will cut the number of claimants to this vital benefit, will involve inappropriate assessment that may lead to stress amongst claimants and result in less people being eligible as the criteria is narrower.

One of the key changes is that of introducing medical assessments. We believe this may cause unnecessary stress for disabled people particularly when they have additional mental health impairments arising from a primary physical, sensory or hidden impairment.

- ADKC members have expressed concern that medical professionals who are not GPs may not be adequately equipped to understand complex multiple impairments.

  “I have a rare impairment that even my GP struggles to understand, how can an assessor make decisions about what I'm entitled to when they don't even understand what my illness is?”
- We are opposed to introducing medical assessments. If they do go ahead, we suggest that assessors with specialist knowledge of the type of disability they are assessing are employed and that all assessors should be fully aware of and work within the Social Model of disability.

Disabled people should be able to exercise choice and control over what their DLA is put towards.

DLA or the proposed PIP should remain non-means tested and be available for both those working and not working.

Multiple Cuts

We are concerned that disabled people will feel benefits cuts “from all sides” as many key benefits have been reformed at the same time having multiple impacts on disabled people. An example of this is the fact that when DLA reforms take effect this will reduce the number of those eligible to receive the benefit and mean more people will be assessed as capable of work. There has not been however, an increase in the amount of resources to support people into work. The “Access to Work” scheme, which historically has not been viewed as effective by our members is currently not receiving increased resources to support increased numbers of disabled people into meaningful employment and allow them to fulfil their potential.

Closure of the Independent Living Fund

The closure of the Independent Living Fund has been a major blow to achieving the aims of the Independent Living Strategy. One disabled person said that she receives £1,800 per month from the ILF. If this was removed it would seriously affect her ability to work full time as she currently does. This would mean she would be much more financially worse off and her quality of life would be reduced. “I wouldn't feel I would be able to contribute and participate properly if I didn't work”

“The ILF funds being reduced mean that people will not enable someone to fulfil their potential”

Crucially, Councils are not required to record the impact that the closure of the ILF is having on disabled people. In Kensington & Chelsea this is not being monitored. This is an important piece of monitoring and essential for Councils to be able to accurately assess whether needs are being met.

Big Society/ Localism

We wish to highlight the contradiction between the government’s aims to increase accountability of government by giving choice back to people but cutting benefits and threatening Independent Living—the very ways that people can respond meaningfully and participate in their communities effectively.

At a recent conference organised by the National Centre for Independent Living (NCIL) one member described the Big Society as “the biggest threat to Independent Living”

Charging Policies
We believe that increasing charges for care will seriously undermine Independent Living. If disabled people don’t receive basic personal care accurately assessed and administered reflecting their needs they will not be able to participate fully within their communities.

ADKC runs a Personal Budgets User group that meets monthly to discuss Personalisation and Independent Living related issues. They expressed concern at the impending changes to charging policies. At a Personal Budgets User Group meeting it emerged that not a single person had received consultation papers on the public consultation into charging policies from the local authority.
THE RIGHT TO INDEPENDENT LIVING

Q1 and 2—Should the right to independent living (hereafter IL) continue to form the basis for Government policy on disability in the UK?

Could current policy be improved and could Government do more?

- Most definitely YES. Government appears to be listening – there are more bodies supporting IL
- There are lots of forms but data appears to substantiate that IL is working
- A key improvement requirement is PHYSICAL ACCESSIBILITY
- More local, funded disability ADVICE CENTRES are needed
- District council FUNDING for private advice centres is needed
- ADVICE must be more freely available.
- Too many FORMS
- ASSESSMENTS must be done by DOCTORS for DLA/ESA.
- Bring back % QUOTAS for employment for disabled people in business
- Need to generate more EMPLOYMENT OPPORTUNITIES
- Employers need more EDUCATION in disability issues (policy)
- A DIRECTORY of ALL disability advice centres for UK needs preparing/distributing to every medical practitioner

Q3/4—What steps could Government and other public agencies take to meet obligations to secure right to IL? What needs changing?

- Apply same access DISABILITY EQUALITY DUTY requirements to owners of private premises as for public premises. Extend the law
- Provide more training for civil servants and providers of public services in application of DISABILITY EQUALITY DUTY

IMPACT OF FUNDING
Q5—Removing the mobility component of DLA for all living in residential care

- Unfair and not acceptable as it would remove all independence from people who could and have a right to make their own mobility choices even though they live in residential care
- The term 'RESIDENTIAL CARE' is not absolutely clear to some – needs properly defining

Q6—CHANGES TO THE INDEPENDENT LIVING FUND

- Reasons for plans to terminate IL Fund in 2012 are not properly understood
- Would appear to remove choices how money is spent hence, removes some independence out of living
- Removing the Independent Living Fund and putting the onus on Local Authorities to provide the alternative funding will undermine the principle of the social model. It is likely to propel some disabled people towards poverty and potentially could cost the community more in the long term.

Q7—THE ‘BIG SOCIETY’

- Why put a label on activities which have run for years? Its not understood if its meant to be different or do different things
- Local Authorities are already seeing voluntary organisations as a means of reducing their own expenditure and off-loading advice and care to them without properly funding them
- We feel ‘VOLUNTARY DOES NOT MEAN FREE’ VOLUNTARY should mean financially supported by central/local government
- Question – will government assist volunteers to return to paid work when the economy and employment pick up?
- Question – how much of the extra 2% corporation tax relief ie not collected could have gone towards supporting the voluntary sector?
**Q8/9—RESTRICTIONS ON LOCAL AUTHORITY FUNDING, SOCIAL CARE BUDGETS. BENEFIT RE-ASSESSMENTS, CHANGES IN SERVICES, IMPACT ON CARE PROVISION, PORTABILITY OF CARE AND MOBILITY**

- Many DWP benefit offices have been closed. PO Boxes are NOT acceptable alternatives
- Disadvantages include inability of deaf people to use telephone for complex benefit discussions – need face-to-face talks
- Far too many changes planned too quickly including re-assessments
- Voluntary organisations have no claim to ‘ACCESS TO WORK’ fund
- Voluntary work could be disadvantageous to some disabled people as viewed by DWP when assessing for ESA
- Employ more disabled people in DWP offices
- We challenge ability of non-medical assessors to make competent decisions
- Having won ALL our benefits appeals we question the quality DWP decisions and the competence of DWP staff. The need better quality training which will result in reduced costs
- More BSL/LIP READING and DEAF AWARENESS training is needed
- Disabled people need to be asked who they would like to represent them to suit individual circumstances – not just be told

**Q10/11—IMPACT OF FUNDING ON ABILITY OF UK TO SECURE IL— IS IL BEING MADE MORE OF LESS DIFFICULT?**

**ARTICLE 19 AND POLICY/BUDGETARY DECISIONS IMPACT?**

- Reductions in funding are making IL MORE DIFFICULT. There will be a direct, negative impact on IL
- There is lack of cohesion in information and communication amongst SOCIAL SERVICES-DWP-LOCAL AUTHORITIES-NHS-ADVICE CENTRES
- Question – are we all working towards the same definition of IL?

**Q12/13—HOW CAN GOVERNMENT INVOLVE DISABLED PEOPLE IN PLANNING/SAVING MONEY and ARE CURRENT ARRANGEMENTS FOR LIAISON WITH AND INVOLVEMENT BY DISABLED PEOPLE WORKING?**
District councils should be required by Government to provide evidence that they have consulted and listened to disabled people and followed up any necessary actions.

Too often, tick-box exercises follow decisions already made, with no intention to change anything regardless of disabled people’s suggestions.

Good example: North Somerset Council’s consultation on the shared surface for Pier Square, Weston-super-Mare

12 April 2011
Written Evidence submitted by John Curran (IL 23)

Brief Explanation Of Who I Am:

I am a 59-year-old tetraplegic with a spinal column injury (SCI) sustained in a mountaineering accident in 1981. My injury has left me disabled in all four limbs, without the ability to care for my own health and hygiene and therefore I am totally reliant on help with my care and hygiene needs.

I live in a semi-detached bungalow which has been adapted to cater for my disability needs. The house has a profile bed with dynamic mattress to prevent pressure sores. It also has an overhead trackline hoist which can move me from my wheelchair to my bed and vice versa.

I have an alarm system which is operated from my Environmental Control and I use this to summon help if required. My Environmental Control is used to control the various electrical pieces of equipment in my house such as television, radio, video, alarm system (above) etc.

I also cannot drive a car and therefore I need someone to take me about in my Wheelchair Accessible Vehicle (WAV).

ILF at Present:

- I receive 23 ILF hours for social inclusion plus 9½ hours gets paid to Community Integrated Care (CIC) for laundry, ironing, cooking and feeding, hoovering etc.
- I employ 2PAs (Personal Assistants) 3 times/week for 7½ hours each day and that leaves me with ½ of 1 hour left at the end of each week. I use this if some unforeseen event occurs that I may need to attend in the year.

If Independent Living Fund were to be scrapped, as proposed in year 2015 and replaced by funding from the Local Council's Social Work Department:

- I could not work anything near 16 hours/week and therefore would not be entitled to ILF under the new rules. This rule would discriminate against those who need ILF most.
- I would be severely limited in my ability to access the outside world and would only be able to sit outside in my garden or at my front door without assistance: i.e. I would be socially excluded from society.
- I would not be able to keep up to date with my finances and pay for my bills as any normal person would do. My PAs help me to do this.
- It is good to be able to pick what I want to eat and actively take part in how it is prepared for me.
- My two PAs would be out of work and registered as unemployed.

All money I receive from ILF is paid directly to my PAs by me and is used exclusively for them.

Restrictions On Social Care Budgeting:

- I would not be able to receive the same amount of funding from the Local Council as the Local Councils budget is also being cut. I do not believe any more money would
be paid by Central Government to Local Government to help pay for this extra funding on their financial pursestrings. I therefore believe I would be a lot worse off with this change in financial policy.

In light of what I have said (above) I do not believe my human rights have been catered for under Article 19 of the UN Convention on Human Rights for people with severe physical or mental disabilities. The nature of my disability is unchanged from where I was deemed to be entitled to ILF but due to economic factors this right would seem to be questionable. This is surely an oxymoron and a political fudge to achieve a cut in the budget at the expense of someone’s human rights.

**Discontinuation of Disability Living Allowance for People in Residential Care:**

Although I do not live in Residential Care I have on several occasions lived in a Nursing Home environment i.e. Residential Care. My experience of living in Residential Care is based on my entitlement to Disability Living Allowance, with the high rate mobility component, and a cost of living allowance paid to me each week.

I had my own car at that time and was grateful of it as I would have been severely restricted in my ability to interface with the outside world. At that time I was grateful for my higher rate of DLA as that helped to pay for the running of my car.

Anyone living in Residential Care without their Disability Living Allowance would be severely restricted in their social life and would find it difficult to pay for the items (below). If I had my car now I would not be able afford it on a cost of living allowance only and my quality of life would suffer as a result.

For any person living in Residential Care and assuming a cost of living allowance of approximately £20/week this would have had to cover:

- Any toiletries, clothing, food, snacks, drinks entrance costs for any outings they would have the good fortune to experience etc.
- Many residents in Residential Care enjoy 1 or 2 holidays/year and this would be impossible to continue with if they were only receiving cost of living allowance: i.e. a resident would have to pay rent for the holiday house, the carers who go on holiday with them, any travel or entrance fees to amusements or activities etc.

I have no evidence for my statements (above) as they are only based on common sense, reasoning and logic but I believe these facts to be true. I hope you will give my statements due consideration.

12 April 2011
Should the right to independent living continue to form the basis for Government policy on disability in the UK?

Absolutely—it is key to understanding and tackling the many barriers and continued entrenched inequalities that exist for disabled people. It is enshrined in the UNCRPD in article 19, but overall the UNCRPD upholds the principle that disabled people including disabled women and children must receive human rights on an equal basis to non-disabled people. At present this is not the case.

The proposed cuts by the Coalition show that this principle is being further undermined. The raft of disability supports which are being withdrawn can only impact negatively on disabled peoples’ human rights and their rights to independent living. From income depletion, reform of current systems of welfare to cuts to social housing, adaptations, housing benefits, loss of jobs in the public sector. All will impact negatively on disabled people to a greater extent including disabled children and families.

Do existing policy statements, including the Independent Living Strategy, represent a coherent policy towards the implementation of the obligations in Article 19 of the UN Disability Rights Convention? Could current policy be improved? If so, how?

We need more than policy rhetoric; we need a full and financed agreement that these issues are fundamental to disabled peoples’ equality. We need a financial commitment to make these happen, we need monitoring and sanctions for those who do not adhere to these principles. At the present time and given the current actions by the Coalition Government it seems unlikely that we will obtain any without a fight. The closure of the Independent Living Fund shows just how far the Coalition are committed to independent living and disabled peoples’ rights.

Existing policy statements appear meaningless. It serves no purpose to create and publicise Independent Living Strategies at the front door while surreptitiously removing all supports to that principle by the back door. The points laid out in the strategy go some way towards realising article 19, but still it is not enough. We need a commitment to accessible housing, inclusive design, new builds, and enough resources to be able to develop adaptations where they are needed and enough community support resources to support those who may need more support to be able to live in the community securely and comfortably. At present that aim is moving further away rather than moving closer to realisation.

What steps, if any, should the Coalition Government, the Scottish Government or other public agencies take better to meet the obligations in Article 19 and to secure the right to independent living for all disabled people in the UK?

Realise that there are extra costs of disability for individuals. We hear ministers saying they agree with the social model, they wish to support those in greatest need and so on. Yet all too often their actions prove that these words are empty of any merit. Disabled people and the disabled peoples’ movement continue to fight the same battles, and make the same arguments time and time again. If there was a real commitment to disabled people and to independent living we wouldn’t need to. We are currently at a stage where we are fighting
to retain the supports for independent living that were fought for in the 1980s- and sadly we are losing.

Article 19 stresses that people should be able to choose where they live and with whom they live and that they should be fully supported within the community regarding different needs. At present these principles are bring severely eroded. They are being eroded through caps on housing benefit in social housing (on which many disabled people depend), removal of the security of tenure from social housing, increases in social housing rents and rents by private landlords.

However, the principle of independent living is not just about where somebody lives, but how they live too- taking away supports, rights and benefits that have functioned to allow disabled people in the UK to be envied throughout Europe. The UK has now changed from an example of how things can be done to achieve rights for disabled people to an example of how fast those rights can be taken away.

**If you consider changes to policies, practices or legislation in the UK are necessary, please explain.**

See all above

**Impact of funding on the right to independent living**

The Committee would particularly welcome evidence on these recent developments:

**The decision, announced in the CSR, to remove the mobility component of Disability Living Allowance for all people living in residential care**

**Changes to the Independent Living Fund**

The removal of the mobility component of Disability Living Allowance announced in the CSR will impede and will remove all hope of independence from those in residential homes. Many will be left with £22 per week for basics. The Coalition claim that disabled people will be taken out by the staff, yet this shows the complete lack of understanding of residential homes and the uses of the mobility component of DLA. Many use this to purchase wheelchairs, scooters etc.

The closure of the Independent Living Fund is short term and opportunistic. Its closure acts as one of the most obvious actions of the Government in undermining the principles, financial supports and understanding of independent living. While it has been agreed that 23,000 ‘severely disabled’ people will stay on the scheme. We have yet to see how the planned abolition of DLA including the higher rate—a marker for continued entitlement to ILF will affect existing claimants. In addition, Adult Social Care in many areas have raised eligibility thresholds while lessening budgets- this will mean that a number of pre-existing ILF claimants may fail to reach the qualifying threshold and therefore lose their entitlement too.

"**The Big Society**"
Restrictions on local authority funding, social care budgets and benefits reassessments

People are losing cash; local authorities even admit that people are losing cash for care. Social workers are saying that disabled people will be lucky if they reach the qualifying criteria for Adult Social Care. Some council’s are attempting to introduce a Benefit, reassessments are causing the most severe emotional and financial destruction evidenced by endless stories in the media.

Increased focus on localisation and its potential impact on care provision, and specifically, on portability of care and mobility for disabled people

What impact does funding have on the ability of the UK to secure the right to independent living protected by Article 19 of the UN Disability Rights Convention?

It makes null and void any ability to do this

How will recent policy and budgetary decisions impact on the ability of the UK to meet its obligation under Article 19 to protect the right of all persons to independent living?

They’ll destroy it

Participation and consultation

What steps should the Government take to meet its obligations under the Disability Rights Convention to involve disabled people in policy development and decision-making, including in budget decisions such as the Comprehensive Spending Review?

Governments should include all user led disability organisations, they may have sections of disability charities and charity coalitions feeding into policy at various points—however, charities do not represent the views of disabled people—only user led organisations can do this. In particular the National Centre for Independent Living is a long standing user-led organisation which sees the impacts of the cuts and proposed cuts on independent living issues. In addition, a break away from a London Centric base would be useful. For example local CILs should be involved in meeting with ministers too, for face-to-face meetings which can set the picture. Written consultations are timely and it is not clear how much or how often points raised within them are taken on board. A Government with a commitment to disabled people should accept that disabled peoples views represent the expert views on living in a disabling society.

Are the current arrangements for involvement of disabled people in policy development and decision-making working?

No. The recent spate of proposed cuts shows that it is not. The Governments’ misinformation on DLA for example as a benefit that prevents disabled people from working was a major error repeated by the media. As far as I know this has not been corrected or rectified. The Government have merely added that DLA is a difficult benefit to understand. There may be a number of paper consultations going out, but these appear to do little but attempt to give the impression that people are being listened to- in reality few people believe that paper consultations do very much to change things, and act as a pacifier. There appears to be little face-to-face involvement with disabled peoples’ organisations, (by which I
mean those run and controlled by disabled people) if this does happen, it appears that the organisations claim that they have not been listened to. Disabled people are fed up with token consultations and want involvement, to be listened to and to be accepted as the experts on disability, disabling barriers and disabling policies, that they are.

One clear example is the Work Capability Assessment or WCA carried out by target driven Atos Origin for the migration from Incapacity Benefit to Employment Support Allowance. Despite the Harrington Report, complaints by DPO’s and CAB’s we are still hearing stories of individuals being declared ‘fit for work’ and placed into the work ready group who have terminal illness, months to live, and/or need 24 hour support.

**Monitoring the effective implementation of the Convention**

*What steps should Government take to ensure that disabled people’s views are taken into account when drafting their reports to the UN under the UNCRPD?*

There are already a range of groups involved in this for England: UKDPC, EHRC, and Disability Rights Watch. However local CILs and organisations run and controlled by disabled people should also be encouraged to provide input into this through shadow reports, or through examples of real life experiences in their localities. Local groups should also be given the support to set a base-line measurement of where they believe their locality is in satisfying the key articles of the convention.

This will be of great use in the 3 intervening years until the next monitoring report is due in terms of identifying a) impact of the cuts b) impact on independent living c) measurement of those things that may have improved.

In addition, individuals should be encouraged and supported to provide input into the monitoring process. The UK is in a better position than most European countries in having user-led groups involved in the monitoring process, but to rely on a few organisations for monitoring purposes is a mistake.

*As part of the national monitoring mechanism, what steps should the EHRC, NIHRC and SHRC take to ensure that the Convention is implemented effectively?*

The EHRC should be a much stronger force for action and sanctions when the convention is thwarted. Currently there is little confidence in the EHRC to uphold, critique or act upon the abuse of disability equality issues overall. This is unlikely to change for the UNCRPD which will be seen as something peripheral to issues arising in the current negative economic and media led rhetorical onslaught on disabled people. Sanctions need to be imposed on those who do not implement effectively by the EHRC but as they (EHRC) are still under review by the Coalition, it is unlikely that this ‘independent body’ will act too ‘independently’ with their survival at stake.

17 April 2011
Written Evidence submitted by RNIB and Action for blind people (IL 25)

Executive Summary

- The right to independent living should continue to be the basis for government policy in relation to disabled people. To make a difference for people with a visual impairment we need to see great improvements in the provision of accessible information.

- Not enough has been achieved in the three-year period since the Independent Living Strategy was published for the government to change direction. Indeed the government has introduced a number of measures that threaten the incomes and independence of disabled people, for instance the proposal to remove the mobility component of Disability Living Allowance from people in state-funded residential care.

- Social care is an increasingly severely rationed area and the responses we received from blind and partially sighted people reflected this. Visual impairment was generally thought to be low on the social care agenda.

- We need the government to urgently clarify its plans for achieving disability equality.

- We would like the government to clarify what mechanisms it has in place to monitor whether the life chances of disabled people are improving.

- Given the very low level of awareness of the Disability Rights Convention's existence, much more awareness-raising is needed if the government is to get real and meaningful input from disabled people to the monitoring and reporting on the Convention.

1. Introduction

1.1 In July 2010 and then again in early 2011, the Office for Disability Issues (ODI) at the Department for Work and Pensions asked us to undertake a survey of blind and partially sighted people’s perceptions of aspects of independent living, using networks of appropriate organisations to tap experiences. The ODI also asked us for our assessment of the UK’s performance in implementing the UN Convention on the Rights of Persons with Disabilities.

1.2 We undertook research to find out more about the experiences of people living with sight loss. In early 2011 we provided additional evidence concerning Article 19 of the UN Convention (on independent living). We were also invited to comment on the impact of the Comprehensive Spending Review on the government’s aspirations to achieve independent living. The original research, which we carried out last summer, was relatively small-scale and qualitative. We were able to draw on the evidence of 42 blind and partially sighted people.

1.3 The people we surveyed on the exercise concerning independent living highlighted the ongoing barriers blind and partially sighted people experience trying to get information in accessible formats. They also talked about the struggle to secure employment and the challenges they face trying to live independently in their communities. The response
delivered to us by blind and partially sighted people is that change, where it is
taking place is incremental at best.

1.4 The response delivered to us by blind and partially sighted people is that much more
needs to be done to promote the UN Convention. Articles 9 (Accessibility), 21 (Access to
Information) and 27 (Employment) were the three areas covered by the UN Convention
that blind and partially sighted people most often raised as important. **In all three areas,**
we believe that the government can do far more to ensure that it meets the
Convention’s requirements.

2. The right to independent living

- **Should the right to independent living continue to form the basis for**
  Government policy on disability in the UK?

2.1 Our research suggests that many blind and partially sighted people feel policies on
independent living have not yet translated into improvements in their own lives.

2.2 A recurrent theme from the responses we received to our 2010 survey was the
frequency with which information in various areas—notably employment, health, social care,
leisure and consumer goods—was not available in accessible formats. The Equality Act
generally required that, from October 2010, information is provided in an accessible format.
It is essential that this obligation is honoured but members tell us that they are still being
denied access to the information they need to live independently.

**The right to independent living should continue to be the basis for government policy but for this to make a difference for people with a visual impairment we need to see great improvements in the provision of accessible information.**

2.3 There were varied experiences with the NHS, but social care attracted markedly more
negative than positive comments. Social care is an increasingly severely rationed area and the
responses we received to our survey reflected this. Visual impairment was generally thought
to be low on the social care agenda.

2.4 A main interest of the questionnaire compiled by the ODI on perceptions on aspects of
independent living was the extent to which experiences had changed over the previous three
years. It was difficult to get respondents to engage with this theme. It seemed that, on the
whole, their perceptions (positive and negative) had not greatly changed for better or worse
within that relatively short span of time.

2.5. **Not enough has been achieved in the three-year period since the**
Independent Living Strategy was published for the government to change
direction. Indeed the government has recently introduced a number of measures that
threaten the incomes and independence of disabled people, for instance the proposal to
remove the mobility component of Disability Living Allowance from people in state-funded
residential care. In our view measures like these bring into sharp focus how far we still have
to go if the UK is to achieve its goal of disability equality by 2025.

- **Do existing policy statements, including the Independent Living Strategy, represent a coherent policy towards the implementation of the obligations in Article 19 of the UN Disability Rights Convention?**
• **Could current policy be improved? If so, how?**

2.6 In terms of its actual impact the Independent Living Strategy no longer appears the best tool for implementing the obligations in Article 19 of the Disability Rights Convention.

2.7 Early on we could see how the strategy "added value". The publication of the NHS Constitution and the document "Transforming Adult Social Care" provided evidence the strategy encouraged integrated policy-making in relation to disabled people.

2.8 However, we are increasingly uncertain this remains the case. The strategy was supposed to be the sticking glue joining up government policy so that it delivered for disabled people. However, the proposals on removing DLA mobility from people with disabilities in state-funded residential care raise serious questions about the practical value of the strategy. In fact we have even heard the government no longer places much emphasis on the strategy and is busy developing new plans.

**We need the government to urgently clarify its plans for achieving disability equality.**

2.9 The proposals on DLA mobility represent a threat to Article 19 and the aspirations of the Independent Living Strategy but nonetheless they seemed to pass through any screening process we assumed the ODI would have been responsible for. The policy was accompanied by an equality impact assessment but there now appears to be very little reference, if any at all, to the aims of the Independent Living Strategy.

2.10 There are few (recent) updates on what has been achieved as part of the Independent Living Strategy on the relevant section of the ODI's website. A great deal of momentum has been lost. Either the Independent Living Strategy needs urgent resuscitation or the government should clarify the alternative steps it will take to achieve its goal of disability equality by 2025, assuming that is still the goal of central government.

• **What steps, if any, should the coalition Government, the Scottish Government or other public agencies take better to meet the obligations in Article 19 and to secure the right to independent living for all disabled people in the UK?**

• **If you consider changes to policies, practices or legislation in the UK are necessary, please explain.**

2.11 In our survey we asked blind and partially sighted people about the UK’s current and planned efforts to meet the requirements of Article 19. The feedback identified many barriers. The top three were a lack of public service personnel awareness and understanding of visual impairment and disability generally; a lack of information in accessible formats and inaccessible consumer goods and services.

2.12 Blind and partially sighted people called for the following remedies to these barriers:

(a) Lack of public service personnel awareness and understanding of visual impairment and disability generally -provide/ improve disability awareness training for personnel.
(b) Inaccessible consumer goods and services—transport should be made easier and safer.

2.13 We were delighted that the European Parliament approved new regulations on passenger rights for bus and coach travel - the new rights will come into force in 2013. Importantly they will apply to all journeys, including local bus services. The rights, which focus on the needs of disabled people and those with reduced mobility, include mandatory disability-awareness training of staff of buses and coaches.

We urge the government to implement the provision on disability-awareness training for drivers at the soonest possible date.

2.14 There are many other steps the government and public agencies could take to better meet the obligations on Article 19. Clearly disability awareness training would be a top priority, not just on coach and bus travel but in many areas of service provision.

2.15 As a minimum we would like to the government to uphold the commitments that have already been enshrined in law, both in the Equality Act 2010 and the UN Convention on the Rights of Persons with Disabilities, which came into force in 2009. In a similar vein, we would like public authorities to meet their obligations under the Public Sector Equality Duty, which involves eliminating discrimination. This brings us to the final remedy blind and partially sighted people identified as a priority.

(a) Lack of information in accessible formats—live up to the Equality Act 2010 and always provide public service information and correspondence in a full range of accessible formats.

2.16 Still too few blind and partially sighted people receive information in a format they can read. Fewer than one in five councils we surveyed in England and Wales confirmed that they provide their council tax forms in large print, audio or braille1. Shockingly nearly three-quarters (74 and 72 per cent) of blind and partially sighted people cannot read the information provided by their hospital or their GP2.

2.17 However some public authorities have taken their obligations seriously, for example NHS Mid Yorkshire has become the first known organisation in the NHS to modify its hospital appointments and pharmacy system, now providing health information in an accessible format. We want other public services to follow the lead set by Mid Yorkshire. This means health services and local councils eliminating discrimination by systematically recording the format that blind and partially sighted people prefer to receive information in. Only then can people with sight loss truly feel independent when using NHS services.

2.18 The previous government promised to consider the legislative route for achieving its goals on independent living unless adequate progress had taken place by 2013.

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1 Lost for words report, Kaye A, Marriott J, Royal National Institute of Blind People (RNIB), 2010

2 Towards an inclusive health service: a report into the availability of health information for blind and partially sighted people, Dr Foster Intelligence, 2009.
We would like the government to clarify under what circumstances legislative action would be ruled out and the mechanisms it has in place to monitor whether the life chances of disabled people are improving.

3. Impact of funding on the right to independent living

- What impact does funding have on the ability of the UK to secure the right to independent living protected by Article 19 of the UN Disability Rights Convention?
- How will recent policy and budgetary decisions impact on the ability of the UK to meet its obligation under Article 19 to protect the right of all persons to independent living?

3.1 Blind and partially sighted people are concerned that the UK Government’s planned cuts to benefits will undermine the enjoyment of their rights under Article 19. They also have concerns about practical help to enable independent living, which is to be restricted to a shrinking pool of disabled people. A reduction in free or low cost advice and representation for blind and partially sighted people in areas like welfare and housing clearly presents another significant risk to the enjoyment of their rights under Article 19.

3.2 Research shows that local services provided to blind and partially sighted people are already of variable quality. 20 per cent of people say they do not recall receiving any visit from social services in the year after they registered as blind or partially sighted. In the year after registration, less than a quarter (23 per cent) of people who lost their sight say they were offered mobility training to help them get around independently. The new context of austerity, with extensive benefit and service cuts, threatens to make matters a lot worse, rather than better.

3.3 Measures contributing to £18 billion welfare cuts will undoubtedly have an effect on the ability of the UK to secure the right to independent living. Key threats to blind and partially sighted people are:

(a) Replacing Disability Living Allowance (DLA) with a “Personal Independence Payment”, using a new assessment. This could mean a reduction of up to one fifth of the overall numbers able to receive the benefit (from April 2013) with possibly 12,000 people registered blind or partially sighted losing their DLA entitlement from this date.

(c) Reductions in Housing Benefits. A wide range of Housing Benefit cuts will also affect blind and partially sighted people, particularly private sector tenants.

(d) Changes to Incapacity Benefits and Employment and Support Allowance. The government has tabled regulations that will give effect to new eligibility criteria (called “descriptors”) which may mean very few blind and partially sighted people qualify for Employment and Support Allowance. It seems likely that the changes in the system will mean that blind and partially sighted people will be found fit for

3 Lost and Found report, Kaye A, Royal National Institute of Blind People (RNIB), 2009
work but without the support to enable them to take up employment opportunities.

(e) **Limited access to in-work support.** We are also concerned about government plans to reduce the scope of the vital and valuable Access to Work scheme, which provides funds to enable employers to buy essential equipment to support disabled people in the workplace. Access to Work needs to be properly funded if government plans to move disabled people off benefits and help them into work are to bear fruit.

- **The decision, announced in the CSR, to remove the mobility component of Disability Living Allowance for all people living in residential care**

3.4 Another key threat is (e)—the removal the mobility component of DLA for state-funded claimants in residential care. This could affect up to 80,000 individuals in total (starting from 2013). It presupposes that disabled people in residential care do not need to get around and participate in their community. It also assumes that residents already have their personal mobility needs met by their care provider. This assumption is wrong and runs contrary to the rights in Article 19.

3.5 A recent report from organisations of disabled people provides evidence that many disabled people in residential care rely on DLA to meet their personal mobility needs. The government has promised to review whether there is an overlap in funding for residents’ personal mobility needs but plans to remove DLA mobility from people in residential care are still included in the Welfare Reform Bill, currently going through Parliament.

3.6 In general terms, the reduction in disability-related benefits will make life harder for blind and partially sighted people. Collectively these and other cuts in welfare are likely to work against people seeking to exercise a right to earn a living through work that they have freely chosen.

- **Restrictions on local authority funding, social care budgets and benefits reassessments**

3.7 We have started monitoring the impact of local authority and other public service cuts to establish whether the services blind and partially sighted people depend on most are being affected. Taking into account that blind and partially sighted people often require additional help to exercise their freedoms - for example to access social opportunities - we are left to conclude that changes in welfare provision, coupled with cuts at a local level, will leave many more blind and partially sighted people adrift.

3.8 In areas like adult social care, the provision of community travel schemes, street maintenance and repairs and access to leisure and library services, we are hearing from blind

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4 Don’t Limit Mobility: The impact of the removal of the mobility component of Disability Living Allowance from adults and children in state-funded residential care, Mencap and 27 other organisations, 2011.
and partially sighted people about cuts that threaten to undermine the government's vision of empowered communities. Moreover, changes to the Social Fund, the Independent Living Fund and the removal of ring-fences from the Supporting People grant will all have a damaging impact. The Supporting People grant is intended to support society's most vulnerable to achieve independent living. However with the loss of the ring-fence protection, we are already seeing local authorities cutting Supporting People services and funds being diverted elsewhere.

3.9 Two in five people registered blind and partially sighted normally rely on buses as their main mode of travel (Pavey, Dodgson, Douglas and Clements, 2009). Unfortunately we have recently heard about a number of cuts to concessionary travel schemes, which enable blind and partially sighted people to travel on buses free or at a subsidised rate off-peak. Sometimes local authorities offer discretionary concessions, which means an individual with a serious sight problem can travel with a companion and the companion is able to travel for free. However, in areas as diverse as Harrow, Kent, Norfolk and Rochdale all of these concessions are being reduced or withdrawn. Many of the people getting in touch with us are expressing concerns they will no longer find it so easy to leave the home.

3.10 We already know many blind and partially sighted people are rationed out of care services because they are deemed as having "moderate" or "low" needs. We are hearing of councils like Birmingham City Council that plan to restrict the use of council funded care to people in the "critical" band. New guidance on eligibility for care services was published in February 2010. It sought to reflect the increased focus on personalisation and prevention as set out in the Putting People First strategy. The revised guidance and equality impact assessment carried out prior to its publication recognised that blind and partially sighted people may be disadvantaged by assessors not understanding the impact of sight loss; it is vital that authorities recognise this failing and work to ensure that blind and partially sighted people are treated fairly and do not miss out on essential support and services.

3.11 It is disappointing that a year has passed and very little has changed. Adult social care services still appear to have very little appreciation of the barriers blind and partially sighted people experience to living independently. Social care assessments are still built around a "deficit model" meaning they focus on what individuals cannot do rather than identifying the support individuals would like to achieve full independence.

3.12 The cuts being proposed in some areas are unprecedented in terms of their scale and their impact on people living with sight loss. In late 2010 Norfolk County Council proposed to close the Sensory Support Unit for people who have lost their sight. Following a period of consultation, in early 2011 it decided to shave forty per cent off the service's budget. This is a service that provides rehabilitative support to people adjusting to a life without sight. These cuts are clearly non-trivial. The unit, which costs £1.1 million to run, deals with 2,000 assessments a year and has 1,962 people receiving its services. Local people that have

5 Prioritising need in the context of Putting People First: a whole system approach to eligibility for social care—guidance on eligibility criteria for adult social care, England 2010 (Department of Health.)
benefited from the Sensory Support Unit claim the changes will end up costing more in the longer-term as people have to move into residential care or become more isolated and marginalised.

- **The Big Society**

3.13 The reality that many of our members are facing is so far at odds with the vision of empowered communities it raises really serious questions about whether or not the 'Big Society' will help blind and partially sighted people. In fact we believe that the cuts outlined above would leave many blind and partially sighted people without the means to live independently and fully participate in their communities. As such, we believe the proposed cuts do not fit with the UK’s obligations under Article 19 of the Convention.

3.14 Getting and keeping a job, accessing transport, receiving benefits to be able to live as part of the community, being able to read information, access health services and buy and use goods and services: all these fall under Articles 9, 19, 21 and 27 of the UN Convention and all are essential to living a decent life. In the UK, blind and partially sighted people do not yet enjoy equality with their sighted peers in any of these areas, and in some of them the UK looks set to move further away from achieving equality.

**4. Participation and consultation**

- Are the current arrangements for involvement of disabled people in policy development and decision-making working?

4.1 We have been participating in the "Network of Networks", which means we have gathered blind and partially sighted people's insights on government policy for the Office for Disability Issues. Other disabled people's organisations were involved too. Although this worked fairly well it is clearly not the only way of involving disabled people in policy development and decision-making.

4.2 We are aware of a number of advisory groups, which provide Ministers and officials with direct access to disabled people. Groups like Equality 2025 provide essential guidance and advice on strategy but government must not assume that by consulting these groups that it has fully involved disabled people in decision-making.

4.3 Recent developments cast some doubt over the government's commitments to eliminate discrimination. In recent weeks the Cabinet Office has launched a web-consultation called "The Red Tape Challenge" which invites views on whether the Equality Act should be repealed. A new consultation recently launched by the Government Equalities Office questions whether the Specific Duties brought into effect through the Equality Act are too burdensome. To ensure policy development and decision-making continues to involve disabled people we need to guard against new threats to anti-discrimination legislation.

**5. Monitoring the effective implementation of the Convention**

5.1 Our research shows that the Convention is important to many blind and partially sighted people, once they know about it. However, the majority had never heard of it.

**More needs to be done to raise awareness of the Disability Rights Convention’s existence and contents.**
5.2 Respondents wanted to know the contents of the Convention but most importantly they wanted a clear expression of how it will affect their lives. Our research shows also that the Convention can be misunderstood, and that its relevance to the UK needs spelling out. We found much support for the Convention, but some cynicism that it would not bemeaningfully implemented.

5.3 Clearly, for blind and partially sighted people, information about the Convention needs to be provided in accessible formats. Many also wanted to be informed about the Convention in face-to-face meetings or through simple and clear briefings.

5.4 Some respondents expressed scepticism about the Convention. Discussion with our members in particular reveals that two concerns lie behind such responses. Firstly, to some the Convention seems too broad and vague to apply in practice. Secondly, there is the impression that like other discrimination law, a law’s existence does not guarantee its enforcement.

“I will only acknowledge the importance of the convention when I become aware of specific “improvements” in the life of disabled folk that have been brought about through its activities/campaigns.”

5.5 Respondents acknowledged that many areas of life covered by the Convention were important to them. However, three Articles, 9, 21 and 27, figured particularly highly in the responses we received.

“I think the convention is important for disabled people as it helps to reduce the barriers that disabled people face in everyday life. For example making information more accessible by stressing people’s rights to have access to information and making this a duty for people providing that information.”

- What steps should Government take to ensure that disabled people’s views are taken into account when drafting their reports to the UN under the UNCRPD?

5.6 Given the very low level of awareness of the Convention’s existence, much more awareness-raising is needed if the government is to get real and meaningful input from disabled people to the monitoring and reporting on the Convention.

5.7 RNIB and Action have done some of this work through the "Network of Networks", which possibly represents one route for ensuring disabled people's views are taken into account. However, we believe that the government, the Equalities and Human Rights Commission and the whole of the disability sector have a big awareness-raising task ahead if disabled people are to become acquainted with the Convention.

5.8 The current lack of awareness of the Convention is an obstacle to ensuring the active and full participation of disabled people’s organisations in the implementation, monitoring and reporting on the Convention.

6. Conclusion
Independent living should still serve as the basis for policy making in relation to disabled people, but it is unclear what emphasis the government wishes to place on the Independent Living Strategy. For the government to meet its obligations on Article 19 in the UN Convention on the Rights of Persons with Disabilities it needs to clarify its plans, especially now cuts in services and welfare pose new threats to the independence of blind and partially sighted people.

21 April 2011
Summary of our written evidence:

In our written evidence we suggest a variety of areas where the right to independent living is being restricted by government policies and funding decisions. We address policies around employment, benefits, access to justice, access to information, eligibility criteria and we consider the human rights implications of recent government actions. We make fourteen recommendations as part of our written evidence.

Recommendations:

1. Increase the availability of supported housing.

2. Each police force should have a disability hate crime strategy that brings in the expertise of disabled people to develop it and support officers to implement it.

3. There should be regional funding for third party reporting centres that increase the numbers of people reporting hate crime and provide them with support as victims and making sure the case is followed up.

4. Parliament needs to pass a legal right to support in order to access information that anybody else would have access to.

5. Increase the training for staff who deal with the public on how to increase disabled people’s access to their rights.

6. Look at the quality of training that employment advisors get, particularly whether they are given training and standard about supporting disabled people.

7. Disabled people could be brought in who have experienced the world of work to advise employment advisors on the barriers they faced and how they overcame them.

8. There need to be programmes supporting families to stay together rather than tearing families apart and taking away people’s right to a family life.

9. Funding Self-Advocacy groups is a way of giving support, employment and the opportunities for independent living to people with learning difficulties. If the government is serious about its goals for increasing independent living and employment of disabled people it needs to provide emergency funding to prevent the closure of Self-Advocacy groups.

10. Support should not be denied on the basis that you want to make choices about your life that everyone else can make including getting married, having children or having a job.

11. Government needs to fund outreach work including conferences explaining the benefits changes to people with learning difficulties across the UK.

12. The mobility component for people living in residential care home should be kept.
12. To spend money wisely increasing independent living policy-makers need to look at the people skills necessary for implementing the policy. Without this services and new policies will not be implemented well. Working with Disabled People’s Organisations is important for doing this well.

13. Having more disabled people publically discussing their rights would be a positive step towards increasing understanding of human rights and their importance for disabled people.

Who we are:

People First is a self-advocacy organisation run by people with learning difficulties. We coordinate a network of 97 local self advocacy groups across the UK.

Right to Independent Living

People First believes that increasing Independent Living is a vital principle for government policies. We welcome this inquiry. We hope that the committee will look at the excellent principles in the Independent Living Bill put forward by Lord Ashley.

There is more the government could be doing to give disabled people the same rights as everybody else to live independently. The main barriers are:

- Availability of supported housing.

RECOMMENDATION: Increase the availability of supported housing.

- Lack of communication between councils and housing associations which is important for providing joined up support to people with learning difficulties.

- Harassment and hate crime experienced by disabled people is a barrier to independent living. There is a shortage of people providing support to deal with hate crime and its not be taken seriously by the police. There is a generally dismissive attitudes towards disabled people experiencing bullying and harassment. At present disabled people do not feel they have access to justice.

RECOMMENDATION: Each police force should have a disability hate crime strategy that brings in the expertise of disabled people to develop it and support officers to implement it.

RECOMMENDATION: There should be regional funding for third party reporting centres that increase the numbers of people reporting hate crime and provide them with support as victims and making sure the case is followed up.

- Lack of accessible information day to day is a barrier for people with learning difficulties making informed and independent choices. It also means that you may not know your rights, for instance as a tenant.

RECOMMENDATION: Parliament needs to pass a legal right to support in order to access information that anybody else would have access to.
Written Evidence submitted by People First (IL 26)

- Lack of understanding about disabled people’s right to access information and right to independent living amongst the general public. This has an impact on the way disabled people are treated and their rights are restricted. The public often see the disability, not the ability.

RECOMMENDATION: Increase the training for staff who deal with the public on how to increase disabled people’s access to their rights.

- The training that employment advisor receive does not prepare them to support disabled people fulfilling their ambitions and entering well paid and stimulating jobs.

RECOMMENDATION: Look at the quality of training that employment advisors get, particularly whether they are given training and standard about supporting disabled people.

RECOMMENDATION: Disabled people could be brought in who have experienced the world of work to advise employment advisors on the barriers they faced and how they overcame them.

- Employers hold discriminatory attitudes towards disabled people. They may not know about the support available to their organisation such as Access to Work.

- There is not proper enforcement of disabled people’s right to independent living.

- Parents with learning difficulties are frequently prevented from keeping their children.

RECOMMENDATION: There need to be programmes supporting families to stay together rather than tearing families apart and taking away people’s right to a family life.

The impact of funding and policy changes

- There is a shortage of support services and this is getting worse. People First groups across the UK face closure or their funding cut severely. The impact of this is that support structures that self-advocacy groups provide will no longer be there. The support that people need to make independent choices will be gone. The role these groups had preventing people who were living independently from reaching crisis point will not be there. This will mean that people’s access to independent living is being worsened.

RECOMMENDATION: Funding Self-Advocacy groups is a way of giving support, employment and the opportunities for independent living to people with learning difficulties. If the government is serious about its goals for increasing independent living and employment of disabled people it needs to provide emergency funding to prevent the closure of Self-Advocacy groups.
People with learning difficulties can be denied support from a social worker because they are living in a couple rather than living alone. The choice to be in a relationship is penalised by not being entitled to support.

RECOMMENDATION: Support should not be denied on the basis that you want to make choices about your life that everyone else can make including getting married, having children or having a job.

- People do not understand what is meant by the Big Society and are sceptical of the things said about it.
- The changes that the government is making to benefits have not been explained clearly or accessibly. As a result people with learning difficulties are frightened about what is going to happen. For example, because of the way changes are reported, many people with learning difficulties know that DLA is being stopped but they do not know that PIP is replacing it. They are afraid they will not have money to live on.

RECOMMENDATION: Government needs to fund outreach work including conferences explaining the benefits changes to people with learning difficulties across the UK.

- Removing the mobility component of DLA for people in residential care goes against independent living and everything that this inquiry would want to achieve.

RECOMMENDATION: The mobility component for people living in residential care home should be kept.

- The Learning Disability Coalition recent report Social Care: The Continuing Crisis showed the negative effect that local authority budget restrictions are going to have on the important services and support that people with learning difficulties need. For example, 65% of people with learning difficulties want to work whilst 6% currently do. The LDC research found that 38% councils expect to cut specialist employment services.
- Without the Independent Living Fund there will be more barriers for disabled people living independently.
- These changes make independent living less achievable for many disabled people. At the same time making such deep cuts to budgets mean that there will be greater long-term financial and personal costs dealing with the crises that developed because of lack of support services.

RECOMMENDATION: To spend money wisely increasing independent living policy-makers need to look at the people skills necessary for implementing the policy. Without this services and new policies will not be implemented well. Working with Disabled People’s Organisations is important for doing this well.

Participation and consultation

- The government has already taken action to get Disabled People’s Organisations involved by running a steering group. People First is a member of this group. We
have been putting forward suggestions around accessibility and Article 19 in particular.

- To take part properly people with learning difficulties need to understand their rights. All of the information in the UN Convention on the Rights of Persons with Disabilities needs to be put in accessible formats if the government is going to fulfil its responsibilities as a signatory.

- It is important that disabled people and the public have confidence in the bodies responsible for making sure people get their rights. We hope that this Committee can be part of the process of building confidence in the bodies that enforce human rights.

RECOMMENDATION: Having more disabled people publically discussing their rights would be a positive step towards increasing understanding of human rights and their importance for disabled people.

21 April 2011
Written Evidence submitted by Choices and Rights Disability Coalition and North Bank Forum (IL 27)

1. THE RIGHT TO INDEPENDENT LIVING

1.1 Could the Government do more to give disabled people the same rights as everyone else to live independently?

Overall, the group felt that the Government could do more to ensure that disabled people have the same right as everyone else to live independently. One person stated that:

‘At the moment we are safeguarding the rights we have rather than asking for new ones’

1.2 What could they do to make this happen?

Generally, the group felt that the current Coalition Government’s agenda of strict cuts, many of which affect disabled people and their ability to live independently, should be slowed and in some instances such as Disability Living Allowance should be stopped. Although the group acknowledge that the deficit should be paid there was a worry that disabled people were going to be a group hardest hit. This is due to the massive inequalities that exist between disabled people and non disabled people. Disabled people are more likely to live in poverty, be unemployed and consequently be the ones most reliant of services and benefits which they need to maintain their quality of life.

Some of the group felt that this consultation should have happened much earlier as decisions have already been made about the services, funding and benefits need to live independently.

‘There was a general feeling from the group of too little too late—why are the government concerned with asking the views of people with disabilities now?—When decisions have been made and policies are already being implemented’

1.3 Do you think the Government needs to change any laws or the way it does things?

There are many laws that exist which are there to protect disabled people; however there is no support, guidance or advocacy available to support disabled people to exercise these rights. One of the respondents stated that it would support disabled people if organisations could take a DDA case out on behalf of an individual. This would limit the stress and emotional work placed on the individual.

‘People are scared of the implications and repercussions of taking out a DDA case [...] losing their job [...] or being barred from a leisure facility’

‘There is no point having the rights if it is impossible to access them or challenge them’

The group were concerned regarding proposals that the UK Equality and Human Right Commission could be losing their funding to provide much needed advocacy services in the area of gaining rights. The group recognised that this could include disabled people gaining support with exercising rights under Disability Discrimination.
The group were also concerned about the cost of legal fees to exercise rights and that they would put off many disabled people. Also finding a solicitor who was willing to take on a DDA case was perceived to be an issue.

‘Access to a solicitor can be impossible, as there is no legal aid, and disabled people on benefits cannot get a solicitor’

Within this context the group felt that rights were easier to gain if you had money therefore were not easily attainable for poor people which include many disabled people.

1.4 If so, what needs to change?

The group agreed that a legal aid should be provided for disabled people attempting to exercise their rights and that advocacy services should be funded so that disabled people can gain the support they need to gain access to rights.

‘Support services are needed for disabled people to challenge their rights in the realm in the context of: Housing, education, employment and benefits’

Information currently provided in this area should be accessible which means provision for Deaf people; this will need to include access to a British Sign Language interpreter.

2. LACK OF MONEY

The government needs to save money. The Joint Committee would like to hear how people have been affected by:

2.1 Changes to benefits

The group discussed how the changes in benefits have only just started to impact on disabled people. It was felt that any discussions in this area needed to include what the perceived effects would be once changes to benefits such as the Disability Living Allowance were in operation.

The Incapacity Benefit reassessment programme and changes in the mobility component for people who live in residential care was discussed In regards to reassessment of Incapacity Benefit claimants, the group felt that this programme was solely focused on reducing the numbers of claimants rather than supporting ill and disabled people who are unable to work. The impact of this has been the development of much stricter criteria for levels of capacity people need to be eligible for Incapacity Benefit.

‘My friend has had a stroke; this has left her partially sighted and restricted use of her arms. Up until now she has been claiming incapacity benefit. She has just been assessed and they have stated that she is fit for work [...] they just stopped her benefits [...] she is appealing but until then she is just left’

Another respondent raised the issue of practical arrangements of assessments for Incapacity Benefit in regards to accessibility of venues and information

‘The assessments were held on the fourth floor [...] the information provided was not accessible [...] Deaf people are always missed out, they just presume that a Deaf person can read’
Written Evidence submitted by Choices and Rights Disability Coalition and North Bank Forum (IL 27)

One respondent stated that ill and disabled people will be forced onto Jobseekers Allowance and then made to enter job programmes. One respondent explained that

‘I have been on work experience programmes that have had me painting benches and doing gardening [...] my boyfriend said it was like Community Service’

It is well documented that disabled people suffer more than any other minority group in regards to inequality in areas such as employment and education. The group believed that these inequalities were fuelled by discrimination of disabled people particularly in the areas of work.

‘Employers think that disabled people will continually be on sick and won’t work as hard as non-disabled people [...] this is not often the case [...] being an employer of disabled people I think disabled people actually work harder’

Because of this and with the additional complexities that the current UK’s economic climate brings, the group felt that disabled people will be plunged into deeper poverty from which they cannot recover. Additionally the group were worried that disabled people would be forced into low skilled ‘voluntary’ work programmes that would impact on their confidence, self esteem and mental health.

The group discussed the dilemma people with fluctuating conditions face during Incapacity Benefits assessments and employment, for example people with ME. Their condition may not be recognised as a major barrier to work during assessment, but will be too difficult to incorporate into a strict working environment due to periods of illness. The group suggested that flexible benefits would help in these areas so that disabled people could work and claim benefits in a much more fluid way.

The group had concerns in regards to the Disability Living Allowance restriction of mobility support for people living in residential care. The group felt that this was severely limiting the independence of some of the most excluded people in society. Many had strong concerns for disabled people in residential settings who would lose their ability to maintain vital contacts with family and friends, as well as limit their ability to develop new relationships. This made others fearful that this would be impact negatively in a number of ways:

- Increase in mental illness (depression)
- Decrease in confidence and self esteem
- Irritate health conditions potentially impacting on their overall health
- Increase dependence on residential staff
- Increase dependence on family members
- Increased isolation

The age restrictions proposed for the replacement for Disability Living Allowance, Personal Independence Payment, was a worry to several people in the group.
‘It does not make sense that disabled people stop being disabled when they retire and that the additional costs they incur disappear. The current system whereby you keep the provision if you are receipt of it before retirement seems to be a sensible solution to the age/disability dilemma’

2.2 Cuts in funding

The impact of funding cuts on the Voluntary and Community Sector (VCS) was discussed at length. The VCS currently act as a provider for many local authority services in the realm of independent housing provision, direct payment support, infrastructure support, transition services, care provision and a whole host of activity which supports disabled people in the realm of maintaining independence:

- E-health programmes
- Support groups and self help
- Social activities
- Advice and advocacy

This funding is vital, not only in terms of providing services to those who need it, but is vital for the additionality it fosters. The VCS are very good at adding value to the services it delivers and any of the support groups and social activities are an add-on not provided by the local authority. Consequently, reduction in funding will severely limit the scope of the VCS to support disabled people and their quest for independence. Reduction in funding to the VCS will also impact on disabled people in other ways. It is well documented that disabled people are much more likely to be employed in the VCS than any other sector and as such a reduction of the VCS will ultimately reduce the job opportunities for disabled people. Additionally the group discussed how a reduced VCS will severely impact the volunteering support and opportunities. A lack of investment in infrastructure organisations will result in a reduction in coordination of opportunities and support to organisations in terms of employing and supporting their volunteers. The group described how the quality of volunteering opportunities would be impacted on and therefore the impact this would have on the experiences of disabled people who utilize volunteering opportunities as a means of gaining employment experience.

Several people in the group discussed how complex the area of funding and services are and that they were fearful that vital resources will be lost because different departments may not feel it is their responsibility to fund specific adaptations, for example an electronic chair lift.

2.3 Changes in services

The group discussed that reduced services will obviously reduce opportunity for disabled people to live independently. The reduction in Local Authority funding for aids and adaptations is a prime example of this. The effects are reflected in the length of the waiting list and therefore the time people have to wait for the vital alterations to their home (in some cases now the predicted waiting time is 2 years). This of course will impact significantly on those who are unable to pay for much needed adaptations. They will have to inevitably have to depend on others for support.
In addition to this members discussed the current rules in regards to selling a property once adaptations have been made. One member stated that:

‘Grants for adaptations should be softened in regards to disabled people [...] currently you are not able to sell an adapted home for 5 years after adaptations have been made this is too long [...] If you wish to move you cannot’

The same member suggested that:

‘The local authority could utilize and take ownership of adapted homes [...] there is a current short supply of adapted properties for disabled people’

The group were concerned by the extent of the closure and reduction in services. The following were cited as ones that would particularly impact on disabled people’s independence:

**Transition services**—the services that support disabled young people through transition from children services to adult services was seen as inadequate before cuts. The group feared that further cuts and reduction in services would enhance the stress and chaos disabled young people and their families’ experience. The support will not be readily available to inform disabled people of their choices and the opportunities that exist for independence.

**Day Centres**—the closure of day centres was a worry for the group. Having a reliable day care provision was seen as an important part of some disabled people’s routine and might be the only part of their routine that they can access and use independently.

**Young Carers** One group member stated that:

‘Young carers group only got funding for one more year then there will no more funding to support young carers [...] what about their right to independence’

**Social activities**—reduction in funding for many VCS organisations reduces the capacity of VCS to deliver the softer social services, for example a disabled swimming club.

The group discussed how the reduction in funding combined with high fuel costs would affect public transport. The group stated that the cost of public transport has already started to rise and reduction in funding would further restrict the availability, flexibility and reliability of a public transport service. The group strongly felt that public transport wasn’t reliable or flexible enough to meet the needs of disabled people in its current form; further restrictions would simply make it even more difficult for disabled people to travel independently.

The group discussed how personalisation was a massive step forward in regards to providing disabled people with the opportunity to live independently. The groups felt that current practice surrounding Direct Payments and Personalisation was based on quantity over quality and this was a result of lack of resources committed to the service.

‘Current local authority practice was about getting numbers through a service rather than quality of service’

‘Social workers are over stretched, they have more cases than they should have and this leads to inconsistency in provision’
Written Evidence submitted by Choices and Rights Disability Coalition and North Bank Forum (IL 27)

‘Length of time that people have to wait for an assessment is unacceptable [...] it leaves someone without a service and they become over reliant of family and friends [...] leaves them in a situation of crisis [...] I have heard of people waiting as long as 18 months’

However others in the group felt that social service departments in other areas were not as stretched and suggested that joining department’s together and sharing resources would help reduce inconsistency.

‘Mental health services drop in sessions [...] social support now closed people feel that they have no support’

2.4 The way local councils decide whether you can get a service or not.

The group discussed their concerns over the proposed re-assessment of all disabled across areas such as Disability Living Allowance Reform and Incapacity Benefit. Both of these rights are seen as vital to the independence of disabled people. The group felt that there is a postcode lottery across Local authorities in regards to provision of service.

‘The way local councils decide whether you can get a service or not—There needs to be a consistency between Local Authorities—there are many differences between local councils’

The group also stressed their concerns of the way people are being assessed and the waste of resources reassessing all disabled people is.

‘People who are not medical professional are making decisions of disabled people ability to undertake work and carry out tasks [...] this is just get people off benefits’

‘Time it takes to get re assessed is going to massive [...] what a waste’

Members also reviewed how assessments happen and the frequency of them.

‘Currently we have to undergo lots of assessments for one condition or impairment [...] proposed changes for more rigorous assessments will result in even more assessments [...] what a waste of cash’

The group also described how the current Governments drive to implement stricter assessment protocols would narrow who could expect additional rights.

‘Needs, complex, medium and low. Some areas are only supporting the most complex needs and no support for any less’

‘Disability is becoming redefined [...] actually you will only gain additional rights if you have multiple or complex needs. I feel disabled people with medium to low needs who are active, working and independent will be hit the hardest by rigorous re assessments and will lose the support they rely on to live independently. I think we will see an increase of these disabled people having to rely on others more for support’

‘The state will only support the most disabled of people [...] these people are less likely to live independently’

Finally the group felt that assessments should be standardised and this could avoid the current postcode lottery.
Written Evidence submitted by Choices and Rights Disability Coalition and North Bank Forum (IL 27)

‘Assessments should be standardized across the country’

‘Post code lottery of who is entitled to what’

‘Need to take the care budget where you need to go, rather than where you are’

‘Need to be able to buy your care in an area where you visit’

2.5 The Joint Committee would like to know if you think these things are making being independent more or less difficult.

The entire group felt that these things will make independent living more difficult. Some of these points have been described in the previous sections.

The following statements underpin previous discussions:

‘More dependence on neighbours and families […] disabled people as dependant is something we are trying to irradiate’

‘What will happen to those people who haven’t got good neighbours or family and friends?’

‘Reduction in adaptations will mean that more people will not be able to live in their own homes’

‘Reduction in the support for carers will mean that actually carer’s independence will be impinged upon. Carers must be a priority they save the state millions of pounds a year and support disabled people to live more independent lives’

‘Reduction in funding and services will mean that more people are living in crisis for longer’

‘Independence should be a right’

‘Reduction in benefits will mean less resources therefore less opportunities for disabled people to live […] mobility recourses not funded would mean that disabled people will not be able to travel independently to where they want to go they will have to rely on the good nature of others’

‘Services and funding are quickly disappearing that enable disabled people to live independently […] mental health drop ins […] Access to work […] DLA […]’

‘Isolation is my worry […] we see so much of it already it’s just going to get worse’

‘More disabled people will have to move back with parents and other family members […] the alternative will be residential care […] who will pay for that and how much will it cost […]’

‘Cuts are the biggest risk to independent living […] slow down the cuts and rethink targeting the most vulnerable […] those least likely to say anything’

3. Getting involved and saying what you think

3.1 The UN Convention is about rights for disabled people and it says governments must involve disabled people in decisions that affect them.
How can the Government involve disabled people in planning services and deciding how to save money?

All of the group’s members welcomed any opportunities which involved disabled people in making decisions about the things that affect them. The groups felt that process for participating in the work Human Rights Commission was not clear, particularly how organisations and individuals were chosen to sit on such committees and boards. The group was not sure what participation in the Human Rights Commission would involve particularly in regards to:

- Expected levels of knowledge
- Where they would be expected to travel to
- How their participation would be used
- How their needs would be met, in regards to accessibility of venues and information

‘There needs to be more publicity that the comments from people with disabilities would be welcome’

‘There needs to be more advertising in public places e.g. libraries, GP surgeries, Post Offices—rather than relying on people visiting the website to find out about consultations’

Members additionally discussed that disabled people should be appropriately compensated for their involvement from having their expenses paid for to being paid for their involvement.

‘Remunerate people properly, pay people the statutory rate for mileage’

Being in touch with M.Ps was discussed as part of this work and some members felt that their local M.Ps were in accessible.

‘Local MP’s should consult with local people with disabilities. Experiences have been that often MP’s hold surgeries in inaccessible buildings and at times that make it impossible for people with disabilities to attend—receive no information about how to engage with their MP or with other government bodies’

3.2 How well are disabled people involved in planning and making decisions?

The group felt that currently disabled people were participating at a consultation level, which of course does not equate to making decisions. The feeling across the group that over consultation was becoming a drain, especially when the body consulting does not take into account the things disabled people want or need.

‘There is currently a duty on statutory services to consult but not to take on board recommendations [...] We are consulted and say the same things over and over again [...] I think they are waiting for us to say something different [...] something that fits in with what they want to hear [...]’

‘People with the power do not want to give it up [...] You ask for the cuts to be done slower but they have the power to change your life [...] they don’t care’
Written Evidence submitted by Choices and Rights Disability Coalition and North Bank Forum (IL 27)

‘Legislation should be changed so that a proportion of disabled people themselves are sat on the decision making panels, which make the decisions that affect them’

4. Sticking to the UN Convention in summer 2011 the government has to say how well it is sticking to the UN

4.1 Convention about rights for disabled people. How can it make sure it includes ideas from disabled people in its reports?

Overriding the group felt that disabled people should have a more active role in the commission and in shaping the UN Convention. One of the ways of doing this could be through a disabled people’s parliament.

‘The Human Rights Commission could establish regional disabled people’s parliaments that represented locally, but fed in to a national disabled people’s parliament’

‘Fund workers and disability organisations to promote the work of the Human Rights Commission’

‘Easy read information could be disseminated through disability organisations and groups’

4.2 These are the: Equality and Human Rights Commission (EHRC). How can they make sure the UK? Government sticks to the UN Convention?

The group commended the current work of the EHRC is the area of disability and wished for these commission to expand. Having said this: The group felt that the Equality and Human Right Commission (EHRC) should be strengthened and be more independent than they currently are. The current consultation which describes the types of reform the commission needs indicates that the EHRC could be stripped of its powers to support disabled people. The European Union should fund some of the work that the EHRC does, for example advocacy, research and policing. So that it is truly independent and therefore in a much stronger position t challenge.

The group felt that Disability groups that work with disabled people could be used and funded to bring the work of the EHRC down to a much more local level, for example providing a role for advocacy, monitoring and research.

Finally the group would like to thank the Human Rights Commission for the opportunity to feed into this consultation and hope that some of the recommendations are used to shape its future work and priorities.

20 April 2011
Written Evidence submitted by Disabled Persons Transport Advisory Committee (DPTAC) (IL 28)

Written Evidence submitted by Disabled Persons Transport Advisory Committee (DPTAC) (IL 28)

1. The Disabled Persons Transport Advisory Committee (DPTAC) welcomes the invitation to submit evidence to the inquiry by the Joint Committee on Human Rights (JCHR) on protecting the rights of disabled people to independent living.

2. DPTAC, established under the Transport Act 1985 was set up to advise Government on the transport needs of disabled people.

3. In addition to the comments provided below, DPTAC consider its response to the recent Department for Work and Pensions consultation on Disability Living Allowance reforms will be useful to this inquiry.

The right to independent living

Q1: Should the right to independent living continue to form the basis for Government policy on disability in the UK?

The right to independent living should continue to underpin the government’s policy on disability to ensure that disabled people have the freedom to choose and control the services they need to live their daily lives. However, as the aims are still to be met and are unlikely to be achieved within the time frame of the current policy (5 years) the strategy will require updating.

We are far from having a transport system where people have the same level of choice, control or freedom and this is what policy makers should be aiming for.

Q2: Do existing policy statements, including the Independent Living Strategy, represent a coherent policy towards the implementation of the obligations in Article 19 of the UN Disability Rights Convention? Could current policy be improved? If so, how?

The transport statements are still broadly relevant however they should be updated to reflect the increasing personal mobility needs of disabled people, including reference to infrastructure, equipment and emerging technological advances.

Q3: What steps, if any, should the coalition Government, the Scottish Government or other public agencies take better to meet the obligations in Article 19 and to secure the right to independent living for all disabled people in the UK?

The devolution of transport services to local authorities means there are discrepancies in the range of options and services available to disabled people. This can result in confusion and the random application of legislation, for example, the DfT review of the Blue Badge scheme has found significant variance in the way local authorities issue blue badges. Transport services therefore need to be closely monitored and audited by government to ensure disabled people have the same opportunities and access to transport as non disabled people wherever they live and wish to visit in the UK.
Q4: If you consider changes to policies, practices or legislation in the UK are necessary, please explain.

Examples of public transport policy that still need addressing are:

Personal Mobility Vehicles (PMV)—current legislation is out of date, there is growing use of PMV’s due to the increasing elderly population; use of PMV’s on public transport; safety concerns for users and pedestrians; need for clear guidance for users and the industry; insurance and training requirements for users.

Blue Badge—DPTAC has been involved with the review of the blue badge scheme over many years and is pleased guidance is being tightened. We hope that DPAC will be able to continue to advise on proposals to update legislation.

Shared Surfaces—DPTAC has provided advice on the review of shared space and supports the need for clearer guidance to assist local authorities on design criteria to ensure shared space schemes are accessible disabled people, particularly those with sight impairments.

Taxis—Regulation and the Implementation of provisions on providing assistance following the Equality Act 2010.

Buses—Improvements and consistency of accessibility across the country and better progress towards meeting the 2020 deadline. Better awareness of the reasons for why wheelchair users should have priority use of wheelchair spaces.

Impact of funding on the right to independent living

Removing the mobility component of Disability Living Allowance for all people living in residential care—This decision makes the assumption that disabled people living in residential care would not want to go out independently and even do not have a job. The government also do not consider that some people may be using the allowance to fund a mobility scooter instead of a vehicle so they can go outside. Cutting this benefit undermines independence and goes against the convention which recognises that disabled people should have a right to access community life without discrimination.

Changes to the Independent Living Fund—The changes to ILF will diminish the life chances of many people with severe disabilities. ILF should not change without a clear idea of how benefits are going to be paid in a universal system promoting independent living for disabled people. The government wants local authorities to take over the funding of personalisation, but considering cuts to local authority funding it is not clear how authorities will be able to fund the millions that the ILF has funded in the past. We strongly believe that changes to ILF will lead to more disabled people having their choices limited – and their opportunities for contribution and participation being reduced.

In the meantime restricting ILF to those in work should be reviewed and extended to allow those working in a voluntary capacity to gain further financial support.

"The Big Society"—The Minister for Disabled People, Maria Miller, has said that the Government's vision for a "big society" would put disabled people's organisations (DPOs) in a stronger position to support disabled people. However, with many DPOs struggling to
survive, it is unclear how realistic is it to expect them to be in a position to play an active role in “the big society”.

Q5: What impact does funding have on the ability of the UK to secure the right to independent living protected by Article 19 of the UN Disability Rights Convention?

Funding for transport infrastructure that enables disabled people the same freedom to travel and access other services as non disabled people is essential. Disabled people incur significant costs and although the mobility component of DLA can help mitigate against this, ILF offers additional funding to those who need it.

Q6: How will recent policy and budgetary decisions impact on the ability of the UK to meet its obligation under Article 19 to protect the right of all persons to independent living?

Any reduction in the budget will negatively impact on the right of disabled people to live independently. The recent consultation about changes to DLA is very worrying and causing great anxiety as it appears the government is committed to withdrawing benefit from a great many disabled people. If this proves to be the case it will have a huge impact on the UK’s obligation under Article 19 to protect the right of all persons to independent living.

Please read DPTACs response to the DLA consultation for further information—particularly relevant in respect of the questions 5 and 6 above.

Participation and consultation

Q7: What steps should the Government take to meet its obligations under the Disability Rights Convention to involve disabled people in policy development and decision-making, including in budget decisions such as the Comprehensive Spending Review?

The coalition government has not yet shown any commitment to involve disabled people in early decision making and this has resulted in poorly thought out consultation documents. The consultation on the reforms to DLA is an example, and one which has caused a great deal of distress to disabled people. DPTAC is a unique organisation that is able to consider issues and offer independent pan-disability advice to government on transport policy but at an early stage.

The involvement of similar groups at an early stage would help government consider all options prior to wider consultation and avoid the sense that feedback is not really required as the decision to cut has already been made.

The decision to disband DPTAC will also have an impact here, see comments provided below.

Q8: Are the current arrangements for involvement of disabled people in policy development and decision-making working?

In relation to transport policy, DPTAC works with government when policies that impact upon disabled people are being developed. DPTAC are also able to take up issues directly
Written Evidence submitted by Disabled Persons Transport Advisory Committee (DPTAC) (IL 28)

with Ministers and officials when it is concerned policies could adversely impact upon disabled people.

DPTAC’s unique position means that it is currently able to get involved early, at a time that makes all the difference. It can also provide a challenge function, before material reaches the public domain and before decisions are made.

However, the announcement that DPTAC will be abolished within the Public Bodies Bill will mean that there will no longer be an Independent Committee providing pan-disability advice on the accessibility of transport services.

Monitoring the effective implementation of the Convention

Q9: What steps should Government take to ensure that disabled people’s views are taken into account when drafting their reports to the UN under the UNCRPD?

The government should work with disabled people and representative organisations to identify good practice and prioritise areas requiring improvement. The government needs to demonstrate trust by being open and involving disabled people in early decision making and include this work in responses to the UN.

Q10: As part of the national monitoring mechanism, what steps should the EHRC, NIHRC and SHRC take to ensure that the Convention is implemented effectively?

With regard to transport impacts, these bodies should be easily accessible to disabled people and seek their views on services across the UK. This should be done annually possibly by a ‘citizen’s panel’ of disabled people/organisations and via local authorities. This would enable the government to check whether the convention is being implemented equably across the UK and prioritise areas requiring further investment, i.e. support and training.

April 2011
Executive Summary

The Changing Places Consortium\(^6\) believes that every individual with a disability should have access to the right of independent living, no matter the severity of the disability and the level of support required to access this right.

One of the greatest barriers to independent living for people with severe and multiple disabilities is the lack of public toileting facilities, which meet their needs. Standard accessible toilets do not meet the toileting need of many disabled people, thus limiting those individuals independence and the implementation of their human right to independent living. The evidence provided in this submission calls on the Government to address the barriers to independence caused by the lack of appropriate toileting provisions, by incorporating Changing Places toilets into Building Regulations and Government Policies.

The Changing Places Consortium believes that Changing Places toilets enables greater access to independent living and urges the Joint Committee on Human Rights to support the Consortium’s efforts to get Changing Places toilets included in Building Regulations.

The submission focuses on the following two questions identified by the Joint Committee: ‘What steps, if any, should the coalition Government, the Scottish Government or other public agencies take better to meet the obligations in Article 19 and to secure the right to independent living for all disabled people in the UK?’ and ‘If you consider changes to policies, practices or legislation in the UK are necessary, please explain’

About Changing Places

Around 250,000\(^7\) people living in the UK need personal assistance to use the toilet or change continence pads. This includes people with profound and multiple learning disability, multiple sclerosis, muscular dystrophy, cerebral palsy, motor neurone disease, acquired brain injuries, spinal injuries, Parkinson’s disease and many disabilities common in the elderly population. As shown by Government projections on the future demand on adult social care services, this figure is rising rapidly. This is due to advances in medical science in areas such as the care of premature babies, improvements in managing people who suffer a stroke or head injuries and greater understanding of conditions. In addition with better healthcare, people who

\(^6\) The Changing Places Consortium is made up of a group of organisations who work together to support the rights of people with profound and multiple learning disabilities (PMLD) to access their community. Members of the Consortium include; Centre for Accessible Environment, Mencap, PAMIS, Nottingham City Council, Dumfries & Galloway Council, Valuing People Support Team (DH) and the Scottish Government. Alongside our Consortium members, the Changing Places campaign is supported by over 100 organisations including All Party Parliamentary Group on Learning Disability, British Toilet Association, Every Disabled Child Matters, Scope, Disability Alliance, Help for Heroes and Carers UK.

\(^7\) Dr James Hogg: Changing Places Toilets; Estimates of Potential Users, White Top Research Unit, University of Dundee, 2009
would previously have died are surviving and those with complex needs are living much longer.

Standard accessible toilets are often too small for the individual to receive personal care, particularly enough floor space for the individual, their carers, a wheelchair and any medical equipment. Standard accessible toilets do not have the equipment that many need for the personal assistance for example standard accessible toilets are required to have the toilet in a corner, close to grab rails, however individuals who require two carers to support them to use the toilet require enough space for a carer each side of the individual for support. Furthermore standard accessible toilets do not have any facilities to help carers move individuals around or a Changing Bench for continence pads to be changed.

Changing Places toilets have been designed to meet the needs of these groups of individuals. Changing Places toilets are larger than standard accessible toilets and have additional features, including a height adjustable adult-sized changing bench, centrally placed toilet and a hoist system, designed to meet these individuals’ needs.  

![Picture 1: Changing Places toilet](image)

As of the 13th April 2011 there are a total of 272 Changing Places toilets in the UK, registered with the Consortium. These Changing Places toilets are a result of intensive local

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8 Specifications for a Changing Places toilet are found in British Standard 8300. Further details can be found on the Changing Places Consortium’s website [www.changing-places.org](http://www.changing-places.org)
campaigns often run by people with a disability, carers and families who have targeted a local service or business.  

**Changing Places: enabling human rights**

Without Changing Places toilets, people who need support from one or two carers to use the toilet or to have their continence pads changed are faced with two options, stay at home or be manually lifted out of their wheelchair by their carers and changed on unhygienic and often dangerous toilet floors, something professional carers are not permitted to do. The lack of appropriate toilet facilities for people with profound disabilities has led to many carers and families choosing to leave the person with the disability at home or the individual themselves deciding not to take part in various activities of daily life. This sees a curtailment of independent life and results on people with a disability being isolated from the rest of society.

Changing Places increase opportunities for individuals to access an independent life, providing them with greater choice and control over what they do on a daily basis and plans for their futures. Whilst the individual may still require assistance from support staff and/or families, Changing Places provides them with the chance of doing the things that everyone else takes for granted including, accessing education, healthcare appointments, socialising, household chores including shopping and, as shown by Joyce, can even open the opportunity to employment. All of these are the result of being able to access the right to an independent life.

Where Changing Places have been built, they have transformed lives. Individuals who have used a Changing Places toilet have told us:

- “Allows me to access community buildings rather than attend a day centre 5 days a week on an industrial estate.”
- “I can go in to the city of York 24 hours a day and know I can use a toilet, plan my day around what I want to do not around where and when I can use the toilet.”
- “It means that I can participate in meetings and get involved in training.”
- “I can work longer hours.”

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9 Details on the location of Changing Places toilets and building type can be found in Appendix 2
10 See Appendix 1 for Joyce's case study and other case studies.
11 Quotes from: The Changing Place Consortium's survey of Changing Places users, October 2010
Due to the nature of how the existing Changing Places toilets have come about, there has been a postcode lottery of provision with some areas of the country having a good number of facilities and others failing to provide any Changing Places toilet. This as essentially created a post code lottery of access to the right of independence.

Individuals and their families, who do not have a Changing Places toilet in the area where they live, have let us know about how the lack of facilities has limited their independence:

**Case study—Kunal**

Kunal is cared for by his mum.

Kunal is a 19 year old man with profound and multiple learning disabilities. He attends a local college and enjoys music, swimming and spending time with his large extended family.

Kunal uses a wheelchair and has very little motor control. He communicates using facial expressions and some small gestures. Kunal's disability means he needs support 24-hours a day – this support is provided by his mother.

Kunal and his mum need to use a Changing Places toilet when they are out in the community. Kunal needs support with every aspect of his personal care, so an adult size height adjustable changing bench is essential. Kunal is a tall, well-built man and needs a hoist to transfer him from his wheelchair to the changing bench – it is impossible for his mum to lift him. However, there are no Changing Places facilities that Kunal can use.

"It is such a struggle to go out. A standard accessible toilet is of no use to us as it does not provide any of the facilities we need. When we do go out in the community we have to return home within 1-2 hours so Kunal can be changed. If the family ever needs to go out for more than a few hours Kunal has to stay at home with a carer – he hates this. No-one likes to sit at home staring at four walls."

The lack of Changing Places toilets places extensive limitations on Kunal's life.

"If there were Changing Places toilets in public venues we could go to shopping centres for the day together, like other families. Kunal loves fast food restaurants. If there was somewhere to change him we could go out more often and stay for longer— without worrying about getting home. "

Due to the nature of how the existing Changing Places toilets have come about, there has been a postcode lottery of provision with some areas of the country having a good number of facilities and others failing to provide any Changing Places toilet. This as essentially created a post code lottery of access to the right of independence.
“It means we can’t go out for the day. We can only go out for short periods of time. We can’t access normal family activities such as going for meals, visiting the zoo, visiting shops, etc. We always have to be aware of the time and have to get home to change her or we have to tend to our daughter on the floor.”

“We are totally restricted on where we can go to with our profoundly disabled daughter and how long we can be out of the house. It is very socially isolating.”

"If Changing Places toilets were provided in public places it would really change my life. As a disabled woman, this would enable me to go out whenever I liked – instead of having to plan my life around when I have to go to the toilet!"

“We are restricted from accessing facilities in the community as we can only go out for a couple of hours without having to return home for personal care. If we do not go home then we are faced with having to sit in a very uncomfortable, undignified and distressing condition.”

“A fun day shopping trip with friends or any other social activity in my local community cannot happen because there is know changing places toilet for people like me.”

“I wish these toilets were mandatory provision whenever a new convenience is built, and in places such as libraries, hotels etc.”

“My opportunities to go out into my community are severely limited—even to attend events arranged by social services or the PCT—as the only Changing Places toilets in my area are within day centres.”

“Not having Changing Places toilets throughout the country is socially divisive and isolating and does nothing to help the move to integrate people with Profound and Multiple Learning Disabilities and their families into mainstream society. It is nothing short of a disgrace that the Government do not insist on local authorities making sure there is a Changing Places toilet accessible 24/7 in their area.”

“Dignity, respect and free from potential infections or illness. A place to use in safety and in a dignified manner. Is it too much to ask? More and more people will need a facility like this in the future—INVEST NOW. Build up a network we can be proud of over the coming years.”

Building Regulations

The Consortium believes that the Government must step in and take action to ensure that all disabled people, including people with severe or multiple disabilities have access to the right of independent living.

The Consortium has identified building regulations as an aspect of Government legislation which can achieve the level of Changing Places toilets that are needed. We have urged the Government to include the building of Changing Places toilets into Approved Document M in relation to larger buildings and complexes, under Building Regulation Part M. If this was to
Written Evidence submitted by Changing Places Consortium (IL 29)

happen, it will see Changing Places as a compulsory feature for any large building, for example shopping centres, multimedia complexes, stadiums, motorways services and airports. The Department for Communities and Local Government are currently exploring the possibility.

Although the proposed changes to building regulation only covers large buildings it is likely that it will not see increased provision in rural or low populated areas, the Consortium believes that this is a start to the fulfilment of Article 19. As such the Consortium seeks support from the Joint Committee for the campaign and its efforts in getting Changing Places into Building Regulations.

**Other ways to increase access to Article 19**

The Consortium has identified other ways in which the Government can take action to improve the access to Article 19 for individuals whose needs are met by a Changing Places toilet.

The main providers of Changing Places toilets are local authorities and private companies. Primarily this is due to the nature of the buildings that they own and because campaigners tend to identify and target a specific building for a Changing Places toilet, which they use on a regular basis. The Consortium believes that the Government is in a position to influence decisions made at a local level and introduce policy to encourage the take up of Changing Places toilets at a local level. The Consortium has identified local planning policies as a possible route to get Changing Places toilets built in areas without any existing facilities.

Scottish MSPs, through the Petitions Committee, looked at how the Scottish parliament could increase the number of Changing Places toilets in Scotland. One avenue involved the use of disability and access legislation to place a duty on local authorities to ensure the disability needs of the wider population were being addressed, including meeting the toileting needs of people with a disability. During the discussions, one MSP suggested that the consideration of a Changing Places toilet within a town or city could constitute an outcome measure for meeting statutory Equality Impact Assessments. Imposing duties on local authorities to the above affect would assist in meeting the measures of success.

**Additional Equality and Rights Legislation**

The Changing Places Consortium believes that the provision of Changing Places toilets is one option to the fulfilment of other domestic and international equality and rights based legislation, alongside existing Government policy.

**UN Convention on the Rights of Disabled People**

In our October 2010 submission, we highlighted two articles in the Convention, which we believe provides legal underpinning for Changing Places.

- **Article 9—Accessibility**

  The Consortium believes that Changing Places toilets increases the access for disabled people to this human right as it removes a barrier of accessing the physical environment on an equal basis with others, in particular Article 9(1)(a) “Buildings, roads, transportation
and other indoor and outdoor facilities, including schools, housing, medical facilities and workplaces.”

The Consortium also believes that the building of Changing Places toilets fulfils the following appropriate measures which should be undertaken by party states:

9(2)(a) To develop, promulgate and monitor the implication of minimum standards and guidelines for the accessibility of facilities and services open or provided to the public.

9(2)(b) To ensure that private entities that offer facilities and services which are open or provided to the public take into account all aspects of accessibility for persons with disabilities.

- **Article 30—Participation in cultural life, recreation, leisure and sport**

As outlined earlier the barrier of toilet provision has stopped many individuals from accessing their rights to cultural life, recreation, leisure and sport. Many individuals are reduced to being out for no more than two hours at one time, in some cases limited to 40 minutes, before they have to go home. This substantially limits what the individual can do in this time and prevents them from participating in cultural activities. Changing Places widens the opportunities of disabled people, particularly where they are located in places where activities take place, including sports and leisure facilities.

**Equality Act 2010**

Under the Equality Act 2010 it is unlawful for service providers to treat disabled people less favourably because they are disabled, both directly and indirectly. Service providers have to make reasonable adjustments for disabled people in the way they deliver their services. This is so that a disabled person is not put at a substantial disadvantage compared to non-disabled people in accessing the services. The Consortium firmly believes that Changing Places is a reasonable adjustment for people whose disability has led to a need for toileting assistance.

**Disability Discrimination Act (Disability Equality Duty)**

Although the Equality Act replaced most of the Disability Discrimination Act (DDA) the Disability Equality Duty in the DDA continues to apply. The Disability Equality Duty covers everything done by public sector organisations (including central Government and local authorities) which includes policy making and services that are delivered to the public. The Consortium believes that Changing Places should be provided for in local authorities published Disability Equality Scheme statements and action plans.

**Human Rights Act 1999**

The Human Rights Act reinforces the concept that people should not be discriminated against because of their disability under Article 4: Prohibition of Discrimination. All public authorities in the UK have an obligation to respect the Convention rights, whether you are delivering a service directly to the public or devising new policies.

**Valuing People Now**
Written Evidence submitted by Changing Places Consortium (IL 29)

The Governments policy set out in Valuing People Now (Department of Health) identifies a clear direction for improving the lives of people with a learning disability in a number of policy areas, including personalisation.

**Carers Strategy 2010**

The Carers Strategy sets out a range of policy which is intended to improve the lives of carers. The strategy includes a commitment on Government to provide personalised support both for carers and those they support, enabling them to have a family and community life. The strategy also commits the Government to providing support to carers to remain mentally and physically well.

**Conclusion**

The Changing Places Consortium firmly believes that every disabled person should have access to their human rights, no matter what disability they have or the severity of the disability and this is the foundation on which the Changing Places campaign was started on.

People with severe disability are unable to access some of their human rights because they do not have access to toileting facilities which meet their needs. Too many disabled people and their families have to make the tough choice of whether to stay at home all day or have their continence pad changed on the floor of a public toilet. Not only is this isolating and degrading for the disabled person, but it limits any possibility of living an independent life.

Changing Places toilets are a solution to this barrier and have opened up access to the right of independent living for many disabled people.

20 April 2011

**Appendix 1 – Case Studies**

**Gabriel**

Gabriel has Multiple Sclerosis and lives near Oxford. He needs Changing Places toilets.

Gabriel is not able to stand and he uses a wheelchair all the time. He requires the assistance of a carer, particularly when away from home. Gabriel is incontinent and he requires a hoist, a changing bench and a centrally placed toilet. It is crucial the room is big enough for a carer and his wheelchair.

Gabriel likes going out in town to meet ex-work colleagues for a drink or lunch, to go shopping or attend meetings. Because there are hardly any Changing Places toilets in Oxford, Gabriel is extremely restricted as to where he can go. He has on numerous occasions had to cut a trip into town short, be it for work or leisure, and return home because of the need to change
Gabriel explains: ‘The provision of Changing Places toilets would enable me to take part in a greater number of activities, for longer periods, safe in the knowledge that if I need Changing Places facilities that they are available.’

‘The knowledge that there is now a specific facility in Oxford city centre with a hoist system and a changing bench means that I can travel into Oxford in the knowledge that the facilities are there for me to change if required.’

Joyce

Joyce is 33 and is events and promotions officer for the organisation PAMIS. Joyce really enjoys her work—which has only been made possible because a Changing Places toilet has been installed in the building she works in.

"I have cerebral palsy and have quite high support needs for everyday tasks," Joyce explains. "I use a powered wheelchair at all times and I need full assistance in personal care, including going to the toilet.

"PAMIS, at the University of Dundee, have put in a Changing Places toilet with all the equipment I need – a hoist, peninsular toilet and plenty of space for two carers.

Without this facility I would have to stay at home, as my paid personal assistants are not allowed to lift or transfer me without a hoist due to moving and handling policies. I would therefore miss out on the benefits of working and making a real contribution to helping other people with disabilities."

As well as her job, Joyce also enjoys reading, listening to music and going out and about in her local community to places like pubs and restaurants. However, she has not been so lucky in finding Changing Places toilets in these places, meaning her social life is restricted.

"It is very difficult to go out because very few places have accessible toilets for people with disabilities, and those that have do not meet my needs. My days out have to be cut short because there are no Changing Places toilets with the right equipment and room to manoeuvre my wheelchair.

"If Changing Places toilets were provided in public places it would really change my life. As a disabled woman, this would enable me to go out whenever I liked—instead of having to plan my life around when I have to go to the toilet!"

Case Study - Anthony Wealthall

Anthony is 22; he lives in Nottingham with his mother Yvonne who is a single carer. He has profound multiple learning disabilities, and has a gastrostomy which means he has to be fed through the stomach (PEG fed), Anthony also
has a tracheotomy to enable him to breathe. These conditions mean his mother has to do all Anthony’s personal care.

Changing his continence pads, feeding him through a tube every 2/3 hours. Yvonne also has to use a suction machine to sucking out excess phlegm to clear his airways. (This procedure may be required 2/3 times per hour on a day when Anthony’s chest is bad.)

For these regular procedures to be carried out with dignity when away from home, Yvonne has to find somewhere suitable or return home within a couple of hours.

Finding a place to change his continence pads is of course a major issue Anthony cannot weight bear and requires a hoist to get out of his wheelchair and onto a changing bench in order for Yvonne to change his continence pad.

Yvonne is determined to give Anthony and herself all the opportunities to enjoy life and do the things non disabled people take for granted. Shopping, eating out, visiting places but she relies on their being adequate away from home toilet provision.

Changing Places toilets have made such a difference as she can now visit Nottingham City Centre knowing Anthony and herself have the right provision which enables them both to use the toilet with dignity.

Caring for Anthony is a mammoth task for Yvonne and she currently receives Day Care from SCOPE funded by the Health service at a cost of £1325 per week. The SCOPE day service also takes Anthony and other profoundly disabled adults out and about and the issue is exactly the same for day care services i.e. they need away from home toilet facilities to allow them to access the community. Changing Places toilets allow both users and staff themselves to use a toilet as the alternative is to return home after a couple of hours.

The pressure on Yvonne is enormous it can be 24 hours a day seven days a week so without 5 days day care, a night nurse 4 nights a week and 4 days a month respite she would not be able to manage.

Changing Places Toilets enable Yvonne and Anthony to live as normal a life as possible. Should Yvonne’s health deteriorate the cost of full time care for Anthony would be well in excess of £3000—£3500 per week due to his intensive personal care needs.

Ashleigh, Abigail, Scott and Edward
Ashleigh, Abigail, Scott and Edward have profound and multiple learning disabilities and live, together with their team of dedicated carers in a residential home in a town close to Aberdeen City. All are wheelchair users, their communication is not verbal, they have complex health care needs and require 24-hour support for their everyday care needs. All 4 require Changing Places facilities when they are away from home.

There are now a number of Changing Places toilets in Aberdeen City and Aberdeenshire, which means the four young people can get out and about in their local community. Wider provision means that Ashleigh, Abigail, Scott and Edward can now also be much more adventurous and travel to different areas of Scotland. Some of the places they have been able to visit recently and activities enjoyed included:

**Safari Park, St Andrew’s**

Ashleigh spent a lovely day in July to the university town of St Andrews. First they spent some time at the Safari Park, she loved all the different animals, then they had a lunch in the City, visited a number of the sights including the beach in the afternoon and stayed on for an evening meal. This was all made possible as there were Changing Places toilets in Dundee and Boughty Ferry—both relatively near to St Andrews.

**Music Concert**

Scott is a great fan of the group Westlife and earlier this year he was able to attend a Westlife concert. He had a great time listening to the music alongside his non disable peers. His staff were able to plan the trip well in advance and check out the location of Changing Places toilets on the route to the venue.

**Dundee City**

These four young people regularly visit the city of Dundee for a day out either individually, with their carers, or as a small group. They often go there to shop, have lunch and/or an early evening meal and they regularly visit PAMIS at the University of Dundee to borrow Multi-sensory stories from their library and also have a cup of tea. Lorraine said, “the first time we visited PAMIS we did not even check if they had a Changing Places toilet, we just expected an organisation like that to have such provision. We can go to Dundee without much forward planning, visit some attractions in the City and have some lunch and then pop in to PAMIS to use the accessible toilet before our long journey back home. Abigail loves the multi-sensory stories and she, rather than staff, can now choose herself which one she wants to borrow.”

**Case study—Simon**

Simon is a young man who lives in Cambridge. He has a profound learning disability, epilepsy and scoliosis. He is a wheel-chair user who needs 24hour support with all aspects of his care, including going to the toilet.

Simon is a keen football supporter—he supports Manchester United and Cambridge City. He enjoys going to see Cambridge City play home matches. He
loves the atmosphere at a match—particularly the noise and the chance to interact with lots of people. The atmosphere is best when his team is winning! Unfortunately, football stadiums don’t have suitable toilets for Simon to use.

‘There is no option but to leave the game early if Simon needs to be changed’ says his supporter. ‘Sometimes this means going before half-time.’

‘It is horrible having to leave the stadium early—often it is just as the atmosphere is getting really good that we have to go. It doesn’t feel fair that Simon can’t participate like everyone else.’

‘I think Simon would love to see Manchester United play or go to an England match but that is not a possibility. There is no way we could travel that distance and then go to a stadium without a suitable changing facility—we would be stranded!’

Simon needs a Changing Places toilet, with an adult-sized height-adjustable changing bench where his continence pads can be changed, a hoist to lift Simon from his wheelchair to the bench, and plenty of space.

‘If there were Changing Places toilets in football stadiums it would mean a lot more freedom for Simon. He would be able to stay and enjoy a whole match at his local stadium like anyone else. He could also go to away matches and have the opportunity to go and see Manchester United or England play.’ his supporter explains.

‘For people with similar needs to Simon who aren’t going to matches at all because there are no Changing Places toilets—this would open up an amazing experience to them.’

Appendix 2—Further information on Changing Places toilets

As British Standard BS8300: 2009 shows, Changing Places can be built and installed in a wide range of settings, from town halls to major transport hubs. Our data on existing Changing Places toilets supports this, showing that there has been a wide range of building types. The BS8300: 2009 reads:

‘A CP facility should be provided in larger buildings and complexes, such as:

(a) major transport termini or interchanges, e.g. large railway stations and airports;
(b) motorway services;
(c) sport and leisure facilities, including large hotels;
(d) cultural centres, such as museums, concert halls and art galleries;
(e) stadia and large auditoria
(f) shopping centres and shopmobility centres;
(g) key buildings within town centres, e.g. town halls, civic centres and main public libraries;
(h) educational establishments;
Where should Changing Places toilets be provided?

In our service user survey, the findings of which are outlined below in more detail, we asked the question of where individuals would like to see more Changing Places toilets. Below is a taste of the places people would like to see Changing Places toilets at:

a) Football stadiums

b) In all places where there are toilet facilities for the general public. Like Parks, Shopping Precinct, Leisure Centres, In ALL Town and City centres, Theme Parks, Forestry Commissions, etc.

12 Changing Places Survey, October 2010
c) in every town centre or tourist attraction - it would mean freedom to go where she and we wanted

d) All major shopping centres, and community centres and Parks

e) motorway services, hospital outpatients, airports, museums, concert halls

f) town centre, library, local supermarket

g) Leisure Centres, Shopping Centres, Bus Stations, Train Stations & all new build public buildings

h) Cinema, Bowling, Out of hours facility, town centres, country parks, theme parks,

i) Every shopping centre, every hospital, every GP health village, each seaside town, rail and bus stations

j) Out of town retail parks

k) All large public venues and town centres. Motorway service stations, shopping centres and retail parks, HOSPITALS!

l) In town centres / community centres / libraries / leisure venues / cultural venues / country parks. Anywhere!

Written Evidence submitted by Independent Living in Scotland (IL 30)

1. Independent living in Scotland

The Independent Living in Scotland project

1.1 The Independent Living in Scotland project [www.ilis.co.uk](http://www.ilis.co.uk) is funded by the Scottish Government, hosted by the Equality and Human Rights Commission (EHRC) and steered by a group of disabled people. It is part of the wider Scottish Government initiative on
independent living. It aims to support disabled people in Scotland to have their voices heard and to build the disabled people’s Independent Living Movement (ILM).\(^\text{13}\)

1.2 This response should be read alongside “Ready for Action”, a policy document, developed by disabled people to highlight what needs to change in order for independent living to be a reality\(^\text{14}\) and the ILiS responses to the Scottish Parliament’s Finance Committee Inquiry into Preventative Spending and the Scottish Government’s Commission on Public Sector Reform in Scotland.\(^\text{15}\)

**The wider independent living in Scotland agenda**

1.3 The project is part of a wider Scottish Government initiative to mainstream the principles and practices of independent living within the general economic and social policy of Scotland (see para 4–11 of the Scottish Government’s response to your inquiry for more details). Scotland’s commitment to independent living is set out in Scotland’s “Vision for Independent Living”: [http://www.ilis.co.uk/independent-living/a-vision-for-independent-living-in-scotland/](http://www.ilis.co.uk/independent-living/a-vision-for-independent-living-in-scotland/).

**Independent living**

1.4 Independent Living means “disabled people of all ages having the same freedom, choice, dignity and control as other citizens at home, at work, and in the community. It does not mean living by yourself, or fending for yourself. It means rights to practical assistance and support to participate in society and live an ordinary life”. With such support, disabled people can exercise their rights and duties of citizenship via their full and equal participation in the civic and economic life of Scotland—thereby changing the public misperception of them as being a drain on society’s resources rather than an active contributor.

1.5 The principles of independent living, i.e. **freedom, choice, dignity and control**, do not only relate to the specific services and provisions for disabled people, but to the whole of disabled people’s interactions with society; its organisations, facilities and structures; and every aspect of their quality and equality of life.\(^\text{16}\)

- Full access to our environment
- Fully accessible transport
- Technical aids and equipment
- Accessible and adapted housing
- Personal assistance

\(^\text{13}\) [www.ilis.co.uk](http://www.ilis.co.uk)


\(^\text{16}\) “The Essential Guide to Independent Living”; ILiS, 2009
Written Evidence submitted by Independent Living in Scotland (IL 30)

- Inclusive education and training
- An income, including income within the state-benefit system for those unable to work
- Equal opportunities for employment
- Accessible and readily available information
- Advocacy and working towards self-advocacy
- Counselling, including peer counselling
- Accessible and inclusive healthcare provision
- Communication and appropriate support for communication
- Civic participation

2. Independent living as the basis for policy and practice

Independent living and human rights

2.1 Independent living recognizes that all of these areas of particular rights are crucial for disabled people to realise their human rights. Without such a cross cutting approach, equal enjoyment of human rights is not possible for disabled people:

“They have just introduced new low floor buses round here, but the council are cutting my support package, they said they don’t have enough money, what use is a low floor bus, if I can’t get out of bed in the morning?"

2.2 Further, independent living recognises and promotes a preventative and proactive approach to supporting disabled people to realise their human rights.

2.3 It is welcomed that the right to independent living is underpinned by Human Rights protections e.g. the European Convention on Human Rights and the Human Rights Act. The added value of the UNCRPD brings the reality for disabled people to the fore in the interpretation of human rights and supports the principles of independent living as key drivers in the realisation of these rights.

Should the right to independent living continue to form the basis for Government policy on disability in the UK?

2.4 Independent living offers a principled, proactive, cross cutting, human rights based approach to policy making that strives to ensure disabled people have the same freedom, choice, dignity and control, as non disabled people. We welcome such an approach to policy making.

2.5 Despite its value and the human rights protections that underpin it, the right to independent living is not yet realised.

17 Ambassador for independent living, recruited by ILiS

18 “Submission to the Finance Committees Inquiry into Preventative Spending”; ILiS, SDEF and Inclusion Scotland, 2010
2.6 The interim report of the Life Opportunities Survey\textsuperscript{19} states that:

(b) 17\% of disabled adults experienced restrictions in their learning opportunities compared with 9\% of non disabled adults

(c) 74\% of disabled adults experienced restrictions in using transport compared with 58\% of non disabled adults

(d) 12\% of disabled adults experienced difficulty accessing rooms within their home or difficulty getting in or out of their home compared with 1\% of non disabled adults

(e) 29\% of disabled adults experienced a restriction to accessing buildings outside their home compared with 7\% of adults without impairments

2.7 Further:

(a) When the extra costs of being disabled are taken into account, 47.5\% of families with disabled people in the household, live in poverty\textsuperscript{20}

(b) Only 50\% of disabled people of working age are in work, compared with 80\% of non disabled people of working age\textsuperscript{21}

(c) Disabled people officially constitute only 6\% of formal volunteers and around 4.3\% of public appointments across Britain. This is compared to 20\% of the population at large\textsuperscript{22}

(d) 23\% of disabled people have no qualifications compared to 9\% of non disabled people\textsuperscript{23}

(e) By the age of 26, young disabled people are more than three times as likely as other young people to agree with the statement “whatever I do has no real effect on what happens to me”\textsuperscript{24}. It should be noted that for many specific groups, e.g. people with learning disabilities and mental ill health, the stats can be much more extreme

2.8 This has implications for; the human rights obligations underpinning independent living; the reality of the human rights of disabled people; and the future of policy and practice aimed at implementing the UNCRPD.

3. **Independent living policy and the implementation of the UNCRPD**

\textsuperscript{19} The Life Opportunities Survey”; Office of National Statistics, 2010

\textsuperscript{20} “Destination Unknown”; Demos report, 2010

\textsuperscript{21} Office for National Statistics—Labour Force Survey, Jan - March 2009

\textsuperscript{22} DRC (2006) Disability Agenda “Increasing Participation & Active Citizenship”


\textsuperscript{24} Burchardt (2005) “The education and employment of disabled young people: frustrated ambition”
Do existing policy statements, including the Independent Living Strategy, represent a coherent policy towards the implementation of the obligations in Article 19 of the UN Disability Rights Convention? Could current policy be improved? If so, how?

3.1 There are various policies and practices that impact on the realisation of Article 19; some focusing on independent living at a strategic level e.g. the independent living agenda in Scotland (1.3) and the UK strategy on independent living; some in relation to economic policy and approaches and others on the structures laid out in 1.5.

Overarching policy on independent living

3.2 Whilst policy direction in Scotland has focussed on independent living in the past 3 years (see 1.3), evidence shows that independent living for the majority of disabled people is still not the reality.\textsuperscript{25} Scottish political, social and organisational structures have been slow to meet the needs of disabled people and to recognise their rights.\textsuperscript{26} Further, a recent report into compliance with the Human Rights Act in Scotland, carried out by 4 third sector organisations, states that “there is little evidence to suggest that human rights are being mainstreamed across the public sector in Scotland”.\textsuperscript{27}

3.3 At a national level, the Core Reference Group (CRG) on Independent Living has provided a shared, national focal point on independent living in Scotland. This has been useful in affecting conceptual change around independent living, recognizing that it is a corporate, strategic issue, building relationships and coproducing an approach to the issues. It has also identified that disabled people have a crucial insight to the issues that affect them and that they are assets, essential to the progression of the agenda. We suggest such a cross-cutting approach continues.

3.4 However, the group has been less effective in achieving outcomes across the wider public sector, on a local level or in achieving ‘tangible’ outcomes on independent living.

Prevention vs. life and limb provision (please see ILiS response to the Scottish Parliament’s Finance Committee Inquiry into Preventative Spending\textsuperscript{28})

3.5 Retrenchment into the more “traditional” economies of cutting, trimming and delay, leads to restricting demand, by raising thresholds. Disabled people are left to rely on informal support systems, have less opportunities to participate in their community and are

\textsuperscript{25} “Ready for Action”; ILiS, 2009

\textsuperscript{26} “Ready for Action”, ILiS, 2009

\textsuperscript{27} “Delivering Human Rights in Scotland”; Amnesty International, Scottish Womens Aid, Scottish Association for Mental Health, Scottish Refugee Council, 2011

\textsuperscript{28} http://www.ilis.co.uk/get-active/independent-living-policy/ilis-consultation-responses/
pushed further into poverty; accumulating more need for both themselves and informal supporters, in later years.

“Not being able to get out makes you so much less confident and unable to cope”

“I fear poverty of opportunity as well as no money”

3.6 The gulf between demand and supply, therefore, grows. This approach segregates disabled people within their own homes or day centres denying them the opportunity to participate within the community and to realise their rights in the UNCRPD. Despite this, ‘life and limb’ is prevalent in terms of access to support for independent living today.

3.7 **Disabled People’s Organizations:** Many Disabled People’s Organisations, often those providing support that prevents future dependency, e.g. advocacy organisations, are losing their funding.

Yet, empowering disabled people enables them to contribute to the civic and economic life of their community, coproducing solutions and lowering demand for greater state provision in later crisis situations:

“GDA increases your confidence in yourself as you feel empowered and there is strength gained from the number of people you meet via GDA”

“GDA understands that by nurturing people to share their experiences networks widen, understanding of rights increases and individual abilities develop. People are revitalised though this informal mentoring system.”

3.8 **Community care:** Many disabled people do not receive “community support services, including personal assistance, necessary to support living and inclusion in the community and to prevent isolation or segregation from the community”. This means that they are not able to “make choices equal to others” (UNCRPD).

Local authorities are reprioritising resources to those who need critical levels of support, i.e. ‘life and limb’ provision. This creates false economy; it builds up a backlog of people who, for lack of early intervention, eventually become critical. Further, in some case, even ‘life and limb’ support is being cut back to provision that challenges the dignity of the individual:

“When my social worker told me that they had to cut budgets I had no idea that would mean things were going to get so bad. I need help to go to the toilet. There is not enough money to take me to toilet more than twice a day. When my carer comes in to me in the morning, I go to the toilet and before she goes, she puts on an incontinence pad for me so that I can do the toilet in my chair. I have been told to wet or soil myself. When they come back at night to make my

29 Rights to Reality: GDA Young disabled People’s project; Circle Course, 2010

30 “Thriving or Surviving”; Disability Lib, 2008

31 External Evaluation of Glasgow disability Alliance

32 http://www.ilis.co.uk/get-active/independent-living-policy/ilis-consultation-responses/
dinner, they change my pad. I am so embarrassed; I don’t let my friends visit me anymore. I am so isolated and sometimes I can’t see a way out”.

3.9 A further example of ‘cutting and trimming’ that compounds this situation is the closure of the ILF to new applicants. Previously, basic provision would have been ‘topped up’ by the Independent Living Fund (ILF), supporting disabled people to participate fully in society. Without the support of the ILF, and with less money and higher thresholds at LA level, many disabled people will be left with basic support, or even be taken into residential care.

3.10 Welfare Reform: Much of the Welfare Reform agenda proposes significant ‘cuts and trims’ to the support available to and the income of disabled people. The UK Disabled People’s Council found that 90% of DPOs feared that cuts would have a negative impact on disabled people. Disabled people face a ‘double whammy’ when it comes to cuts, in their pocket and in their services: they are disproportionately affected by them.

3.11 The new assessment for DLA (PIP) aims to cut the amount of PIP available by 20% and it is likely that this figure will be higher. Further, the assessment takes wider provision into account e.g. it looks less at the ‘ability to walk’ and more at the ability to ‘get around’; e.g. if someone has an NHS wheelchair, they would be deemed to ‘get around’, so this would result in a reduction in their PIP. This approach fails to consider reductions and constraints on other budgets and the individual freedom afforded by DLA currently, to top-up/purchase more suitable provision than is available through statutory organisations. It also fails to take into account the wider environment which can and often does restrict wheelchair users’ freedom of movement. Further, the ‘cost of disability’ would be transferred from central e.g. DWP, to devolved or local Governments: e.g. the NHS or care and support who cannot meet the demand. Disabled people will be pushed further into poverty and they will not have access to the crucial support they need to realise their rights as outlined in the UNCRPD.

3.12 Against this backdrop of both the poverty and inequality of disabled people as well as reductions in services to support them, further attacks on income broaden the gap between their rights and their actual experience of them; such “regressive government policies seriously undermine the rights of disabled people and the UN Convention on the Rights of Disabled People”.

Charges for services

3.13 Disabled people are not only seeing fewer services and less money, but higher charges for them. Many local authorities are looking to the individual income of disabled people to...
meet demand. This leaves many disabled people with impossible human rights choices between paying for their home and family, or paying for their care.

“*My local authority are allowing us £109 a week to live on and taking 75%, i.e. the rest of our income, towards care. I feel this is far too high and as a home owner with a disability and will give me a big problem, and I guess countless others*”

“*Today I have received a letter from Community Care Finance, Glasgow City Council stating that I will being paying 50% more for my home care charges, starting from April 2011*”

**Localism and inconsistency**

3.14 “*It’s bad enough when we don’t have the rights but it’s worse when we think we can rely on them but someone has chosen not to implement them. I would rather know no buses in my area were accessible and not try to get one, than wait for the one promised bus a day that never turned up*”.

3.15 There are clear variances in how the rights set out in the UNCRPD are translated into action across the public sector. It is not clear who is accountable when these rights are not met (please see the ILiS response to the Scottish Government’s strategy for Self Directed Support for an example of this). This lack of clear accountability means disabled people are denied remedy and access to justice in relation to their rights. This is further compounded by the limited access to the justice system itself, as reported by disabled people.

3.16 There is evidence of inconsistency between the policy aspirations of Government and the practical application of these polices by devolved Government’s and local authorities. Many decisions that impact on the equality of disabled people and their quality of life are devolved to local authorities. This can result in disparity between local authorities and subsequent inconsistency of provision for disabled people across Scotland.

3.17 The requirement to support and resource Disabled People’s Organisations is applied inconsistently across Scotland by individual local authorities. This has implications for developing the critical mass of disabled people able to coproduce at a strategic level; to broadcast the voices of disabled people; and to provide peer support and peer advocacy.

38 Emails to ILiS April 2011

39 Participant at an ILiS outreach event, 2010


41 “*1 in 4 Poll: the Scottish Justice System*”; Capability Scotland, 2009

3.18 Recognising the assets of local communities and the need for coproduction in facing the future demographic and economic challenges is essential, \(^{43}\) localism has nevertheless led to inconsistency in provision \(^{44}\) (please see ILiS submission to the Commission on the future of Public Services in Scotland). An example particularly relevant to the realisation of Article 19 of the UNCRPD is in Portability of Care and Support (please see ILiS briefing on the portability of care\(^{45}\)). The inability to ‘port’ care packages means that disabled people do not enjoy their rights to “choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement” (Article 19).

**Joined up approaches**

3.19 Shared policy, planning, budgeting necessary for independent living is seldom the case:

3.20 A woman approached her social worker saying that she needed a wheelchair to get around and a ramp to get out of her house. Instead, she was offered a package of home care. This was because her social worker could not access other budgets to offer the wheelchair or the ramp. The budgets to do so were not part of a shared resource for health and community care.\(^{46}\)

3.21 Silo provision, not only creates barriers of opportunities, but results in confusion among the public and professionals alike, of ‘who does what and what is done’.

**Enforcement**

3.22 Enforcement of human rights is also crucial to their implementation yet this continues to be an issue; Leonard Cheshire, reported in 2009 that “rights in legislation are simply not translating into reality for many disabled people”\(^{47}\). A number of factors impact on this:

(f) Access to justice—Only 42% of disabled people claim to have equal access to justice and 44% report barriers in accessing justice\(^{48}\)

\(^{43}\) “Submission to the Finance Committees Inquiry into Preventative Spending”; ILiS, SDEF and Inclusion Scotland, 2010


\(^{45}\) [http://www.ilis.co.uk/get-active/independent-living-policy/independent-living-policy-briefings/](http://www.ilis.co.uk/get-active/independent-living-policy/independent-living-policy-briefings/)

\(^{46}\) Letter received by Glasgow Centre for Inclusive Living from a client of theirs, 2010

\(^{47}\) “Rights and Reality”; Leonard Cheshire, 2009

\(^{48}\) “1 in 4 Poll”; Capability Scotland 2009
(g) **The cost of legal action**—57% of people believed they couldn’t afford to take legal action.\(^{49}\) This is compounded by the reduction in the funding available through legal aid and means that for disabled people, 47.5% of whom live in poverty,\(^{50}\) access to legal advice is restricted.

(h) **Fear of repercussions**—“I’m scared to complain, I’ll just end up with nothing”, “when you have a problem with the hand that feeds you, you don’t want to bite it”\(^{51}\)

4. **Improvements in policy and practice to support independent living**

**What steps, if any, should the coalition Government, the Scottish Government or other public agencies take better to meet the obligations in Article 19 and to secure the right to independent living for all disabled people in the UK?**

**What steps should the Government take to meet its obligations under the Disability Rights Convention to involve disabled people in policy development and decision-making, including in budget decisions such as the Comprehensive Spending Review?**

4.1 In addition to addressing some of the issues above e.g. a focus on prevention, joined up working, addressing localism; “Ready for Action” identifies some of the specific priorities, necessary to make independent living a reality for disabled people. It also highlights barriers and recent developments, along with cross-cutting actions for all sectors and a need to address issues in the overall political, social and service structure.\(^{52}\) We recommend this as a starting point against which to measure progress in this area.

**Leadership**

4.2 Cross sectoral leadership is essential for independent living. Leadership is needed at corporate and operational level, it needs political buy in and it needs leaders from within communities e.g. DPO’s. The experience of the CRG in Scotland is that where leadership is shown, independent living is recognized and valued.

**A joined up approach**

\(^{49}\) “Rights and Reality”; Leonard Cheshire, 2009

\(^{50}\) “Destination Unknown”; Demos report 2010

\(^{51}\) ILiS coproduction event, Selkirk, 2011

\(^{52}\) “Ready for Action”; ILiS, 2009
4.3 Independent living and the empowerment of the disabled individual, relies on all of the rights (1.5), being in place and working together. This interconnectedness is not only crucial for the empowerment of the disabled person, but also for the professional. The present system of silo (thematic and geographic) policy making, provision and budgeting, disempowers professionals and disabled people alike. Practitioners, working close enough to disabled people to co-produce outcomes, are often distant from the budgets that would enable them to deliver the right solution. A whole systems approach is needed. We recommend an empowering re-structure of public services (please see ILiS submission to the Commission on Public sector Reform in Scotland).

Localism

4.4 Whilst we acknowledge ‘legitimate’ localism where it creates the opportunities for local communities to coproduce solutions best suited to them, we note that it can create barriers for independent living and, in some instances, comes head to head with the human rights of disabled people. In this case, we believe the drive for localism to be illegitimate and counter to the implementation of the UNCRPD. We would urge the Commission to consider the interface between local accountability, which reflects, on the whole, the goals and outlook of the majority within the locality; and the human rights of disabled people, who nonetheless constitute a significant minority of the local population.

Prevention, coproduction and empowerment

4.5 Co-production is central to the philosophy of independent living and essential to the preventative and cross cutting approach it demands. It recognises that people from various backgrounds, opinions, knowledge and skills working together, from the very outset, bring assets valuable to achieving agreed outcomes. Coproduction must be the process by which we determine how to realise full implementation of the UNCRPD. It needs structural changes, including to budgets, with more control being passed to individuals, groups and front-line professionals.

4.6 Without the empowerment of disabled people and Disabled People’s Organisations there will be no critical mass of disabled people willing and able to coproduce the future of public services. The preventative approaches outlined above are crucial. Empowerment is not only essential to the realization of Article 19, but is underpinned by Articles 4(3) and 29 too; State Parties shall “closely consult with and actively involve persons with disabilities, through their representative organisations” and “shall guarantee to persons with disabilities, political rights and the opportunity to enjoy them on an equal basis with others.....and will support them to form and join organizations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels”.53 In the context of coproduction and independent living, we consider this Article to be crucial to the implementation of the wider UNCRPD.

53 Article’s 3(4) and 29; UNCRPD
If you consider changes to policies, practices or legislation in the UK are necessary, please explain

4.7 We welcome the UNCRPD as a useful tool in the interpretation of the human rights of disabled people. However, the Convention is not part of domestic UK or European law and as such is not 'justiciable' in the domestic or European Courts (please see the EHRC response to the Commission’s inquiry). Given the inequalities and issues in accessing justice that disabled people face, we feel it is essential that the UK bring the rights in the UNCRPD into domestic law at the earliest possible opportunity.

4.8 We also feel that in the absence of adequate advice and advocacy for disabled people, and acknowledging the issues outlined at 3.22, there needs to be a statutory right for all disabled people to access and benefit from independent advice and advocacy services, including from their fully trained and informed peers; and to access and benefit from the full range of legal services necessary to secure their full human and civic rights, as afforded in article 13 of the UNCRPD.

21 April 2011

Commission on the Future Delivery of Public Services: Response from the Independent Living in Scotland Project (March 2011)

1. Independent Living and the Independent Living in Scotland project (ILiS)

1.1 The Independent Living in Scotland project is funded by the Scottish Government and hosted by the Equality and Human Rights Commission (EHRC). It is steered by a group of disabled people. It aims to support disabled people in Scotland to have their voices heard and to build the disabled people’s Independent Living Movement (ILM).  

1.2 This response has been prepared by the ILiS project team on behalf of the ILiS Steering Group. It should be read alongside the joint response to the Finance Committee’s Inquiry into Preventative Spending submitted by ILiS, Inclusion Scotland and the Scottish Disability Equality Forum (August 2010) and “Ready for Action”, a policy document, developed by disabled people to highlight what needs to change in order for independent living to be a reality.

54 www.ilis.co.uk
55 http://www.ilis.co.uk/get-active/independent-living-policy/ilis-consultation-responses/
1.3 Independent living means disabled people of all ages having the same freedom, choice, dignity and control as other citizens at home, at work, and in the community. It does not mean living by yourself or fending for yourself. It means rights to practical assistance and support to participate in society and live an ordinary life. It also means that with such support disabled people can exercise their rights and duties of citizenship via their full and equal participation in the civic and economic life of Scotland—thereby changing the public misperception of them as being a drain on society’s resources rather than an active contributor.

The principles of independent living, i.e. **freedom, choice, dignity and control**, do not only relate to the specific services and provisions for disabled people, but to the whole of disabled people’s interactions with society; its organisations, facilities and structures; and every aspect of their quality and equality of life.57

- Full access to our environment
- Fully accessible transport
- Technical aids and equipment
- Accessible and adapted housing
- Personal assistance
- Inclusive education and training
- An income, including income within the state-benefit system for those unable to work
- Equal opportunities for employment
- Accessible and readily available information
- Advocacy and working towards self-advocacy
- Counselling, including peer counselling
- Accessible and inclusive healthcare provision
- Communication and appropriate support for communication

1.5 Independent living is crucial in the promotion and protection of the human rights of disabled people. Without access to the support and provision, laid out above, human rights cannot be a reality for disabled people.

1.6 Disabled people do not yet have equal access to these rights.

1.7 The interim report of the Life Opportunities Survey58 states that:

- (i) 17% of disabled adults experienced restrictions in their learning opportunities compared with 9% of non disabled adults
- (j) 45% of households with at least one disabled person living in them are unable to afford expenses or make loan repayments. This compares with 29% of households without any disabled people
- (k) 74% of disabled adults experienced restrictions in using transport compared with 58% of non disabled adults

58 The Life Opportunities Survey”; Office of National Statistics, 2010
(l) 12% of disabled adults experienced difficulty accessing rooms within their home or difficulty getting in or out of their home compared with 1% of non disabled adults

(m) 29% of disabled adults experienced a restriction to accessing buildings outside their home compared with 7% of adults without impairments

1.8 Further:

(n) When the extra costs of being disabled are taken into account, 47.5% of families with disabled people in the household, live in poverty

(o) Only 50% of disabled people of working age are in work, compared with 80% of non disabled people of working age

(p) Disabled people officially constitute only 6% of formal volunteers and around 4.3% of public appointments across Britain. This is compared to 20% of the population at large

(q) 23% of disabled people have no qualifications compared to 9% of non disabled people

(r) By the age of 26, young disabled people are more than three times as likely as other young people to agree with the statement “whatever I do has no real effect on what happens to me”. It should be noted that for many specific groups, e.g. people with learning disabilities and mental ill health, the stats can be much more extreme.

1.9 “Ready for Action” identifies some of the specific priorities, from disabled people themselves, which are necessary to make independent living a reality for disabled people. It also highlights barriers and recent developments, along with cross-cutting actions for all sectors and a need to address issues in the overall political, social and service structure.

1.10 We suggest that “Ready for Action” is as a useful starting point for the purposes of the Commission.

The vision for independent living and Scottish Public Services

2.1 Key to making independent living a reality is the need to place the principles of human rights and independent living firmly at the centre of mainstream public services.

59 “Destination Unknown”; Demos report, 2010

60 Office for National Statistics—Labour Force Survey, Jan–March 2009


64 “Ready for Action”; ILiS, 2009
2.2 We welcome the Commission’s review of and vision for the public sector in Scotland. In particular, we welcome the Commission’s focus for a public sector that is innovative and is based on the principles of equality, empowerment, consistency, coproduction and prevention.

2.3 These are principles that underpin independent living. We are pleased that the vision for the public sector in Scotland is akin to this.

2.4 ILiS’s response to the Preventative Spending Inquiry\(^\text{65}\) sets out our case for independent living, highlighting the need for coproduction and prevention in public sector delivery. We have appended this as a key part of our submission to the Commission.

*A vision for independent living in Scotland*

2.5 In December 2009, the Scottish Government, CoSLA and the Independent Living in Scotland project signed up to a Vision for independent living in Scotland.\(^\text{66}\) These signatories were joined by NHS Scotland in 2010. The Vision states that “disabled people across Scotland will have equality of opportunity at home and work, in education and in the social and civic life of the community”.

2.6 Where independent living is not the reality for disabled people, where they are supplied only by services that meet basic life and limb needs and take a paternalistic, top down approach; they are disempowered and denied their right to be full and equal citizens of Scotland. They cannot access society on an equal basis and their capacity to contribute to society goes unutilised and under-resourced. The ability of disabled people to enjoy and benefit equally from the public sector, as envisaged, is greatly restricted.

2.7 For this reason, for the public sector in Scotland to live up to the expectations of the Vision laid out by the Commission it is essential that the principles outlined above must be extended to include independent living and human rights.

3. **Barriers to the vision and achieving positive outcomes for disabled people in Scotland**

3.1 Scottish political, social and organisational structures (including but not limited to those within services traditionally delivered by the public sector e.g. health, social care, some aspects of leisure and housing) have been slow to both meet the needs of disabled people and to recognise their entitlements.\(^\text{67}\)

3.2 In addition to the priorities set out in “Ready for Action” and the circumstances outlined at 1.7 and 1.8 above, a recent report into compliance with the Human Rights Act in Scotland, carried out by 4 third sector organisations, states that “**there is little evidence to**

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\(^{66}\) [http://www.ilis.co.uk/independent-living/a-vision-for-independent-living-in-scotland/](http://www.ilis.co.uk/independent-living/a-vision-for-independent-living-in-scotland/)

\(^{67}\) “Ready for Action”, ILiS, 2009
suggest that human rights are being mainstreamed across the public sector in Scotland".  

3.3 In addition to the key barriers laid out in our submission on Preventative Spending (see appended document), we consider that the following issues present barriers to achieving a public sector akin to that envisaged by the Commission.

(s) localism

(t) thresholds for accessing support

(u) shared resources, and,

(v) paternalism.

Localism

3.4 It is widely noted and accepted that the rights of disabled people are many but that the reality of the provision does not reflect these rights. This in part is a result of inconsistency of provision across Scotland. The European Disability Strategy, which aims “to empower disabled people”, recognises that “achieving this and ensuring effective implementation of the UN Convention across the EU calls for consistency”.

3.5 A participant at a recent ILiS outreach event noted that “it’s bad enough when we don’t have the rights but it’s worse when we think we can rely on them but someone has chosen not to implement them. I would rather know no buses in my area were accessible and not try to get one, than wait for the one promised bus a day that never turned up”.

3.6 The Scottish Government, via the UK Government, has signed up to various human rights instruments, including the United Nations Convention on the Rights of People with Disabilities (UNCRPD). However, there are clear variances in how these rights are translated into action across the public sector in Scotland. Also, it is not clear who is accountable when these rights are not met (see the ILiS response to the Scottish Government’s strategy for Self Directed Support for an example of this). This lack of clear accountability means that disabled people are denied ready remedy and access to justice in

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69 “Rights and Reality”; Leonard Cheshire Disability, 2010

70 http://www.un.org/disabilities/default.asp?id=150

71 European Disability Strategy 2010 - 2020: A Renewed Commitment to a Barrier Free Europe”; The European Commission, 2010

72 http://www.ilis.co.uk/get-active/independent-living-policy/ilis-consultation-responses/
relation to these rights. This is further compounded by the limited access to the justice system itself, as reported by disabled people.\textsuperscript{73}

3.7 There is evidence of inconsistency between the policy aspirations of the Scottish Government and the practical application of these policies by local authorities. This can create tension including organisational tension.

3.8 In Scotland, many decisions which have an impact on the equality of disabled people and their quality of life are devolved to local authorities. This can result in disparity between local authorities LA and subsequent inconsistency of provision for disabled people across Scotland.

3.9 For example, despite the requirement to support and resource Disabled People’s Organisations is applied inconsistently across Scotland by individual local authorities.\textsuperscript{74} This not only has implications for provision locally but also for the critical mass of disabled people able to coproduce at a strategic level and to broadcast the voices of disabled people, which needs to be heard by decision makers.

\textit{Portability of Support}

3.10 Like other people, disabled people also choose to move from one area to another for various reasons. It may simply be because of personal preference, but it can often be through necessity, for example, to be nearer employment or educational opportunities, family, friends or other support networks or because accommodation is no longer suitable.

3.11 The UNCRPD states that disabled people must not be discriminated against and must enjoy freedom of movement, participation, education, employment and respect for family life. However, disabled people who use support services, funded wholly or in part by the local authority, face a number of barriers from within the public sector when then choose to, or have to, move across local authority boundaries.

3.12 As above, this is largely due to the inconsistent application of policies and practice from one local authority to another. For example, this includes eligibility criteria, assessment processes, charging policies, and variations in local provision. Please see the ILiS briefing on Portability of Care for further details.\textsuperscript{75}

3.13 We note that:

(w) Current guidance for local authorities on eligibility criteria states that “it is the responsibility of local authorities to determine the provision of care services in their areas, taking account of their financial and other resources and the costs of service

\textsuperscript{73} “1 in 4 Poll: the Scottish Justice System”; Capability Scotland, 2009

\textsuperscript{74} “Self Directed Support Strategy for Scotland”; Scottish Government, 2010

\textsuperscript{75} http://www.ilis.co.uk/get-active/independent-living-policy/independent-living-policy-briefings/
This means that each local authority makes decisions on what support to offer, based on how much money they have and on their own local political priorities, not on the rights of the individual. This inconsistency can often leave disabled people facing reassessment of their needs and reallocation of resources, based not on need or change of circumstances, but on postcode. This leaves the disabled person in a very difficult position; do they move, perhaps facing a long period of uncertainty and inadequate support; or do they just sit tight, retaining existing support, but denied the possible opportunities that moving may offer?

(x) CoSLA’s guidance on charging for community care does not take the form of a ‘national prescription’. Instead, it offers a framework, based on principles and practice that aims to maintain local accountability and discretion, while encouraging councils to demonstrate that they have followed best practice in determining charges. For example, the guidance recommends a common threshold at which charges begin to apply. After this, LA’s decide how much of an individual’s income they can be required to contribute towards the cost of their community care. The guidance suggests that this so called “taper” could be anything from 5% of disposable income to 100% of disposable income.

(y) Despite this guidance, CoSLA notes that “the level at which people begin to pay charges, varies widely across LA’s”. This variation is consistently substantiated by individual disabled people, including those attending ILiS policy events. For example, a woman, aged 22, lived in one area and moved to another to study. In the original area, she paid £700 per month towards her community care and in the new area, she paid only £130. In this case the move was to the advantage of the individual but, just as often, moving from one area to another may be financially unviable. Again, inconsistency in policy and practice creates a barrier to independent living, freedom of movement and the equal participation of disabled people in the civic and economic life of their communities.

(z) Further, the Social Work Scotland Act 1968, provides that, when someone moves from one area to another, the new area is entitled to re-assess the person for community care services. Many disabled people report that access to suitable support is often dependent on the knowledge and outlook of the person assessing them for those services and provisions needed to lead a full and active life. Practices and approaches vary considerably among staff and between local authority areas. This leaves disabled people not only unsure of whether they will retain their level of support when they are reassessed if they move, but can also act as a deterrent to moving in the first place.

3.14 In light of the many existing barriers that disabled people face in their efforts to participate fully and equally in the civic and economic life of their communities (see statistics at 1.6 and 1.7), and recognising the protections they have under human rights legislation and

76 National Eligibility Criteria”; Scottish Government, 2010
79 ILiS SDS Strategy consultation event, 2009
80 “Life not numbers”; NUS, 2010
conventions, we cannot afford to create these further barriers to mobility and freedom of movement such as those created by not being able to port care packages, e.g. taking up employment or education.

3.15 There is clearly a pressing need to resolve this tension between national policy, localism, and the rights of disabled people

**Thresholds**

3.16 We know that over, the next 4 years, we will see a £3.3 billion real term cut to Scotland’s budget (11%) and that we will not return to last year’s level of funding until 2025/26— a £39 billion reduction in total.81 We also know that, over the next period of 5 years, demand will grow by 8%, whereas supply (public finance) will decrease between 6–12%.82

3.17 Retrenchment into the more “traditional” economies of cutting, trimming and delay, means restricting demand by raising the eligibility thresholds for access to services. As we pointed out in our Preventative Spending submission, this is counterproductive and is a false economy.

3.18 Despite this, we still see policy and practice where only those with the highest, most complex needs or those considered priority cases, receive a service. ‘Life and limb’ provision is prevalent in terms of access to support for independent living today.

3.19 This is further evident in the current UK welfare benefit proposals and in local authority resource allocation policies. It is also evident in the funding of those Disabled People’s Organisations which build the confidence and capacity of disabled people. Empowering disabled people enables them to contribute to the civic and economic life of their community and, in turn, lowers demand for state provision. It also makes genuine coproduction possible, for example improving services through partnerships between planners, providers and service users.

3.20 Such a traditional slash and burn approach to public services will hinder the progression of a public sector based on the principles of equality, coproduction and empowerment. Without the empowerment of disabled people and their user-led organisations their will be no critical mass of disabled people willing and able to coproduce the future of public services.

**Shared resources**

3.21 **Case study 1:** A woman approached her social worker saying that she needed a wheelchair to get around and a ramp to get out of her house. Instead, she was offered a

81 “Know the score on Welfare Reform”; Inclusion Scotland, 2010
82 Improvement Services; 2010
Written Evidence submitted by Independent Living in Scotland (IL 30)

package of home care. This was because her social worker could not access other budgets to offer the wheelchair or the ramp. The budgets to do so were not part of a shared resource for health and community care.\textsuperscript{83}

3.22 This type of silo provision, not only creates barriers of opportunities, but results in confusion among the public and professionals alike, of ‘who does what and what is done’. It also wastes public money, because instead of offering her a one-off grant to build a ramp and provide a wheelchair, the social worker committed the local authority to providing an open-ended service, which the woman did not need or want in the first place.

3.23 Independent living and the empowerment of the individual, depends on a ‘chain’ of support. Where one ‘link’ is missing, disabled people are disempowered and independent living fails to become a reality. It relies on all of the rights, set out at 1.4 above, being in place and working together. This interconnectedness is not only crucial for the empowerment of the disabled person, but also for the professional.

3.24 The present system of silo provision, be it in terms of location or in terms of subject or budget, disempowers professionals. Practitioners who work closely enough with disabled people to co-produce user-defined outcomes, are often too distant from the budgets that would enable them to deliver the right solution.

\textit{Paternalism}

3.25 Disabled people often note that a barrier to controlling their own life is that the control lies with professionals.\textsuperscript{84} For example, in community care, the social worker determines the level of need and the extent of provision for that need.

3.26 Systems that are built around the ‘duty of care’ to the individual entrench the lack of control for the individual as they foster a paternalistic approach, where the professional is seen as a ‘problem solver’. This can foster an exaggerated aversion to risk. However, with limited individual knowledge, limited time and limited access to money, alongside a myriad of different budgets, processes and eligibility criteria, the professional, within the public sector, cannot offer the innovative solutions to ‘solve’ the problem. Not only are they unable to do this on their own, as the example at 3.21 shows, but with little access to the further provision and assets needed, solutions and outcomes cannot and should not, be ‘done’ to people.

3.27 Procedures that are built around systems driven by a ‘duty of care’, which is based on out-of-date attitudes to disabled people enshrined in the 1968 Social Work (Scotland) Act, foster a dominant risk-averse approach to social work management; strict health and safety regimes within social care; and rigid organisational behaviours of social service providers, which, put together, limit the professional in their ability to enable innovative solutions. Consequently, they limit the freedom and empowerment of the disabled person, in terms of their access to independent living and full citizenship (see sections 3.16–3.20 above).

\textsuperscript{83} Letter received by GCIL from a client of theirs, 2010

\textsuperscript{84} “Ready for Action”; ILiS, 2009
3.28 This impasse could easily be resolved if the ‘duty of care’, enshrined by the 1968 Act, were to be supplanted by a ‘duty to empower and support’. For those who require intensive intervention to secure and maintain their security and wellbeing, such a duty of support should meet their needs equally well since ‘support’ may be as intensive and all-embracing as required.

4. **Wider organisational arrangements for an enabling public sector**

4.1 For the purposes of the Commission’s inquiry, we focus on the following recommendations/observations for a public sector, based on the principles of independent living, in addition to those outlined in our response to the Preventative Spending Inquiry.

**Coproduction**

4.2 The current and future challenges facing public services, and the people who use those services, including disabled people, need coproduced solutions. The drive in public policy, underpinned by human rights, independent living and coproduction, is moving towards a position where the state empowers disabled people to be in control of the support they need to participate in society on an equal basis to others.

4.3 An example of this can be seen in social care, where there is a move to Self Directed Support (SDS)—see the SDS strategy for Scotland[^85] for more information. This means that, rather than determining what is needed, providing it, or even controlling the local market for it, the state empowers the community to do so themselves. This harnesses the knowledge, experience and resources of the people who use services when designing policy and service redevelopment.

4.4 **Example:** People who use Housing Support Services, local providers and the local authority in Oxfordshire recognised that the drive towards ‘personalisation’ meant that commissioning, procurement, local provision and marketing must take a new focus.[^86] They also recognised the collective ‘purchasing’ power of the individual in this new way of working, in coproduction. Recognising this, the partnership developed a community networking website, where local people can share interests and so pool resources where appropriate; and thus share community resource and influence local provision.

4.5 In this sense, the state must have a ‘duty to empower’ rather than a ‘duty of care’. Changing the fundamental premise on which public services are built will support the development of policy and practice that are conducive to coproduction. However, this way of working needs empowerment of the individual, the professional commissioner and provider, along with the state.


86 [http://www.up2uscommunity.co.uk/Gateway/up2us/index.aspx](http://www.up2uscommunity.co.uk/Gateway/up2us/index.aspx)
4.6 Coproduction is based on a set of values and approaches that breaks down myths and assumptions and fosters trust, compromise and empowerment, of both professional and the individual. It asserts that everyone involved in public sector delivery, professionals, the individual and the community alike, must be seen as assets who together can come up with better solutions than they can alone. It also changes the role of the professional, the individual, the community and the state.

4.7 This requires culture and structural change that is conducive to coproduction, prevention and shared resources, as well as addressing the issue of paternalism within both state and third sector provision. Coproduction needs a critical mass behind it. It also needs leadership—by professionals, individuals and communities.

4.8 Disabled people are under-represented in the civic life (see 1.7 and 1.8 above) and so for the contribution of disabled people to be realised and leaders to bring others on board, it is essential that the public sector support the empowerment and capacity building of disabled people and the Disabled People’s Independent Living Movement (see “It’s our world too”) as well as ‘life and limb’ provision.

4.9 To do this, independent living must be recognised as a preventative agenda, the benefits of which will be reaped in the longer term due to the increased participation of disabled people and their informal supporters in the wider economic, social and cultural growth of the country. Independent living is often undermined by the lack of such recognition to the detriment of society and the rights of disabled people; as well as the longer-term financial costs to society of not meeting those rights. It is essential that we make best use of the assets of the whole of our society so that we can face the economic and moral challenges we face.

4.10 Equally, professionals must be empowered, and they must learn a new way of working. Structures and practices must create an environment where individual professionals, including those at operational levels, can take responsibility, show leadership, and develop innovative solutions to today’s complex challenges. This needs structural and systemic change, where operational staff have more control over decision-making and budgets. It also requires leadership from management to develop an appropriate organisational culture.

**Joined up policy, practice and delivery**

4.11 Whilst we welcome ‘legitimate’ localism where it creates the opportunities for local communities to coproduce solutions best suited to them, we note that it can create barriers for independent living and, in some instances, come head to head with the human rights of disabled people, resulting, as it often does, in inconsistent practice. In this case, we believe the drive for localism to be illegitimate and counter to the wider public sector reform agenda.

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88 [http://www.ilis.co.uk/uploaded_files/15p_it_s_our_world_too_plainenglish_pdf_level_3_revised_240510.pdf](http://www.ilis.co.uk/uploaded_files/15p_it_s_our_world_too_plainenglish_pdf_level_3_revised_240510.pdf)
4.12 We would urge the Commission to consider the interface between local accountability and the human rights of disabled people in terms of the best way to deliver public services, as set out at sections 3.4–3.15 above.

4.13 Further, the example of portability of support outlined earlier and the application of high level thresholds, both pose challenges for public sector reform, but also for the future of community care provision in Scotland. Much of this debate is centred on the issue of localism versus individual freedoms. This needs wider debate. As such, we would recommend that a further commission to consider the future of social care in Scotland be set up.

4.14 ILiS recognises the role of elected members in making decisions about services and the settlement between LA’s and the Scottish Government. However, we also recognise the commitments made by the Scottish Government and CoSLA, through the programme on independent living and wider agendas such as human rights, equality and growing the economy, to break down barriers to independent living and to make human rights a reality.

4.15 In light of the structural inequalities in Scotland and the challenges posed by localism, alongside silo planning and delivery in addressing these, we recommend an empowering structure for the public sector, based on the principles set out above, that secures sufficient and appropriate access to shared budgets, that supports the innovation needed and that recognises disabled people and communities as essential assets to face the challenge ahead.

March 2011

Finance Committee Inquiry into preventative spending—call for evidence

Joint submission from the Independent Living in Scotland Project, Inclusion Scotland and the Scottish Disability Equality Forum

“...Published material to date indicates that the delivery of Independent Living support to disabled people is more cost effective, or at least no more expensive, than traditional care provision. [...] The small amount of data that did exist at macro level also indicated that considerable cost savings could accrue to the Exchequer, in increased tax revenues and reduced benefits payments, from investing in IL support”.

(Conclusions from the literature review: “The costs and benefits of independent living: Executive Summary”, by Jennifer Hurstfield, Urvashi Parashar and Kerry Schofield, on behalf of the Office of Disability Issues, Department of Work and Pensions

Executive Summary

A.1.0 Introduction:

A.1.1 This is a joint submission from three national organisations within the disabled people’s independent living movement: the Independent Living in Scotland Project, Inclusion Scotland and the Scottish Disability Equality Forum (see Appendix for details)
A.1.2 This joint submission hopes to show how the policies, services and provisions, based on the philosophy of independent:

- can both facilitate and accelerate the economic growth of Scotland
- can reduce the gulf between demand and supply of public services for both disabled people and their informal support;
- can be reconceptualise the ‘work vs. welfare’ debate by enabling welfare recipients to develop markets and provide work for others; and, at the same time, develop their own transferrable management skills
- can overcome the ‘silo’ effects of services and budgets by providing a more ‘holistic’ approach to solving need
- can meet the newer economies of innovation and prevention as laid out by the Young Foundation,\(^89\) via the efforts of disabled people and their own user-led organisations.

A.2.0 Preventative funding and strategic decision making:

A.2.1 Independent living means disabled people of all ages having the same freedom, choice, dignity and control as other citizens at home, at work, and in the community. It does not mean living by yourself or fending for yourself. It means rights to practical assistance and support to participate in society and live an ordinary life. The principles of independent living, i.e. **freedom, choice, dignity and control**, do not merely relate to the specific services and provisions for disabled people, but to the whole of disabled people’s interactions with society; its organisations, facilities and structures; and every aspect of their quality and equality of life.

A.2.2 The principles and practices of independent living provide a positive model for reshaping public services in a way which better meets people’s needs and supports the promotion and protection of human rights; it is more modern, responsive and person-centred; and it can result in real efficiencies—but only if organisations and personnel within them work across portfolios and budgets.

A.2.3 Independent living should be recognised as a preventative agenda, the benefits of which will be reaped in the longer term due to the increased participation of disabled people and their informal supporters in the wider economic, social and cultural growth of the country. It is also crucial in the promotion and protection of human rights of disabled people, both in terms of the role of early intervention in the protection of human rights but also in terms of preventing challenges based on the denial of human rights.

A.2.4 However, a fundamental redesign of the method of delivering services may provide cheaper options to meet need in a more efficient way.

A.2.5 Co-production is central to the philosophy of independent living. It is a method whereby people from various backgrounds, opinions, knowledge and skills working together,

\(^89\) [http://www.youngfoundation.org](http://www.youngfoundation.org)
from the very outset, to achieve an agreed outcome. A Cabinet Office Strategy Unit discussion paper argues that the emerging evidence of its impact on outcomes and value for money, along with its potential economic and social value, as well as its popularity, means that coproduction should be central to improving public services.

A.2.6 In order to hasten coproduction, structural changes need to be made to budgets, with more control being passed to individuals, groups and front-line professionals. A ‘whole systems approach’ is needed to maximise the impact of investment and this must be based on developing good partnership working.

A.2.7 It is essential to challenge the perception of those who see “self assessment” and coproduction as a costly burden rather than an essential element to policy and service development and delivery. For example, to overcome the disempowerment of disabled people through the denial of free access to information, there is a dire need for advocacy; and self-advocacy. If these services that are often seen as non essential for funding but which prevent higher costs arising later on, through the lack of provision or the delivery of inadequate and inappropriate provision

A.3.0 Preventative funding of services and provisions:

A.3.1 In previous recessions, the knee jerk response of retrenchment into the more “traditional” economies of cutting, trimming and delay, would have meant restricting demand, by raising the access threshold criteria to services. This would have led to a disproportionate disadvantage being placed on disabled adults, particularly on those, who, with a little support, could have actively participated in the economic growth of the country. Instead, they would have been left to rely on their own informal support systems; thus creating more stress and poverty upon their family and friends; accumulating more need for both themselves and informal supporters, in later years. In effect, the growing gulf between demand and supply would have just kept on growing. Such traditional services merely segregate disabled people within their own homes or day centres, denying them the opportunity to participate as equal citizens within the community. Services, designed on the principles of independent living, allow disabled people to do just that.

A.3.2 The silo thinking and complexity of the health and welfare system, not only creates barriers of opportunities, but results in confusion among the public of ‘who does what and what is done’. By denying people access to information, users cannot contribute to more imaginative and cost-effective solutions. What independent living shows is that the inter-connectedness of services and budgets and what happens to the quality of one’s life depends upon the interface between health, social care, housing, transport, education, the environment, welfare benefits, employment, etc. etc.

A.3.3 Given present-day demand trends, the Finance Committee may well consider entitlements to services and benefits; and how these are resourced and financed. This joint

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submission accepts that this may include, inter alia, the extent to which services are free at the point of use (tax financed) and the extent to which fees or charges are in place. However, this should not be examined in isolation from questions of relative priority; and that it should be informed by clear principles (not simply driven by financial pressures)

A.3.4 The existing and forthcoming Public Sector Equality Duties are one tool to help mitigate against the potential negative and disproportionate impact of decisions that are taken in isolation and that can lead to a myriad of unintended consequences and indeed, as described above, false economies

A.3.5 In conclusion, this joint submission hopes that the Finance Committee would recommend to the Scottish Parliament that the support necessary to enable disabled people to live independent lives as full and equal citizens, will attract priority; and that any review of how that support can best be delivered in the future will include disabled people as equal partners, in the spirit and enactment of co-production.

1.0 Introduction

1.1 Due to the constraints of time and resources, this is a combined submission from the Independent Living in Scotland Project; Inclusion Scotland and the Scottish Disability Equality Forum. These bodies form part of the Independent Living Movement in Scotland. Please see appendix 1 for a background to the Independent Living Movement, Independent Living Movement and the 3 organisations submitting this response.

2.0 What is independent living?

2.1 Independent living means disabled people of all ages having the same freedom, choice, dignity and control as other citizens at home, at work, and in the community. It does not mean living by yourself or fending for yourself. It means rights to practical assistance and support to participate in society and live an ordinary life. The principles of independent living, i.e. freedom, choice, dignity and control, do not merely relate to the specific services and provisions for disabled people, but to the whole of disabled people’s interactions with society; its organisations, facilities and structures; and every aspect of their quality and equality of life:

- Full access to the environment;
- Fully accessible transport;
- Technical aids and equipment;
- Accessible Housing;
- Personal Assistance;
- Inclusive education and training;
- An adequate income; including that within the state benefit system for those unable to work;
- Equal opportunities to employment;
- Accessible and available information
- Advocacy, including peer advocacy;
- Counselling, including peer counselling
- Accessible and inclusive healthcare
- Communication and appropriate support for such
2.2 The principles and practices of independent living provide a positive model for reshaping public services in a way which better meets people’s needs; it is more modern, responsive and person-centred; and it can result in real efficiencies — but only if organisations and personnel within them work across portfolios and budgets.

3.0 What is co-production?

3.1 Co-production is a method whereby people from various backgrounds, opinions, knowledge and skills working together, from the very outset, to achieve an agreed outcome. It values everyone involved as equal and allows the ‘trading’ of each others skills, experience and knowledge to be respected and employed to its maximum. However, the perception and aspirations of the end user is the main driver.

3.2 Co-production means bringing the lived knowledge and experience of the individual, family and community into setting strategies, plans and the delivery of services; allowing individuals, families and communities to take a lead role in the shaping of policy formation and resource utilisation; and most importantly, public service commitment to support and develop the capacity to self direct outcomes.

3.3 A Cabinet Office Strategy Unit discussion paper has highlighted the importance of coproduction; its potential; and how to accelerate its implementation. They argue that the emerging evidence of its impact on outcomes and value for money, along with its potential economic and social value, as well as its popularity, means that coproduction should be central to improving public services. However, they also argue, that, in order to hasten coproduction, structural changes need to be made to budgets, with more control being passed to individuals, groups and front-line professionals. In addition, the paper argues that there needs to be more support for civic society and mutual help, which the coalition government is now calling ‘the big society’; as well as, improved performance regimes and professional training and culture change.

4.0 Independent living is a preventative agenda

4.1 In terms of social, health and welfare economics, independent living should be recognised as a preventative agenda, the benefits of which will be reaped in the longer term due to the increased participation of disabled people and their informal supporters in the wider economic, social and cultural growth of the country. Independent living is often undermined by the lack of such recognition to the detriment of the benefits to society and the rights of disabled people; as well as the longer-term financial costs to society of not meeting those rights.

4.2 Reference, here, should be made to the North East (of England) Improvement and Efficiency Partnership’s report on “What supports independence project: Work phase 1: researching the services that support independence.” The overall aim of the project was to:

“seek to identify what universal, primary and secondary preventative approaches are effective to avoid the development of longer-term dependency and therefore deflect people from inappropriately entering the social care system, because their needs have been met through earlier intervention, targeted prevention and/or re-enablement services, which have maintained individual self-care, functioning, and supported independent living.”

4.3 The key messages from the report’s collected evidence included:

- Prevention and early intervention services need to address the spectrum of need from promoting access to universal services for the general population through to addressing complex needs.
- A broad range of services have a key contribution to make in delivering prevention and early intervention including housing, leisure, transport and community safety.
- Involving users and carers at all stages is essential to ensure that services reflect their needs and wishes.
- A ‘whole systems approach’ is needed to maximise the impact of investment.

4.4 The report also suggested that the successful delivery of preventative services which will make a difference at a population level needs more than just individual (silo) effective services. It needs:

- Such a ‘whole systems approach’ to be based on developing good partnership working.
- Effective and appropriate targeting of preventative interventions as well as improved access for priority groups to mainstream services.
- Investment and change across the whole range of preventative services from universal ones to those targeted on specific vulnerable groups.
- Developing effective prevention strategies, which recognise the role that different services can play in preventing the need for care.
- A strategic approach to commissioning all services to promote independence through an explicit commissioning cycle.

4.5 Although the evidence supported the need for a broad based approach to develop preventative services, the report also highlighted some key services as being especially important. These were:

- Information and advice.
- Housing and practical support.
- Promoting physical activity.
- Ensuring access to mainstream services.
- Reducing isolation and social exclusion; and broadening social and community networks.

4.6 The project also carried out a web-based survey which identified eighty three services supporting independent living. From these they picked twenty five services which demonstrated effectiveness and which met one or more of these criteria:

- Prevention or delay of the development of long-term conditions.
- Delivery of efficiencies for local authorities and health services through the avoidance or prevention of costly social care intervention.
- Value for money.
- Evidenced outcomes for individuals, authorities and an area/locality.
- Building social inclusion.
- Sustaining or improving wellness.

4.7 The conclusions made by this first part of the project were that within the broad span of preventative services most appear to have a positive impact. Looking at the top four services they identified the following key factors in ensuring success.

- Understanding and involving citizens, users and customers.
- Developing a clear vision and effective partnership working to deliver it.
- Using both universal and targeted approaches.
- Providing services that are tailored and flexible.
- Investing in services and capacity development.

5.0 Independent living: reconceptualising the ‘work versus welfare’ debate

5.1 Before looking further at the ways in which independent living can benefit the economies of prevention, it might be fruitful to consider independent living within the context of the present ‘work versus welfare’ debate.

5.2 Indeed, E O’Shea and B Kennelly,93 both economists at Galway University, question the value of basing welfare economics on the present basis of utilitarianism. They suggest that the full participation of disabled people in the economic life of the country will depend on how much society ‘sacrifices’ general efficiency, i.e. the good for the all (the mantra of utilitarianism) to aid and employ disabled people. They state:

“The relationship between efficiency equity is best discussed within the framework of alternative theories of welfare economics.”

They argue that within utilitarianism, efficiency is valued above equity, which is an unsatisfactory framework for the redistribution of resources and what they call ‘choice sets’ (i.e. opportunities) to enable disabled people to overcome the additional barriers they face in gaining employment. They state:

“Equalisation of choice sets may require judicious manipulation of economic and other barriers in order to overcome the accumulated and exogenous (beyond the control of) disadvantages faced by disabled people. This is why …. Independent living programmes should be evaluated. They should be seen as part of the response to the unequal capabilities of disabled people.”

5.3 Sociologists working within the field of disability studies have questioned the traditional culture which surrounds the schism between ‘dependent welfare recipients’ and the ‘waged work’ ethic of today’s welfare reforms. Questions have arisen around the validity of the ‘cost-effectiveness’ studies done by such bodies as the Audit Commission into direct payments; the method by which disabled people can control their support by being given money to choose and pay for services, rather than being given a direct service controlled by others, notably the local authority. These questions surround the parameters of the research, which mainly compare the self-directed support, controlled by the disabled person, with support services controlled by the local authority; or on the personal well-being and self-esteem of the disabled person within either support system. The research does not, for example, look at the wider issues of how self-directed support gives the disabled person and/or their informal carer greater flexibility over their time and space to enter the labour market themselves, thus contributing to tax revenues. In addition such research does not look at how such support reduces the disabled person’s and their informal carer’s physical and mental stress, thus reducing later demand on health and social services.

5.4 Further, they argue that independent living shines a new light on the traditional view that the person must be either a ‘welfare dependent’, within the social welfare system, or a ‘waged earner’, within the labour market. Within the independent living paradigm, the disabled person either becomes an ‘employer’ of Personal Assistants (helpers) or a ‘customer’, buying care services within the market. In both categories the ‘welfare

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94 As defined by the economist Amartya Sen, i.e. someone’s personal resources, both intrinsic and extrinsic


dependent’ now creates job opportunities for support (care) workers, which would not have been there before, or a market in which support services have new customers, who would not be there before.

5.5 As an ‘employer’, the disabled ‘welfare dependent’ gains and employs the transferrable skills of management; interviewing, supervision, staff development, accounting and other interpersonal skills; all of which would be classified as ‘work’. At the opportune time when the future of the Independent Living Fund is uncertain, it has been argued by some English writers, that direct payment and individual budgets policy, presently emanating from the Department of Health should be the responsibility of the Department of Business, Enterprise a Regulatory Reform. This wholesale change in public sector design and delivery is crucial for the progression of social justice and equality in today’s times.

6.0 The growing gulf between demand and supply

6.1 The graph below shows the growing divide between demand (pink line) and supply (blue line, government predictions: yellow line, Improvement Scotland predictions) which is forecasted for the coming five years. This shows that over this next period of five years demand will grow by 8%, whereas supply (public finance) will decrease between 6–12%.

Source: Improvement Services 2010

98 A non-departmental public body (NDPB) distributing the Department of Welfare and Pensions money to people who self-direct their support

6.2 In previous recessions, the knee jerk response of retrenchment into the more “traditional” economies of cutting, trimming and delay, would have meant restricting demand, by raising the access threshold criteria to services.

6.3 Only those with the highest, most complex need or those considered priority cases, such as children and older people, would have received a service. Frequently, this would have led to a disproportionate disadvantage being placed on disabled adults, particularly on those, who, with a little support, could have actively participated in the economic growth of the country. Instead, they would have been left to rely on their own informal support systems; thus creating more stress and poverty upon their family and friends; accumulating more need for both themselves and informal supporters, in later years. In effect, by following the more traditional economies, the growing gulf between demand and supply would have just kept on growing.

7.0 Listening to disabled people

7.1 In a letter to Baroness Rosalie Wilkins, a woman from Glasgow expressed her frustration at the lack of a one-off co-ordinated response to her request for aids and adaptations. Instead she had been confronted for four months with a continuous barrage of assessments for social care:

“I am 37 and I am desperate to rejoin the world. Relying on when my husband can come home and see me in the evenings is a tough way to live. I do not, like most people, have a steady supply of friends and family to take me out places. I live in a flat that at the outside door has four steps. There are two changes in my life I’d need to access the outside world. I need a ramp. I need a motorised chair. Without these I am not independent.”

7.2 This extract highlights a number of issues.

7.3 First, the complexity of the health and welfare system results in confusion among the public of ‘who does what and what is done’. The lack of such open information gives local authorities too much power to ‘assess’ disabled people, who are disempowered by this lack of information. Being so disempowered, their self-knowledge of what they need is barred from the knowledge of what is available and how to get it. The only legal duties, specifically in relation to the provision of social care and adaptations, local authorities have towards disabled people, is to provide them with information and to assess their needs. The provision of any resultant services is merely permissive. By denying people access to information (in order, they say, to avoid disappointment due to the ‘inability’ of local authorities to provide) such people cannot contribute to more imaginative and cost-effective solutions.

7.4 Secondly, since the only solution to this woman’s call for help was to be assessed for home care, a service controlled by the local authority, her requirement for a motorised wheelchair (supplied by the NHS) was ignored. So such ‘silo’ thinking only led to her situation remaining static. The one off provision of a ramp and a referral to her health board

100 Letter dated 12 March, 2010 to Baroness Rosalie Wilkins, House of Lords
for the wheelchair could have been done in days; and to the greater satisfaction of the lady concerned. Furthermore, the solution offered by the woman herself, would have been far more cost effective as a one off “cost” (barring minimal maintenance costs) than the ongoing relationship between a care provider and user may have been. This not only demonstrates that it is effective and crucial to not only ask but in fact promote the views of the end user, but also goes some way to alleviating the fear of those who see “self assessment” as a costly burden rather than an essential contribution.

7.5 Such ‘silo’ thinking between, health, housing and social care has also led to thousands of pounds being wasted in ‘blocked’ hospital beds, because the recumbent cannot find suitable housing and support in the community. Although the Scottish Government has strived to reduce blocked beds in recent years, people with newly acquired impairments in particular, still experience delays due the need for community care assessments and adapted property. Nevertheless, what independent living shows is that the inter-connectedness of services and budgets and what happens to the quality of one’s life depends upon the interfacing between health, social care, housing, transport, education, the environment, welfare benefits, employment, etc. etc. The Scottish Government consultation on Equipment and Adaptations in 2008 acknowledged the problems faced by local authorities and health bodies in working jointly together to provide joined up services.

7.6 Third, to overcome the disempowerment of disabled people through the denial of free access to information, there is a dire need for advocacy; and self-advocacy in particular. Unfortunately, like freedom of information, independent advocacy services have been, and to some extent still are, seen as a luxury local authorities can ill afford. Yet it is these very services which prevent higher costs arising later on, through the lack of provision or the delivery of inadequate and inappropriate provision.

7.7 As an example of actually listening to the needs of disabled people, one Scottish local authority acted on what their clients with learning difficulties were telling them. They wanted a job, rather than go to their day centres, which were old and unwelcoming. So rather than spend money on upgrading the buildings, the authority changed their service.

7.8 They now support the largest number of supported employment places in Scotland. The disabled people within the scheme are supported to hold down real jobs in the open labour market. They have an average income of £120 per week higher than they had when attending the day centres; their social networks have increased; and they are contributing to the economy of their local communities.

8.0 The Young Foundation Twelve Economies Framework

8.1 The more innovative economies, such as those outlined by the Young Foundation below, which meet the philosophy of the independent living agenda, allow disabled people to take their rightful place as full citizens contributing to the recovery of their country.

102 http://www.youngfoundation.org
8.2 Naturally, elements of the IL agenda may require new or additional investment or the realignment of budgets in a way which promotes equality for disabled people. As the Young Foundation point out, rather than cutting or trimming services, (i.e. the more ‘traditional’ economies) a fundamental redesign of the method of delivering services may provide cheaper options to meet need in a more efficient way (i.e. the economies of ‘innovation’).

**Table 1**

The Twelve Economies Framework

Traditional Economies:

Stopping—pure economies which comes from stopping doing things

Trimming—freezing pay, spending, reducing service quality, ending ‘extras’

Delay—postponing capital, pay rises, promotion

Intermediary Economies

Scale—organising services or processes in a larger manner, e.g. aggregating call centres, back office, delivery units

Scope—bringing multiple functions together, e.g. multi-purpose call centres, websites, personal advisers, doubling up (solving two problems with a single intervention)

Flow—managing flows of events, customers, to achieve economies of specialisation, reduce failure demand

Penetration—economies that come from geographical concentration, e.g. combined heat and power, street concierges, doubling up roles of postal deliveries

Innovative Economies

Responsibility—passing responsibility out to citizens (with changed scripts — e.g. waste, street cleaning, tax returns) or introducing charges

Commitment—shifting provision from low to high commitment people and organisations
(tapping into volunteer labour, social enterprises, etc)

Circuit—reducing costly events through effective prevention (e.g. recidivism in crime, hospital re-admissions), with financial tools such as Social Impact Bonds

Risk, regulation, monitoring—moving to readier acceptance of risk, reducing monitoring regimes

Visibility and information—mobilising public eyes (e.g. MPs’ expenses) and the power of shame, and information enrichment—to improve performance

Source: Young Foundation (2010) “Innovation and Value: new tools for local government in tough times

8.3 Public bodies should be discouraged from escaping into entrenchment; of cutting back on the new methods of independent living and self directed support, to provide the more traditional services of institutionalised home and day care, for example. Such traditional services merely segregate disabled people within their own homes or day centres, denying them the opportunity to participate as equal citizens within the community. Services, designed on the principles of independent living, allow disabled people to do just that.

8.4 This joint submission now draws heavily upon some of the more preventative of the ‘twelve economies’ outlined by the Young Foundation. Table 1, above, which comes from a short paper Geoff Mulgan, the Foundation’s director, wrote for the Public Finance / Zurich Municipal risk and innovation round table, describes these twelve economies. Geoff Mulgan was previously Head of No. 10’s Strategy Unit.

9.0 Independent living is an economy of ‘responsibility’ and ‘commitment’.

9.1 Within the twelve economies of the Young foundation, are those of ‘responsibility’ and ‘commitment’; i.e. giving citizens responsibility to run things for themselves, or working alongside paid staff to provide services together

9.2 Self-directed support enables disabled people to have choice and control over their own lives. They receive money, a ‘direct payment’, to pay for the support they need, from the person, or organisation, they choose and at a time when they want that support. This gives them the responsibility over their lives and those supports which enable them to live those lives in the manner of their choice.

9.3 Such systems of support have been found to provide greater quality of life; facilitating more opportunities for social and economic participation in the community at large. As one recipient of a direct payment said:

103 http://www.publicfinance.co.uk/features/2009/11/flight-paths/
9.4 Ever since its inception, the Independent Living Movement has recognised that disabled people who take on such responsibility also require support to carry out the duties appended to that responsibility. That is why, collectively, they have developed their own centres of excellence where disabled people provide information, training and advice to other disabled people.

9.5 Historically, these have been grossly under-financed and have struggled even in the ‘good times’. These ‘centres for inclusive living’ (CIL), or ‘self-directed support organisations’, need to continue, if society is to foster responsibility among its citizens. Many of these organisations provide high quality services, which give better value for money than ‘in-house’ services. But their resources are being continually under-mined by local authorities many of which consider ‘in-house’ services to be the cheaper and ‘safer’ option.

9.6 Nevertheless, there is a greater expectation of good, high quality service from organisations run on the economy of responsibility, as shown by a recipient of such a service:

“I don’t mind being let down by the professionals […] they fail you because to them it’s just a job at the end of the day. I do feel a greater depth of disappointment with the […] CIL because I expect them to have the gut feeling I have when I deal with disability issues and if that doesn’t come through then I am disappointed.”

9.7 For some, the idea of volunteers working alongside paid workers may seem rather unfair and discriminatory. But for others, the opportunity to show their commitment to a service, or segment of society, may prove to be rewarding in itself. The present Independent Living Core Reference Group, or any other opportunity whereby talents, skills and knowledge may be freely shared and acknowledged; and which provides the facility of ‘co-production’; is an example of an economy of ‘commitment’.

10.0 Co-production as an economy of ‘visibility’, as well as ‘commitment’


105 http://www.sdsscotland.org.uk

http://www.leeds.ac.uk/disability-studies/archiveuk/Barnes/report%20stage%20two.pdf
http://www.leeds.ac.uk/disability-studies/archiveuk/Barnes/CILfinaltext.pdf

10.1 For disabled people to have the right to ‘freedom, dignity, choice and control’ carries a second implication: that we move rapidly to a system of public services which are focused on outcomes and based on co-production. This means accepting people who use services as equal partners in deciding strategy, service design and service delivery. More generally, it means recognising that individuals, households and communities have experience, skills and resources that are essential to achieving positive outcomes. Enabling them to be partners is not just the right thing to do in principle; it is practically sensible given the challenges that public services face. Making ‘best use of resources’ means drawing in the widest range of resources possible and only ‘co-production’ allows that to happen.

10.2 As well as being an economy of commitment, co-production is also an economy of visibility, for it allows disabled people, like other users of services, or funders, such as taxpayers, to see the issues and conundrums behind the decision-making process. Such greater transparency often leads to a greater understanding and acceptance of why things are done. This can lead to greater social cohesion and mutual support.

10.3 Co-production is not the same as ‘consultation’ or ‘engagement’: It is about full partnership in the development of policy and service design. It, of course, means disabled people understanding the financial constraints the public sector will face, but it also means policy makers and service managers understanding the legitimate aspirations disabled people have for their lives; and respecting the expertise they bring to the table. Given the complexity of the future challenges, it would be very odd to exclude a major source of knowledge and creativity, at the outset. Disabled people have experience based knowledge of how well resources are used at present to support outcomes and that is an essential resource for any review.

10.4 However, for coproduction to be used to its optimum, there must be a fair transference of knowledge and sharing of skills and so any cuts to the budgets of organisations which support the voices of disabled people, will mean that the grassroots influence, peer support and capacity building necessary to participate in any co-production will be undervalued and under resourced.

10.5 Co-production, as it applied to self directed support for example, would also reduce the confusion, and lack of visible information, over the funding of support. It would assist in the understanding, and possibly aid the reduction, of the complex interplay of different funding packages, providers, benefits; as well as the impact on the cost to the disabled user because they have an earned or pensioned income.

10.6 Such varied scenarios lead to inconsistencies in approach to such charges, between local authorities across the country. For example, in complex packages of care, dependent upon a number of funding streams, any reduction in one service, or funding stream, may have severe repercussions for the disabled person, who has to deal with other streams of funding, which may well be conditional on that which is reduced, or stopped all together. Indeed, the potential for such changes and confusion creates a culture of fear and an unwillingness to claim rights.

10.7 Co-production with disabled people is still in its infancy, but as a paradigm for development and maintenance of systems and services, it is slowly beginning to be accepted as the way forward. The Scottish Government’s Housing Department has just recently agreed to fund two pilot projects to develop Local Housing Strategies, using the principles of co-production.
11.0 Independent living as a ‘circuit economy’

11.1 There is often a predilection within public services to be reactive and only intervene after a crisis; rather than be proactive and preventative. Such preventative services commonly save on more costly support packages later, when such crises inevitably occur. The Young Foundation point out economies can be made through early intervention as well as being lost through mismatched incentives between stakeholders. These they call ‘circuit economies’

11.2 If funding where truly related to ‘outcomes’ rather than ‘outputs’, as it should, then thinking outside the box would encourage budget holders within different public bodies to share their resources more freely. A health authority in the England, for example, gave £0.5m to a local roads department to salt the pathways in freezing conditions. This funding reduced the pressure on their A&E department, by cutting the number of presenting cases of sprains and broken limbs after falls. Similarly, if health authorities were to contribute to the support packages of disabled people, this would reduce their dependence on more critical and expensive health care needs, later on in life; as would the expansion of community based therapies, such as physiotherapy, which in many areas are only available to acute cases. Research by Turning Point in 2010 said that integrating health and social care would save the NHS £2.65 for every £1 spent.

11.3 Another example of funding not being related to outcomes has been sent to the Independent Living in Scotland Project by a disabled man who wrote about his trials and tribulations in trying to acquire a grant for him and his newly married disabled wife. Although he was eventually successful in obtaining a grant to make his house accessible, the one thing he could not get a grant for was to build an integral garage built onto the side of his house. He states:

“'That 'need' was completely outwith the remit of the Social Work budget to meet. Yet, that garage allowed me to keep economically active for the next twenty odd years. Without it, without doubt, due to my ataxia, I would have slipped and fallen many a time and been off work for weeks.”

11.4 There are many examples of services for disabled people being cut, which are not necessarily a long term saving. The closure to new applicants of the Independent Living Fund, which assisted local authorities to fund complex need care packages, is a severe blow to disabled people; and the uncertainty of the Funds future is a particular worry to those whose quality of life and participation within society and its labour market. Personal Assistance, which the Fund supports, is critical to independent living for disabled people. Without such assistance to get up and get ready for work in the morning, a disabled person cannot hold down a job. Cuts to this critical service, have meant that many disabled people are being denied opportunities in all areas of their lives including civic and social participation; work; and learning; with a consequential impact on their health and dignity.

11.5 There are also many hidden resources within the community itself. Although some care and circumspection may have to be taken around certain aspects of personal assistance, much of the low level support may be provided from within the community, itself.
“Timebanking” is one aspect of the New Economics Foundation’s intrinsic “Core Economy”.108

11.6 Here, neighbours build up ‘time’ to receive assistance by giving ‘time’ to another neighbour. So an old person could baby sit, or teach a musical instrument, for one neighbour, in return for a third neighbour to do some shopping or carry out some DIY. Within the community’s own intrinsic “core economy” the helped become the helper. The equality of mutuality achieves personal value and social cohesion.

11.7 As the New Economics Foundation say:

“First comes a rejection that money and market price (as in professionalised services) is the sole acceptable measure of value. Timebanking rejects price, valuing all hours equally, because price equates value with scarcity relative to demand. Timebanking values what it means to be truly human and to contribute to each other as humans – as members of the human family. Those are the universals that enabled our species to survive and evolve: our willingness to come to each other’s rescue, to care for each other, to stand up for what we believe is right. There are domains we all recognise are beyond price: family and loved ones, justice, patriotism, spirituality, the environment. We cannot allow a rejection of market price to mean a denial of economic value.”109

11.8 Of course, such initiatives will require some funding, for development, co-ordination and administration, they must be supported by the provision of advocacy and peer support for them to be meaningful and effective, however, it will be within the circuit economy, for it will be low level funding to prevent low level need from developing into higher level need requiring the higher level funding of professionalised services

12.0 Independent living as an economy of ‘scope’ and ‘doubling up’

12.1 By looking at the holistic needs of disabled people, independent living services can provide many economies. By providing several services within the one centre of excellence, such as self-directed support advice and training; pay-roll and employment advice services; along with housing and employment services, there are several economies that can be made, including that of scope.

12.2 Although the circuit economy would ensure that at least a proportion of new build houses can accommodate wheelchair users; and that whenever an adapted house is vacated, rather than pulling out that adaptation another disabled person is found for it, it can be argued that this is often difficult to achieve when working within existing traditional economies. However, the Glasgow Disabled People’s Housing Service (GDPHS), part of the Glasgow Centre for Inclusive Living, provides local housing associations with a register of


109 Op cit
disabled people and their housing needs, which reduces the need to remove adaptations, which may have cost many thousands of pounds, to house a non-disabled person. It also provides disabled people looking for houses with a register of adapted houses and increases the speed of searching for suitable accommodation.

12.3 This housing service also ‘doubles up’ by providing an employment service for long-term unemployed disabled people as well. Working with local housing associations, the GDPHS places long-term unemployed disabled people in work experience positions throughout the city, supporting them and introducing them to various training opportunities which are available; but once again such an innovative service is vulnerable to the vagrancies of funding.

13.0 Independent living and resources

13.1 Given present-day demand trends, the Finance Committee may well consider entitlements to services and benefits; and how these are resourced and financed. This joint submission accepts that this may include, inter alia, the extent to which services are free at the point of use (tax financed) and the extent to which fees or charges are in place. There would be a concern that this should not be examined in isolation from questions of relative priority; and that it should be informed by clear principles (not simply driven by financial pressures).

13.2 To put the matter into perspective, the total sum raised in charges for adult care in 2008/09 was £350m: slightly more than the cost of freezing the council tax for a third year (£310m). Reviewing whether more should be raised through charges needs to be linked to other choices, like freezing council tax, and a principled discussion about priorities.

13.3 Equally, questions should be raised as to why it is proper to charge for services which enable a disabled adult to live an independent life, participating in the lives of their families and communities, as it is their right so to do; but improper to charge for admission to art galleries and museums: and why it is proper to provide free nation-wide bus travel for those over sixty, irrespective of income, but improper to provide subsidised taxi-fares, which have been common in many other European countries since the early 1970s, for those unable to use busses. Such questions do need reflection and discussion. The principles of what is tax financed and what is charged does need to be more explicit and coherent. For example, one study in England has shown that people may accept tax rises, if such rises were hypothecated; and the reasoning made transparent.

13.4 If entitlements to resources are to be reviewed, the basis for entitlement, not just the extent of it, needs to be carefully examined. The current system is a jumble of age related, condition related, income related and circumstance related entitlements with very little consistency within or between them; as can be seen in paragraph 12.3 above. The core point is that entitlement to services and benefits for disabled people should not be reviewed separately from other services and benefits; and consistency of principle should be applied across the range. The existing and forthcoming Public Sector Equality Duties are one tool to do this, to mitigate against the potential negative and disproportionate impact of decisions that are taken in isolation and that can lead to a myriad of unintended consequences and indeed, as described above, false economies.
14.0 Independent living and the future

14.1 The current and future challenges facing public services, and people who use those services, in Scotland, require a ‘co-production’ approach. This would bring the knowledge, experience and resources of people who use services to bear on policy and service redevelopment. Any review should focus on ‘best use of resources’ and not simply on spending cuts; and be open to looking at all resourcing options for the future. The three contributors to this inquiry, perhaps along with the Core Reference Group, and its constituent members; although this joint submission cannot speak on their behalf; would be happy to participate in and/or organise a co-production ‘preventative spending review’.

14.2 It is clear that a 'co-produced' review of policy, service entitlement and finances would itself need to be properly resourced. Each partner in co-production needs research support, facilitation and advice but in the past those who use services and their user-led organisations have lacked these resources whereas the public sector has been well resourced. Planning for the preconditions of co-production could usefully begin now.

14.3 As an example, if current arrangements for care and support are to be reviewed, core information will be necessary and could usefully be collected and collated now. It would be extremely useful to have integrated information on benefit and service entitlements and eligibility criteria at UK level, Scottish level and local level across Scotland. This would enable an examination of the consistency, fairness and coherence of current arrangements and the options for a more principled future approach.

15.0 Conclusion

15.1 Roy Porter in his seminal book on the history of medicine wrote:110

“The social costs of sickness thus converted (Edwin) Chadwick to the ‘sanitary idea’: that is prevention.”

15.2 This joint submission from three of Scotland’s national disabled people’s organisations hopes the Finance Committee will also accept that the ‘social cost of sickness’ within society just does not include public health issues, but public support to the independent living of people, disabled or not; i.e. choice and control over their lifestyles; and freedom and dignity within them.

15.3 This joint submission welcomes the support from the Scottish Government, with its vision of independent living and commitment to co-production, recently signed, alongside COSLA. The forthcoming spending review, and specific policy and service reviews which may follow, will be the acid test of that commitment to independent living and co-production.

15.4 This joint submission hopes to show how the policies, services and provisions, based on the philosophy of independent living:

- can both facilitate and accelerate the economic growth of Scotland by more fully harnessing its people resources
- can reduce the gulf between demand and supply of public services for both disabled people and their informal support;
- can reconceptualise the 'work vs. welfare' debate by enabling welfare recipients to develop markets and provide work for others; and, at the same time, develop their own transferrable management skills
- can overcome the 'silo' effects of services and budgets by providing a more 'holistic' approach to solving need can meet the newer economies of innovation and prevention as laid out by the Young Foundation, via the efforts of disabled people and their own user-led organisations

15.5 This joint submission also hopes that the Finance Committee would recommend to the Scottish Parliament that the support necessary to enable disabled people to live independent lives as full and equal citizens, will attract priority; and that any review of how that support can best be delivered in the future will include disabled people as equal partners, in the spirit and enactment of co-production.

20 August 2010

111 [http://www.youngfoundation.org](http://www.youngfoundation.org)
Written Evidence submitted by Shelley Bark (IL 31)

Independent Living.

Question 1. Yes I think that the government could do more by grantee money for Disabled who live independently without having help. Therefore the Severely Disabled People need to feel Secure of knowing that they can employ someone.

Question 2. The Government could encourage and Train Social Workers to assess and encourage Disabled People who want to become Independent. To make sure there is support and maintenance of Care Package.

Question 3. To make sure the individual have the right Care Package which meet not only there need but the right to have an independent live in the community as they see fit.

Question 4. The attitude of the Local Authorities to be more aware of the Disabled People in what they are asking for and have some continuity in the way they are dealt with so we can make a repour with one other.

Question 5. Changes of Benefits will affect most People because it means people will have less money to spend. With the extra 2.5 on most things means we will have less to spend which will affect everything down the line.

Question 6. I think cutting Funding will, yes save money now but in the long term it will like going backward into time and Disabled People will not be able to cope pay for enough car which means Disabled People will make more people redundant. This would be made people unemployed and the government will have to pay redundancy money.

Question 7. At the end of the day for me personally I am independent who has carers 24 hrs. a day which I am an employer which mean that I will keep the best care has I can. Really I am entitled to a basic care package which why would it change.

Question 8. If we do not have a service which provide Disabled People money to employ people then what is going to happen because without money no care and without care I will have no other option than go into a care Home.

Question 9. Yes it making independent more difficult because If we cannot employ people then I cannot be independent and be a part of the Community

Question 10. I think Disabled People must get involve by asking people go to meetings and other events so they be involve with every step on the decision making. Or if a Disabled Person cannot be there in person, they can be involved by writing their answer down by email, post or phoning in. Keep the disabled people update by the internet

Question 11. People think that they know best because they have qualifications but the best people to ask to be the Disabled People who has everyday life experience. So it is very important to involve Disabled People every step of the way.

Question 12. By making sure they read everything that Disabled person has written down and any other communications they May receive.
Written Evidence submitted by Shelley Bark (IL 31)

22 April 2011
Summary: For the reasons set out below, existing independent living policy, law and administration in the UK do not represent a coherent strategy towards implementation of the obligations in Article 19.

1. The UN Convention on the Rights of Persons with Disabilities (the Convention) has as its goal a ‘paradigm change’ from welfare to rights: from viewing people with impairments as objects of compensation for their exclusion, to their acceptance and inclusion as full and equal rights-holders. Article 19 is fundamental towards this paradigm shift. As your Committee’s call for evidence confirms, the Convention builds on both Civil and Political and Economic, Social and Cultural Rights International Covenants. Nowhere are the two more closely integrated than in Article 19.

2. Article 19 sets out the right to live independently and be included in the community. It requires States ratifying the Convention to recognise the equal right of all disabled people to live in the community, with choices equal to others. These are civil rights to autonomy and participation which are a pre-requisite for the exercise of all other Convention rights and freedoms.

3. Article 19 also requires ratifying States to ‘take effective and appropriate measures’ to facilitate disabled people’s full enjoyment of their rights to autonomy and participation. These measures should include ensuring that (a) the person has the opportunity to choose where and with whom they live and is not obliged to live in a particular living arrangement; (b) they have access to a range of services to support living and inclusion in the community, and to prevent isolation and segregation; and (c) ensuring that services for the general population are available on an equal basis and are responsive. These are economic, social and cultural rights.

4. The integration of economic, social and cultural rights with civil and political rights in the Convention serves an important purpose. As Quinn and Bruce explain, ‘economic, social and cultural rights have an enabling function—they provide a bridge whereby persons with disabilities can take their place as valued and often highly productive citizens […] they enable people to take charge of their own lives. It is in this sense that economic, social and cultural rights enhance freedom.’

www.ohcgr.org/english/issues/disability/study.htm

113 Chair of the UN Ad Hoc negotiating Committee, Daily Summary, Seventh Session, 19 January 2006, pm http://www.un.org/esa/socdev/enable/rights/ahc7sum19jan.htm

5. When the UK ratified the Convention, it undertook a duty under international law to ensure and promote the full and equal realisation of all human rights—civil, cultural, economic, political and social—for all disabled people in its jurisdiction. The Explanatory Memorandum placed before Parliament prior to ratification confirms that the Convention “encompasses civil and political as well as economic, social and cultural rights. These rights cover all areas of life [...]”.

6. However, in practice, successive UK governments have failed to incorporate economic, social and cultural rights into domestic law. In 2007, the UK's Fifth Report to the UN Committee on Economic, Social and Cultural Rights (the UN Committee) states categorically that:

“The ICESCR [International Covenant on Economic, Social and Cultural Rights] has not been and is not expected to be incorporated into domestic law. This means that the rights contained in the Covenant are not directly enforceable by domestic courts.” Furthermore, “the Government is not convinced that it can incorporate the rights contained in the ICESCR in a meaningful way within the British legal system.”

7. Following their meeting with the UK delegation in 2009, the UN Committee:

“[…] urges the State party to ensure that the Covenant is given full legal effect in its domestic law, that the Covenant rights are made justiciable, and that effective remedies are available for victims of all violations of economic, social and cultural rights. The Committee reiterates its recommendation that […] following ratification of an international instrument, the State party is under a legal obligation to comply with such an instrument and to give it full effect in its domestic legal order.”

8. Successive UK governments have argued that they implement the ‘principles and objectives’ of the ICESCR through the policies, laws and practices of the welfare state. Under this argument, rather than being identified as constitutional rights of equal importance to and indivisible from the civil and political rights they enable, requirements for housing options, support services and access to general services such as those under Article 19 become ‘welfare entitlements’ subject to the gift (or denial) of the State.

115 Cm7564, 3 March 2009


117 ibid, paras 74 – 5

118 Concluding Observations of the UN Committee on Economic, Social and Cultural Rights, E/C.12/GBR/CO/5, 22 May 2009, para 13

119 see e.g. UK Opening Statement to UN Committee on Economic, Social and Cultural Rights, Geneva, 12 May 2009

120 as evidenced in the recent aspects of funding cuts noted in your Committee’s call for evidence
Economic, social and cultural rights remain invisible in independent living policy, law and administration; individuals, policy-makers and law-drafters\textsuperscript{121} alike are unaware of their rights; the opportunity to make the ‘paradigm change’ from welfare to rights thinking which is the fundamental goal of the Convention is fatally undermined; and there is no recourse to the international human rights framework on issues such as progressive realisation or justiciability to guide implementation.

9. For these reasons, existing independent living policy, law and administration in the UK do not represent a coherent strategy towards implementation of the obligations in Article 19.

10. A coherent strategy for implementation of Article 19 would acknowledge its basis in international human rights law, including the law relating to economic, social and cultural rights, and would raise awareness of those rights amongst all concerned. It would explain the government’s strategy, with benchmarks, for progressive realisation of the economic, social and cultural rights involved to the maximum of available resources.\textsuperscript{122} And it would put in place accessible and effective legal remedies for those whose rights have been breached.

11. For a State which took part in drafting and has ratified the UN Convention on the Rights of Persons with Disabilities, a human rights-based approach to all of the rights set out in Article 19 should be the starting point for promoting, protecting and ensuring the full and equal enjoyment\textsuperscript{123} by all disabled people of their Article 19 right to live independently and be included in the community.

25 April 2011

\textsuperscript{121} see current Law Commission review of Adult Social Care legislation
http://www.justice.gov.uk/lawcommission/350.htm

\textsuperscript{122} in line with the UN Convention on the Rights of Persons with Disabilities, Article 4(2), and the General Comments of the UN Committee on Economic, Social and Cultural Rights

\textsuperscript{123} UNCRPD Article 1: purpose
Introduction:

The rights of disabled people have been increasingly threatened by a series of administrations in the UK parliament. In particular the right to independent living has already been taken away from some groups of disabled people as the vital national funding body has been frozen and placed on the road to abolition. This is making the future extremely bleak and alarming for a whole range of disabled people, but particularly younger disabled people who are willing and able to make a significant contribution to society if the appropriate support is available to them.

Background:

I am 30 years old and have a genetic neuro-muscular condition called Spinal Muscular Atrophy, which means that I need assistance to carry out the most basic physical tasks, and use an electric wheelchair for mobility at all times. I am currently a Mathematics teacher at a Comprehensive school, having completed my degree at the University of York, PhD at the University of Warwick and PGCE at the University of Sheffield.

During my studies at York and Warwick I successfully managed a team of live-in care staff who provided me with 24 support throughout the 8 years I was away at University. This was funded by a combination of my home Local Authority, the Independent Living Fund (ILF), and some help from my Disabled Student’s Allowance while at York.

Since then I have been living back home, with my parents providing a lot of my care requirements, while I secured my first permanent job and prepared to start my independent life. My care package has been reduced to covering little more than my work hours during this time, with the assumption that it could be stepped back up once I had found somewhere I could live independently with carers.

While I have been back at home the government have completely dismantled the care funding system, freezing the ILF and earmarking it for closure in 2015, with no explanation as to what if anything will replace it. This means I am now stuck, on my lower level care package, unable to make any progress towards an independent life, totally reliant on my parents for care which will cease to be sustainable in the short to medium term.

Argument:

There are two vital components required to enable severely disabled people like myself to have the opportunity to live as independently as possible and have the choices available to the rest of the population. The first is the system of Direct Payments from Local Authorities to service users which enables disabled people to have some control over how they are cared for and who by. I know how vital this is as I was the first recipient of Direct Payments in my Local Authority 12 years ago and they revolutionised my ability to live independently. After spending my first year at University struggling to manage a series of indirectly funded agency care staff, the Direct Payment allowed me to employ my own regular staff who I could train to meet my specific needs.
The second vital component is the Independent Living Fund, a national body designed to iron out any regional variations in services, and provide sufficient funding for those most in need without over-burdening any particular Local Authority. Whether in its current form, or under a new title come 2015, this system must remain in place or there will be unthinkable consequences for the lives of thousands of disabled people. Without the ILF I could not continue to employ care staff, so I could not get to work, and as my parents get older my only future would be in some kind of residential care home. After the scandalous decision to remove mobility allowances from people in residential care this would leave me trapped in a care home, unable to work or do any of the things that constitute an independent life.

If government policy continues in its current direction I will go from having a chance of an independent life, contributing to society and earning enough to provide for myself in most respects, to being cut off from normal life, totally dependent on the state for everything in a costly care home. Therefore, apart from these policies being totally against the human rights of disabled people, they are also hopelessly short sighted and would lead to many people becoming a massive financial burden on the state. A whole system of care homes would need to be created to house an under-class of severely disabled people.

If however the government decides that it does want to follow through on making it possible for disabled people to have choice and freedom in our lives then there is something that does need to be added to the system to make that a reality. That is, to make care packages portable from one LA to another. Currently it takes several months of assessments and arguments for a disabled person to move from one area to another, making it very difficult for me to compete effectively in the job market or simply choose to live somewhere other than the Local Authority I happened to live in at the age of 18. With the amount of administration it would save by removing this barrier to disabled people, I am confident that it would make economic sense to ensure that care packages could be transferred from one LA to another, perhaps with the aid of a body like the Independent Living Fund.

Conclusion:

The government has a duty to look after the most vulnerable members of society, and it desperately needs to recognise the existence of younger disabled people who want to make a significant contribution to society despite their complex care needs. They need to realise that it makes far more economic sense for these people to take an active role in society rather than being entirely dependent upon it. This necessitates a national body to provide secure care funding to those in need, enabling them to manage the rest of their lives in a financially independent fashion. To have genuine choice, control and freedom in my life I need this system to be in place as soon as possible so that am no longer stuck in my childhood home unable to make progress towards an independent future. If the government does not listen and act to make the lives of disabled people possible in the near future, then there is a terrifying situation on the horizon for myself and many other severely disabled people.

25 April 2011
Written Evidence submitted by the Independent Mechanism for Northern Ireland (IL 35)

Introduction

1. Under Article 33(2) of the United Nations Convention on the Rights of Persons with Disabilities (Convention), the UK Government designated the four equality and human rights commissions to make up the UK’s Independent Mechanism. In Northern Ireland, the Independent Mechanism is represented by the Equality Commission for Northern Ireland (ECNI) and the Northern Ireland Human Rights Commission (NIHRC), hereafter referred to as the Independent Mechanism for Northern Ireland.

2. The Independent Mechanism for Northern Ireland is the ‘independent’ element within the framework, established by the State Party, under Article 33(2). The Independent Mechanism for Northern Ireland has clearly defined and separate roles and responsibilities, from those of the State Party and civil society, to promote, protect and monitor implementation of the Convention in Northern Ireland.

3. The evidence provided will address all four broad areas outlined by the Committee from the perspective of the Independent Mechanism for Northern Ireland. The evidence draws upon, and reflects, the statutory remits of both the NIHRC and the ECNI.

The Right to Independent Living

Northern Ireland Executive Policy on Disability

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124 The Equality Commission for Northern Ireland (‘the Commission’) is an independent public body established under the Northern Ireland Act 1998. The Commission is responsible for implementing the legislation on fair employment, sex discrimination and equal pay, race relations, sexual orientation, disability and age. The Commission’s remit also includes overseeing the statutory duties on public authorities to promote equality of opportunity and good relations under Section 75 of the Northern Ireland Act 1998 (Section 75) and the disability duties under the Disability Discrimination Act 1995.

125 The Northern Ireland Human Rights Commission (the Commission) is the national human rights institution (NHRI) for Northern Ireland. It was created in 1999 under the Northern Ireland Act 1998, pursuant to the Belfast (Good Friday) Agreement of 1998. The Commission is accredited with ‘A’ status by the UN International Co-ordinating Committee of NHRI. It has a range of functions including reviewing the adequacy and effectiveness of Northern Ireland law and practice relating to the protection of human rights, and advising on whether a Bill is compatible with human rights. In all of that work, the Commission bases its positions on the full range of internationally accepted human rights standards, including the European Convention on Human Rights (ECHR), other treaty obligations in the Council of Europe and United Nations systems, and the non-binding ‘soft law’ standards developed by the human rights bodies.


[138]
4. As the Committee will be aware, no regional strategy similar to the Independent Living Strategy currently exists in Northern Ireland. However, in June 2004 the Northern Ireland Executive established the Promoting Social Inclusion (PSI) Disability Working Group to identify the barriers to employment, education, transport, housing, access to information and lifelong learning for disabled children and adults, and to make recommendations on how these might be removed taking account of wider policy development.

5. The PSI Working Group delivered a comprehensive report to the Northern Ireland Executive in December 2009. Two chapters of the report focused on different aspects of independent living:

- The principles of choice and control, which primarily relates to individual budgets and the promotion of Direct Payments; and
- Independent living, in respect of housing, transport and participation in leisure and cultural activities.

6. The report recommended that the Northern Ireland Executive undertake a review of independent living and place it at the centre of its focus on disability issues.

7. The Independent Mechanism for Northern Ireland acknowledges the extensive work that was carried out in producing the PSI Report, welcomes its references to the Convention, and is supportive of the 20 recommendations made in respect to independent living.

8. The Independent Mechanism has worked closely with the Office of the First Minister and deputy First Minister (OFMdFM). However, we are concerned that the PSI Report took five years to complete and although published in December 2009 it is still awaiting a formal response from Northern Ireland Executive.

9. The Independent Mechanism for Northern Ireland is also concerned that the PSI report is referred to as the basis for the implementation of Convention in Northern Ireland. However, the report does not cover all the rights contained in the Convention. In addition, as time has passed the statistics on which this work is based are becoming outdated. The Northern Ireland Executive will need to carry out a review of Independent Living and update disability statistics.

10. The Committee has asked if the right to independent living should continue to form the basis for Government policy on disability in the UK. If the recommendations within the PSI Report are finalised, it appears likely that it will inform the disability, and independent living, policy of the Northern Ireland Executive.

**Legislative Reform**

11. The ECNI has been calling for urgent legislative reform of the disability equality legislation in Northern Ireland; particularly in light of developments in Great Britain where the introduction of the Equality Act 2010 has meant that disabled people in Northern Ireland
now have less protection against discrimination and harassment than disabled people in Great Britain.127

12. Whilst the ECNI endorses many of the changes to the equality legislation affecting disabled people introduced in Great Britain by the Equality Act 2010, as these changes are in line with our previous recommendations for legislative reform, in certain areas it feels that the Equality Act 2010 has not gone far enough in ensuring effective protection for disabled people.

13. One recommendation the ECNI has made for legislative reform of the Disability Discrimination Act 1995, which was addressed in the Equality Act 2010, and is specifically relevant to the progressive realization of rights within Article 19 of the Convention, is that landlords and managers are required to make disability-related adjustments to the physical features of the common parts of let residential premises, where it is reasonable to do so and when requested by a disabled tenant or occupier.128 Such additional protection for disabled people in Northern Ireland will reduce the risk of disabled people being isolated in their own homes, when a simple alteration, such as a handrail or ramp, would enable the disabled person to access the common parts of their home.

**Impact of Funding on the Right to Independent Living**

14. In February 2011 the Northern Ireland Executive Departments issued separate spending plans for consultation. The NIHRC responded to several of these plans, including those of the Department of Health, Social Services and Public Safety (DHSSPS). The NIHRC had concerns in relation to the potential implications of budget cuts, notably in terms of reduced service levels, no new patients on high cost drugs, extended waiting lists and restricted access to community care. The NIHRC was also concerned about the impact of budgetary cuts on policy initiatives addressed in recent and current consultations, including:

- implementation of the Bamford Review of mental health and mental capacity legislation;\textsuperscript{129}


\textsuperscript{128} The introduction of such a duty would require landlords to make alterations to the physical features of common parts, such as installing a stair lift, handrail, or ramp. The duty to make the alteration to the common parts will only apply where the disabled person is placed at a substantial disadvantage compared to non-disabled persons. In addition, landlords will only be required to make adjustments, where it is ‘reasonable’ for them to do so. Importantly, the costs and any reasonable maintenance costs of the alterations will be borne by the disabled tenant. The Equality Commission’s detailed recommendations for legislative reform of the DDA 1995 and other equality legislation is available at: http://www.equalityni.org/archive/pdf/Priorities_for_legislative_reform0602091.pdf

15. The NIHRC is aware of recent problems in Northern Ireland with needs assessments and provision of services to the carers of disabled children, and an ongoing delay in the long-stay patient Resettlement Programme from learning disability hospitals such as Muckamore Abbey. Northern Ireland lags behind the rest of the UK in resettling people with learning disabilities in order for them to live independently in the community. We would refer the Committee to the October 2009 report from the Northern Ireland Audit Office on the ‘Resettlement of long-stay patients from learning disability hospitals’. This report records that as of 31 March 2009, 256 patients remained in long-stay hospitals in Northern Ireland. The Department set a target in 1997 that all patients in long-stay learning disability hospitals would be resettled by 2002. However, that target has been revised repeatedly and is now set for 2013. It is highly likely that budget cuts in the area of health and social services will again hinder the resettlement programme. The NIHRC is aware that judgement is currently awaited on judicial review proceedings heard on 29th March and 8th April 2011 in the High Court in Belfast to challenge the delayed discharge of patients from Muckamore Abbey Hospital.

16. While the Independent Mechanism for Northern Ireland appreciates the importance of a robust stewardship of public finances, we are concerned about the impact of the reforms to Disability Living Allowance (DLA) on the human rights of disabled people in Northern Ireland. In particular, the Committee should note the ongoing challenges faced by Northern Ireland, related to the past conflict and high levels of poverty, with proportionally more people in receipt of DLA benefit in Northern Ireland than elsewhere in the United Kingdom. The Department of Social Development estimates that over 184,500 people in Northern Ireland receive DLA. The proportion of working age people in receipt of DLA in Northern Ireland is approximately twice the level in Great Britain—10.3 per cent of the Northern Ireland population. The NIHRC has noted during the consultation process, on the June 2010 UK budget that one of the central aims of the reform of DLA was to reduce the cost of the benefit by 20%. Reform of the DLA system therefore could result in many thousands of disabled people in Northern Ireland losing entitlement to this benefit or receiving reduced support. Since DLA aids disabled people’s personal mobility, helps them to lead an independent life in the community and for some helps achieve an adequate standard of living, withdrawal of the benefit is likely to result in regression, rather than the progressive realisation of their human rights.


DHSSPSNI, Service Framework for Mental Health and Wellbeing

DHSSPSNI, Consultation on Draft Physical and Sensory Disability Strategy and Action Plan 2011–2015
http://www.dhsspsni.gov.uk/disability_strategy_draft_version_1_-_december_2010-3.pdf

Disability Living Allowance Statistics—Summary of Statistics (August 2010) Department for Social Development
http://www.dsdni.gov.uk/dla_publication_august_10.xls
17. It is clear that budget cuts will impact on the government’s ability to implement some economic, social and cultural rights related to Article 19, particularly if community care is restricted. In some cases there may be a regression of rights for disabled people.

18. Article 19 is unique in that the formulation of a right to independent living has never appeared in any previous human right treaty; however many of its attributes stem from the application to the disability context of traditional economic, social and cultural (ESC) rights. As such, reference has to be made to Article 4(2) of the Convention, which relates to the progressive realisation of ESC rights. States must show that they are taking concrete measures within the maximum of available resources, with a view to achieving progressively the full realisation of Article 19. There must be no regression of rights. The UK Concluding Observations of the Committee on Economic, Social and Cultural Rights issued in June 2009 highlighted concerns about discrimination against persons with disabilities in relation to ESC rights, in the areas of health, housing and employment, as well as noting high levels of inequality and poverty in Northern Ireland and the need to improve data collection in order to monitor progression of ESC rights.

19. At the same time, it should be noted that Article 19 also relates to traditional civil and political rights that must be realised without delay. The principles of equality and non-discrimination run throughout the entire Convention, and as such elements of Article 19 in relation to these principles should be met by the State immediately; for example, non-discrimination with regards to access by disabled people to community services. In sum, it would not be appropriate to frame the question of how to implement Article 19 by solely focusing on socio-economic issues.

Health and Social Care

20. Access to proper health and social care is critical for ensuring an independent quality of life for disabled people. The Bamford Review of Mental Health and Learning Disability Services has concluded that there is clear evidence of inequalities in investment in this area compared with other regions in the UK. An ECNI investigation has also identified that people with learning disabilities face serious challenges such as poor communication from healthcare staff, a lack of understanding of their health needs, and a lack of user friendly written information in accessible formats.134

Transport

21. Access to affordable and inclusive transport facilitates disabled people’s access to health, educational and employment opportunities and contributes to their independence and quality of life, including their involvement in the community and in general day to day social

activities. The provision of affordable and inclusive transport not only progressively realises the rights within Article 19 but also other Convention articles.

22. Over the last five years there has been considerable progress in respect to the provision of accessible and inclusive transport in Northern Ireland. For example, the removal of the transport exemption from the protections of DDA legislation and investment in accessible public transport and infrastructure. The ECNI recommends that other measures are assessed to enhance the independence of disabled people, for example:

- The provision of affordable accessible transport, with the equalisation of the concessionary fares scheme to apply to all disabled people regardless of how they acquired their disability.
- The benefits of the concessionary fare scheme to apply to all bus routes, participation in the scheme should not be restricted by geography.
- Better provision of written accessible information.

**Participation and Consultation**

**Focal Point Action**

23. Under Article 33(1) the designated focal point for Northern Ireland is the Office of the First Minister and Deputy First Minister (OFMdFM). The Independent Mechanism for Northern Ireland has sought regular meetings with OFMdFM to discuss the Executive’s plans to implement the Convention. The Independent Mechanism for Northern Ireland has discussed with the Focal Point the issue of participation and consultation and possible approaches to addressing the particular requirements of the Convention under Article 4(3) and Article 33(3). One such suggestion was the reconstituting of the PSI working group, or some similar arrangement facilitated by OFMdFM. The Independent Mechanism for Northern Ireland notes that OFMdFM has undertaken some engagement with disabled people in respect to the development of its contribution to the State Party report. However, to date the Independent Mechanism for Northern Ireland is not aware of any other formal engagement arrangements between OFMdFM and disabled people in relation to ongoing work on the Convention.

**Public Sector Duties**

135 The PSI Working Group Report on Disability highlighted for example that employment rates for disabled people are very low. In 2009, the employment rate for people with a disability of working age was 31%, less than half that for people without a disability (75%). This low level of employment has persisted over time. The report also acknowledged those other important relationships to affordable inclusive transport—access to services, opportunities and correlation to level social and economic activity etc. The Department of Regional Development acknowledges that access to transport is of particular importance in rural areas where the 2008 Living Cost and Food Survey found that rural families spend 15% of household expenditure on transport.
24. The Convention contains provisions for the close consultation and active involvement of disabled people, and their representative organisations, in decision making, and policy formulation (Article 4(3)) and for promotion of effective and full participation in the conduct of public affairs (Article 29). The effective implementation of public sector disability duties, under the Disability Discrimination Act 1995 (as amended), together with the public sector duties under Section 75 of the Northern Ireland Act 1998, enables government and public authorities to meet the provisions as outlined within the aforementioned and other articles.

25. The ECNI research has noted several good practice examples of consultation and direct engagement with disabled people on a range of policy initiatives associated with the development of Disability Action Plans (under DDA (as amended)), the implementation Article 4(3) under the Convention, and on subject specific matters such as the Accessible Transport Strategy.

26. However, an independent evaluation on the implementation of the public sector disability duties for the ECNI has highlighted that public authorities need to do much more to effect meaningful engagement with disabled people to uphold their right to influence and direct regional and local government mainstream policy.

**Future Work of the Independent Mechanism**

27. The Independent Mechanism for Northern Ireland will continue to engage with the Focal Point and remind OFMdFM of the obligations under the Convention in relation to Articles 4(3), and 33(3).

28. Furthermore, the Independent Mechanism for Northern Ireland is taking forward engagement with Government departments, and decision makers, to promote the effective implementation of the public sector duties to further assist the realisation of rights held within the Convention.

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136 The Disability Discrimination (Northern Ireland) Order 2006 inserted section 49A and 49B into the Disability Discrimination Act 1995 to create the disability duties. These sections came into effect on 1 January 2007. Under Section 49A, public authorities when carrying out their functions must have due regard to the need to: promote positive attitudes towards disabled persons; and encourage the participation of disabled persons in public life. A Guide to the ‘disability duties’ is available at: [http://www.equalityni.org/archive/pdf/ECNIDisPlan.pdf](http://www.equalityni.org/archive/pdf/ECNIDisPlan.pdf)

137 Section 75 of the Northern Ireland Act 1998 places significant duties on public authorities regarding how they carry out their functions and deal with the general public. These duties relate to the promotion of equality of opportunity on a number of equality grounds including disability. These duties on public authorities include the production and review of Equality Schemes, conducting equality impact assessments and including consultation as an integral part of the policy-making process. Detailed explanation and Guide available at: [http://www.equalityni.org/archive/pdf/S75GuideforPublicAuthoritiesApril2010.pdf](http://www.equalityni.org/archive/pdf/S75GuideforPublicAuthoritiesApril2010.pdf)
Monitoring the effective implementation of the Convention

Independent Mechanism for Northern Ireland Activities

29. Under Article 33(2) the task of the UK Independent Mechanism is to “promote, protect and monitor implementation of the present Convention”. As previously noted, the Independent Mechanism in Northern Ireland is jointly represented by ECNI and NIHRC. The Convention is not prescriptive in the functions which the various elements of the framework should carry out, although there are a number of sources of guidance from the United Nations which have assisted the Independent Mechanism for Northern Ireland in determining the type of activities it should undertake.

30. In this regard, the NIHRC and ECNI have promoted and protected implementation of the Convention by:

- responding to consultations using the Convention;
- producing publications and factsheets promoting the Convention;
- promoting the Convention on our respective websites;
- commissioning a legal analysis to identify legislative gaps;
- commissioning an expert paper on the compliance of government policy and practice in the implementation of Convention; and
- holding a Platform Event (1 December 2010) to promote the Convention and the role of the Independent Mechanism.

31. The Platform Event contributed significantly to the Independent Mechanism for Northern Ireland’s engagement with disabled people to monitor and gather information for its contribution to the parallel report to be submitted to the UN Committee on the Rights of Persons with Disabilities, in accordance with Article 33(3). We are currently undertaking a series of engagement/information gathering sessions on Article 28 ‘adequate standard of living and social protection’, and associated articles that may influence the realisation of the article, for our engagement with disabled people.

32. The Independent Mechanism for Northern Ireland has additional focused engagement with the disability sector planned for Autumn 2011. Furthermore, much of the work carried out so far by the Commissions will provide information for the Independent Mechanism for Northern Ireland’s monitoring report, such as commissioning of the legal analysis and the expert paper on policy and practice compliance. As previously noted, the Independent Mechanism for Northern Ireland has met regularly with the Focal Point for our jurisdiction, OFM, to discuss progress made on implementation of the Convention.

33. In order to effectively monitor and measure the implementation of Convention rights, the Government, the Independent Mechanism for Northern Ireland and civil society require robust data and statistics. The United Nations Committee on the Rights of Persons with Disabilities, which oversees the implementation of the Convention, has produced guidelines
Written Evidence submitted by the Independent Mechanism for Northern Ireland (IL 35)

for the State on how it should prepare reports to be examined by the Committee. In relation to Article 19, the Committee asks for evidence of the existence of available independent living schemes, in-house support services and the degree of accessibility for disabled people to community services. This information will require up-to-date statistics. DHSSPS has recently noted:

“It has already been identified that there are particular difficulties with data within health and social care in terms of quantifying the overall response to need because of the variability in definition and comprehensiveness of information. There is, in fact, very little official disability-specific data available to health and social care planners…”

34. The 2011 Census should yield more up-to-date information, but it is unlikely to be available for this monitoring round.

35. Under Article 31, the Convention outlines that it is the State Party’s responsibility to undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention. The UK Independent Mechanism, including the Independent Mechanism for Northern Ireland, does not formulate or implement policies to give effect to the Convention. Therefore, the four Commissions in performing the role of UK Independent Mechanism do not have the responsibility for, or capacity to, undertaking those tasks associated with Article 31, such as primary data collection, that are envisaged in the Convention as falling to the State.

36. The Northern Ireland Human Rights Commission has repeatedly drawn attention to the fact that, although some limited funding has been provided for specific pieces of work on the Convention by the Office for Disability Issues (ODI), no additional core funding has been made available to it for this new and important area of work. This is in marked contrast to some other national human rights institutions, such as those in New Zealand and Germany, which have received substantial dedicated funding for their work on the Convention.

Concluding Remarks

37. The Independent Mechanism for Northern Ireland, while of course supporting implementation of the right to independent living, views all human rights as being indivisible, interdependent and interconnected and would prefer that the national and regional authorities use the implementation of the Convention as a whole to form the basis of their response to disability issues in the UK. Article 19 does not stand alone: it is closely linked to other rights contained in the Convention, concerning work, education, rehabilitation, personal mobility and the right to an adequate standard of living and social protection, participation, accessibility and access to information. Independent living is a key concept but does not cover the full range of Convention rights. The State has committed to respect, protect and fulfil all the rights contained in the Convention and should place full implementation of the Convention at the centre of its legislation and policy making.

Written Evidence submitted by Sense (IL 36)

1. Introduction

1.1. About Sense

Sense is the leading national charity that supports and campaigns for children and adults who are deafblind. We provide expert advice and information as well as specialist services to deafblind people, their families, carers and the professionals who work with them. In addition, we support people who have sensory impairments with additional disabilities.

1.2. About deafblindness

Deafblindness is a combination of both sight and hearing difficulties. Most of what we learn about the world comes through our ears and eyes, so deafblind people face major problems with communication, access to information and mobility. People can be born deafblind (congenital deafblindness), or become deafblind through illness, accident or in older age (acquired deafblindness).

The deafblind population has been significantly underestimated and is set to rise dramatically. There are currently 356,000 deafblind people living in the UK. This is set to rise to 569,000 by 2030. The older you are, the more likely you are to have both a hearing and a visual impairment. Sense estimates that 4.6%, or almost 1 in 20, of over 75s are sufficiently sensory impaired to be considered deafblind; approximately 222,000 people in England, Wales and Northern Ireland. As the population ages, the number of deafblind older people will rise; by 2030, we estimate that this figure will have risen to over 418,000.

2. Summary of key points

Sense would like to make the following key points:

- Deafblind people need one to one support to be able to have the same choice, freedom and control as everyone else in their day to day lives.

- In the current climate, the cuts to social care are the biggest challenge deafblind people face in respect of access to adequate and appropriate social care including one to one support.

- Sense believes that changes could be made to policy and guidance which would improve deafblind people’s chances of having the same choice, control, and freedom as everyone else. For example, an amendment to the Prioritising Need Guidance placing more emphasis on risks to communication would ensure that more

139 A Sense of Urgency, A study commissioned from Professor Emerson at the Centre for Disability Research (CeDR) 2010.

140 As above
deafblind people received adequate and appropriate support to be able to live independently.

- Older people with acquired deafblindness are frequently treated less favourably than younger people with similar sensory impairments in respect of access to social care which would make independent living possible.

3. The Social Care needs of Deafblind People

3.1. The social care needs of people with acquired deafblindness

People with acquired deafblindness are often able to wash, dress and feed themselves; but without communication and mobility support, many deafblind people are effectively condemned to a life of solitary imprisonment in their own homes. Without support, deafblind people are frequently unable to interact with others; access or identify food; access basic information; access leisure activities; work; exercise; get out to the shops or the bank; visit the doctor; deal with post and bills; or navigate around their home in order to carry out household chores such as cooking or cleaning.

A communicator guide is a lifeline to many deafblind people, helping them to remain independent. A communicator guide is a person who provides communication support, and can act as a guide thereby enabling a deafblind person to get out and about.

3.2. The social care needs of congenitally deafblind people

Congenitally deafblind people can have very complex needs. Intervenors are an essential part of the support offered to a congenitally deafblind person. An intervenor is a one-to-one support worker who helps a deafblind person make sense of and interact with the world around them. Intervenors usually work with children or adults who were born with severe visual and hearing impairments and who may also have additional disabilities. Intervenors help people to communicate and receive information. Their role is to enable the individual to benefit from learning and social experiences and to help them have greater access to the local environment. Intervenor support can enable deafblind people to acquire skills, build confidence and do the things that they enjoy. This can include helping people to do everyday activities such as cooking and shopping, enjoy arts and crafts, or experience aromatherapy and massage. Congenitally deafblind people also benefit from structured learning opportunities, based on a thorough assessment of their skills, needs and aspirations. These include developing communication, mobility and daily living skills. We also support some people to take part in work experience or employment where appropriate.

141 Shopping services—For most people who are unable to get out of the house, telephone or on-line shopping is a solution. Deafblind people are unable to access telephone shopping and on-line shopping services are frequently ruled out because food cannot be delivered to the home without the deafblind person placing themselves at great risk by opening the door to someone they are unable to see or hear and therefore identify. For many deafblind people to actually get food into their home, assistance is required.

142 This is important because a deafblind person would be unable to read mail with notification about very fundamental day to day issues. For example notifications that power or water will be cut off, notification of medical appointments, that the rent has gone up, or notification that winter fuel allowance will apply.
4. The right to independent living—The impact on deafblind people of not receiving adequate and appropriate care

Independent living is described by the Office for Disability Issues as being about, “disabled people having the same level of choice, control and freedom in their daily lives as any other person.” Article 19 of the UN Disability Rights Convention places obligations on the government to recognize the equal right of disabled people to “live in the community with choices equal to others” and to take effective and appropriate measures to ensure that disabled people have “full enjoyment by persons with disabilities of this right and their full inclusion and participation in the Community.”

Choice, control, freedom, inclusion, and participation in society is only achievable for many deafblind people if they are receiving a package of care and support that meets their needs. Without adequate and appropriate care and support, deafblind people lose their independence, become socially isolated and are unable to participate in society on an equal footing with everyone else. Adequate and appropriate care and support could be delivered in the family home, a supported living environment or a residential environment. A person could be living in their own home but if they are receiving little or no support then they will have no choice, control, or freedom. Similarly a person living in a residential setting could have a package of care which enables them to live the life that they choose and to be included in their local community.

Case Study: “I recently moved from a residential home to supported living. I found it difficult to live with other people and to get along with the staff working in the residential home. It made me angry and sometimes I lost my temper. Now I interview and choose the people that support me in my home and I get along with them really well. It makes me proud to show people round my house and make visitors cups of tea. In the residential home I had to do what everyone else was doing because there were not enough staff, so unless everyone was going out I couldn’t go out. Now I have one to one support I can go out and about when I like. I go to lots of community groups and I know more people in the local community such as people working in local shops and my neighbours. I have lost over two stone since I moved because I am much more active and I eat more healthily.” P, a congenitally deafblind man with learning disabilities.

5. Impact of funding on the right to independent living

In the current climate, the biggest threats to UK compliance with Article 19 are the cuts to social care packages, social care and disability services, and benefits. As budgets are squeezed, more people will be excluded from adequate and appropriate care and support and the ability of the Government to secure the right to independent living will be compromised. The claim that disabled people will be able to rely on the “Big Society” or voluntary organizations to pick up the pieces ignores the fact that many disabled people need highly trained specialist providers and that the voluntary sector itself is entering recession.

5.1. The decision, announced in the CSR, to remove the mobility component of Disability Living Allowance for all people living in residential care will severely
impact on people’s Article 19 right to live in the community with choices equal to others. DLA mobility component provides vital support for many disabled people in residential care.

The removal of DLA mobility for people in residential homes is based on an assumption of “double funding.” However, evidence shows that local authorities are not currently meeting mobility costs. Local authority services are designed to meet only needs that fall within a set eligibility framework. This identifies four bands of need: critical, substantial, moderate and low. Most local authorities are only funding critical and substantial levels of care. A person who qualifies for DLA mobility will frequently not be eligible for support with mobility according to local authority criteria.

The government has also argued that the cut to DLA will align the rules for people living in residential care with people living in hospital. It is entirely inappropriate to compare patients who are ill in hospital with disabled people living in a residential setting. People in residential homes are not ill, they are disabled, and the Government has stated that it is committed to increasing their independence and participation in society. If disabled people are to participate it is essential that they are appropriately supported to get out and about.

Removing the mobility component of DLA will significantly restrict the ability of those in residential care to play an active role in their local community, be independent and maintain relationships with family and friends.\textsuperscript{143}

5.2. Changes to the Independent Living Fund See point 6.2 below.

5.3. Restrictions on local authority funding, social care budgets and benefits reassessments

We are already seeing evidence of policy and budgetary decisions impacting on people’s Article 19 right to independent living. Many of the people we work with are capable of living in an independent living environment providing they have adequate support. The cuts to social care provision mean that support is no longer available and consequently people are denied access to independent living.

Case Study: J is deafblind working age man with mild learning disabilities living in a Sense residential home. J was supposed to move into a supported living flat, but the local authority have just announced that they are unwilling to fund his care package including vital communicator guide support if he moves. This would mean that J would be living in his own flat but would be unable to get out into the community to volunteer, access social and leisure activities or visit the shops. J says, “It has upset me a lot. The local authority has not let me make my own decisions and they have not been looking after my rights”

For others, the cuts will mean that their ability to participate in their communities, and their choice and control is removed. Without adequate support many of the people we work with

\textsuperscript{143} See DLA Mobility – Sorting the facts from the fiction and Don’t Limit Mobility both prepared by a consortium of disability charities and attached to this submission.
will lead very restricted lives and their ability to cope is impaired. This inevitably leads to problems with physical and mental health.

**Case Study:** M used to attend a Sense day centre 5 days per week but his service has been cut to 2 days. M is completely blind, has a moderate hearing impairment and a moderate learning disability. M was assessed as substantial under the work, education or learning band, the social support systems and relationships band and the family and other social roles band.

M is very vulnerable. He lives alone in a supported living environment. He cannot use public transport without appropriate support. M cannot work and is unable to access other services in the community which might be appropriate for a learning disabled person because of his communication difficulties. Without the support of Sense he would have very limited social interaction or independence. He would be unable to access shopping for himself. Food could be provided by meals on wheels but M would then lose all access to his local community.

Since M’s service has been cut he has become increasingly socially isolated. He rarely leaves his home on the days that he receives no Sense support. He has started to develop mental health issues. The local authority is threatening to cut social care to critical only. If M’s social care were cut to critical only he would lose the support he receives from Sense entirely. M would quickly develop profound mental health problems. In addition, if M did not exercise his ability to use sign language his existing communication skills would over time be lost.

6. Government Policy

We believe the right to independent living should continue to form the basis for Government policy on disability in the UK. Some policies could be improved to better meet the obligations in Article 19 and to secure the right to independent living. In particular:

6.1. The Prioritising Need Guidance[144]—This guidance identifies four bands of need, critical, substantial, moderate and low. Within each band the guidance identifies certain risks to the individual which would occur if their social care needs were not met. Because of misunderstandings and a lack of education amongst local authority employees, social involvement is often accorded a lower priority than for example personal care. Further, a lack of knowledge around the potential risks of receiving inadequate communication support, means that people with sensory impairments are frequently banded as having moderate or low needs when in fact their needs may be substantial or critical. This is particularly the case for older deafblind people. Because many councils only fund substantial or critical bands this means that deafblind people with acute needs are excluded from receiving social care packages.

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144 Prioritising Need in the context of Putting People First: a whole system approach to eligibility for social care—guidance on eligibility criteria for adult social care, England 2010

The Department of Health has recognized that, “the needs of deafblind people are often not identified nor are those in need of community care always in receipt of appropriate services.”\(^{145}\) This conclusion led the Government to reissue the Deafblind Guidance, “Social care for deafblind children and adults” in June of 2009.\(^{146}\) This guidance was issued under Section 7 of the Local Authority Social Services Act 1970 and is relevant to all local social services staff. The Deafblind Guidance places legal duties upon local authorities and requires specific actions to be taken such as identifying and keeping records on deafblind people in catchment areas. The guidance places a legal duty on local authorities to carry out a specialist assessment which must be carried out by a “specifically qualified person”. The Deafblind Guidance goes a long way towards protecting the rights of deafblind people, but improved application of the Prioritising Need Guidance would represent a big step towards ensuring the protection of deafblind people’s rights. Sense would also recommend including a specific mention of the risk to communication in the banding system set out in the Prioritising Needs Guidance.

6.2. Local authority use of the independent living fund and expensive care packages

One challenge for local authorities in the current system is that small numbers of people with very high support needs can disproportionately affect local budgets, especially in smaller authorities. Some congenitally deafblind people would fall into this group, having very high support needs and no means of funding this themselves. Local authorities will resist accepting responsibility for funding a service when a person moves into their area, or will refuse to fund a package that adequately meets needs on grounds of cost. Parents of deafblind children approaching transition to adult services often battle for several years to get their son or daughter an adequate service.

Some local authorities have effectively used the Independent Living Fund (ILF) to top-up large packages of support. Whilst this was not the original intention of the fund, it is how many authorities now use it. If the ILF is removed then we argue that it should be replaced by a central funding pot which will contribute towards the cost of very expensive social care packages.

6.3. Transparency in Outcomes Framework\(^{147}\)

The Department of Health recently published its policy for measuring quality in social care. We are concerned that the new methods of measuring quality, and the reduction in compulsion and regulation will result in lower quality social care which will have a knock on effect on compliance with Article 19.

\(^{145}\) Page 3 Local authority circular, Department of Health, 23 June 2009 Gateway reference: 11835 LAC(DH)(2009)6

\(^{146}\) ibid

\(^{147}\) Transparency in outcomes: a framework for quality in adult social care. The 2011/12 Adult Social Care Outcomes Framework
The framework has a new focus on outcomes (rather than targets) for adult social care. Quality will be measured by how local authorities have performed in relation to each outcome, performance will be measured by a set of indicators. The indicators are inadequate and inappropriate and will fail to capture information which is relevant to deafblind people. For example, one outcome states that “People are able to find employment when they want, maintain a family and social life and contribute to community life, and avoid loneliness or isolation”. As an outcome this is laudable but compliance will be measured by examining the proportion of adults with learning disabilities in paid employment; the proportion of adults in contact with secondary mental health services in paid employment; the proportion of working age adults in contact with social services in paid employment; the proportion of adults with learning disabilities who live in their own home or with their family; and the proportion of adults in contact with secondary mental health services living independently, with or without support. Clearly this data will give no indication of whether deafblind people’s needs are being effectively met in respect of the stipulated outcome. Further, data will be gathered via the Adult Social Care Survey which has no disaggregation of people with deafblindness or sensory impairments. Sense urges the government to revisit the Framework so that the needs of deafblind people are not forgotten when measuring quality in social care.

6.4. Pre-emptive social care assessments

Local authorities have the power to carry out assessments of need and give an indication of how they will meet that assessed need before a person’s ordinary residence transfers. This means that a person who is moving house to a new area, or a person living in a care home which is de-registering from a residential to a supported living home, should in theory be able to have a package in place when they move into the new area. In reality this power is rarely exercised. If an individual has high support needs and can’t manage without support, this means that you are effectively trapped in the local authority you currently live in, as moving not only requires an assessment but also a package to be in place at the time that you move.

Many people in Sense residential homes whose needs would be best met in an independent living environment are dissuaded from moving because they do not want to take the unquantifiable risk that the receiving authority would give them a less favourable package either by reassessing their need and downgrading their risk band for example from critical to substantial; or by deciding to meet the assessed need differently or with a reduced financial package through direct payments. If local authorities were under a duty to carry out pre-emptive assessments it would not ensure that the individual would be assessed at the same level, nor would it ensure a service would be in place when the person moved; but it would be a step in the right direction.

6.5. Approach towards older people
unable to access the telephone, television, the radio, or written materials such as books or newspapers, this simply amounts to solitary confinement. **Case Study:** S is a deafblind older person who lived alone for the whole of her adult life. S found that communicator guide support made a huge difference to her ability to get by, but she was only given 2 hours per fortnight of support. S became increasingly confused due to her deafblindness and her brother who helped with her care found he was unable to cope. S does not have personal care or medical needs other than those associated with her deafblindness. The decision was made against S’s wishes to place her in residential care.

S is now on her fifth local authority funded residential placement. The staff and other residents at the home are not trained to communicate with S so she is extremely socially isolated. In addition the staff do not know how to support S, for example they leave her food on a tray in front of her but don’t communicate with S to tell her that her food is there and as a result S frequently goes hungry. S is isolated, frustrated, anxious, and angry and as a result she displays challenging behaviour including urinating on the carpet. S sees this as her only viable form of protest. The staff treat S like a child calling her “naughty.” S begs her family to help her to commit suicide. The local authority’s unwillingness to fund an expensive package including one to one communicator guide support means that she has no choice, control or freedom.

M is a deafblind working age man with the same level of sensory impairments as S and living in the same local authority. Similar to S, M has no personal care needs or medical needs, other than those associated with his deafblindness. M receives over 40 hours of communicator guide support in his home allowing him to retain independence and control over his life and allowing him to maintain a healthy social life.

### 7. Participation and consultation

Deafblind people are largely excluded from participation and consultation exercises. Disabled people’s and older people’s groups frequently fail to meet the communication needs of people with sensory impairments; and consultation exercises often overlook the complexities of how to effectively involve and engage with deafblind people.

*27 April 2011*
We are an independent self advocacy group for people with learning difficulties in York.

We asked our members to answer the questions about whether people with disabilities are getting their Human rights met; here is what our members had to say.

Are the government doing enough to give people with disabilities the same rights as everyone else to live independently?

Although things are moving in the right direction, the government could do more to ensure that people are given the choice about where they live and whom they live with. One of our members has the worry that if she cannot find somebody suitable who she would like to live with soon, she will have someone forced on her. Most people without any disabilities choose who they want to live with as an automatic right.

Another issue that is still a problem for people with disabilities is not being able to choose your own care worker; a major proportion of a care package can be personal care. It is unfair to expect people to just accept intimate care from somebody who they have not chose themselves, or do not feel comfortable with. Individual care should be about individual choice and whilst some members of our group feel lucky that they have some choice, they feel that it should not be about luck, everyone should know that they have a choice. On a positive note, the members who now live independently are much happier than when they were in residential care and could not imagine going back to that. They are proof that with the right support independent living really changes people’s lives for the better.

For the people who have managed to get their own budgets and then choose their own personal assistants, there are still problems, with how to be an employer. The government could consult with groups like ours who have devised training packages aimed at personal assistants and the people who employ them. With the correct support and training in how to be an employer, what your rights are, what rights your employees have, more people will be able to live independently.

In relation to the question asking whether the government should change any laws?

The members all felt that seemed the wrong thing to do, as why should there be a law about what goes on in your own home? What really needs to be done is to change the attitudes of council workers and care managers in that they need to listen to the people with the disabilities. Also work with them, supporting them with the choices they make whilst providing the training required to ensure that the transitions work.

People with disabilities should also be consulted about new agencies that come into the cities in which they live, if these agencies are going to be providing services to people with disabilities then surely they should be involved from the beginning to ensure that the values of the organisation are the same as the people they will be serving. All new agencies should be telling the people with disabilities what it is that they can offer them if they choose to use their services.
The government also need to ensure that all council offices do what they say they are going to do; consultation is only any good if you are really going to listen and then act on what you have heard. Also, every person entitled to services should receive them no matter where they live. One member summed up the question on creating a law with “you can’t pass a law to make people care can you, re-educating people is the way forward”.

The question of how the government cuts are affecting our members individually, was quite difficult to answer as some members don’t actually know what funding they are getting at the moment, and trying to find out is difficult. All the members of our group are happy with the funding they receive and all said they can afford to do things that they enjoy so feel that this is a positive side to individual funding. They are worrying about what may happen in the future with impending cuts.

One worry for our members is that the more independent and confident they get, the less help they are entitled to. One member felt confident enough to answer question for his own assessment, but very nearly lost his funding because of the way the questions were posed. For example He was asked if he could get about outside to which he replied yes, the fact being that he need support to be able to do this was not asked, luckily a personal assistant was on hand to explain this. People in charge of assessment needs to take into account that it’s not just about the things you can now do, it is also about the things you haven’t yet learnt, like how to behave in social situations.

Cuts to Council Funding:

We are worried that as more professionals lose their jobs, they may end doing jobs that people with learning disabilities are capable of doing. Our particular group has the skills and the equipment to do training sessions, but we worry that these kind of skills will be handed back to professionals. We would like to see more respect for the things that we can do, ideally we would like to work together with professionals so that we can all learn from each other.

As a group York people first do not get any funding from the local council, even though they have developed training for people with learning disabilities in how to become employers and they also support other groups and individuals with disabilities. With funding they would be able to reach out to a wider circle of people with disabilities and ensure that more people could find out about their rights. The government could consult more with groups like ours who really understand the needs and wants of people with disabilities and learn from us how to get it right.

We are aware of day services for people with more complex needs who are being affected by cuts in council budgets. These people are not getting the physical support as much as they need for example physiotherapy and speech and language therapy, seems to have been reduced. Activities offered are not as good quality as they used to be because there is less money to fund it.

Another worry about funding cuts is the withdrawal of mobility payments for people who live in residential care. Without this they could be confined to the same four walls every single day, these peoples basic human right to enjoy an outside life will be compromised. They could easily become depressed as they are not able to get out and enjoy the things in life non disabled people take for granted. Also if disabled people are then confined to home the only experience care staff will learn, is how to look after people, we need staff to
understand more about supporting people to live independently, we do not want to go back to being cared for.

**How can the government involve disabled people in planning services and deciding how to save money?**

When I put this question to the group one member said “Well first off they could actually ask us we are human beings you know and we do like to be asked” we need to be involved in the planning and decision making stages. Also show us that you listen to our views, we do not appreciate token gestures where we are heard then our suggestions completely ignored with no feedback, as that is just patronising.

**How well are disabled people involved in planning and making decisions?**

Not very well is the answer to this question, The government need to keep ahead of what’s happening locally and nationally then feed it back to any groups or individuals who have disabilities sooner., they should also be supporting groups/individuals to go along to any meetings and consultations that concern us. Also providing financial support to enable us to attend meetings that are further away and maybe paying for someone to take notes for us, so we can report back to other people who cannot make it.

**Sticking to the UN convention.**

Personal health passports for every person with a learning disability, this is still not being done nationally, also some of our members have not had a health check with a GP for up to two years. They have not received any invitation to go for one, even though they are registered. The health needs of people with disabilities are still being ignored. Some things still have not changed for everyone.

**How can the UN Convention make sure it includes ideas from disabled people in its reports?**

As this is the first time there has been a consultation from the Joint Committee on Human rights, we are happy to be involved and see this consultation as step in the right direction. We would like to see our views passed on to other groups and organisations. We want to work together as a partnership and we would like to see results, we want feedback, we also want to hear what others have been saying. We want proof that what we tell you makes a difference, because that shows us that you are really listening to us.

27 April 2011
Introduction

Sense Scotland is a leader in the field of communication and innovative support services for people who are marginalised because of challenging behaviour, health care issues and the complexity of their support needs. The organisation offers a range of services for children, young people and adults whose complex support needs are caused by deafblindness or sensory impairment, physical, learning or communication difficulties. Our services are designed to provide continuity across age groups and we work closely with families and colleagues from health, education, social work and housing. This breadth and depth of approach to service delivery helps us take a wider perspective on the direction and implementation of new policies.

We welcome the opportunity to provide evidence in relation to the implementation of the right to independent living for disabled people, as guaranteed by Article 19, UN Convention on the Rights of Persons with Disabilities. As we support people living in Scotland, our submission is based on experience in Scotland.

Our Comments

The right to independent living

Should the right to independent living continue to form the basis for Government policy on disability in the UK?

Yes—both at a UK level and through the Scottish Parliament.

Do existing policy statements, including the Independent Living Strategy, represent a coherent policy towards the implementation of the obligations in Article 19 of the UN Disability Rights Convention? Could current policy be improved? If so, how?

We believe that the good intentions behind many strategies and policies to emphasise rights, control and independence, and to reduce inequalities are being undermined by policy in other areas. We would go further, and say that recent policy developments will increase inequality, and diminish the quality of disabled people’s lives.

The prime example at a UK level is the direction that Welfare Reform is taking and we say more about that below.

At a Scottish level, Sense Scotland has welcomed the Self Directed Support Strategy, and many of the intentions behind the proposed Self Directed Support Bill in Scotland. However, we have major concerns in relation to implementation of national policy at a local level, which is having a devastating impact on the lives of many disabled people. The application of eligibility criteria and resource allocation systems contribute to a context of disabled people receiving only the level of assistance that enables them to survive – not the level that enables people to live comparable lives with non-disabled people.
What steps, if any, should the coalition Government, the Scottish Government or other public agencies take better to meet the obligations in Article 19 and to secure the right to independent living for all disabled people in the UK?

If you consider changes to policies, practices or legislation in the UK are necessary, please explain.

Equality impact assessments need to take place and to be rigorous. All proposals need to be scrutinised fully to ensure that they will not have a negative impact on the lives of disabled people. It is important to remember that they should also demonstrate a positive impact—a standstill position is not adequate, given the disadvantages that disabled people experience and which led to the need for the convention in the first place. Eligibility criteria are being used to justify cuts to services for disabled people which make no reference to the duty to promote equality. A sufficient quality impact assessment of this approach would show this to be the case.

Disabled people, and organisations who can represent the needs of disabled people who cannot engage themselves in consultations, need to be included in any policy development. This needs to include people with complex support needs, in order that assumptions are not made about their willingness or ability to lead more independent lives, given the right opportunities.

It is not sufficient to ‘informally’ consult with disabled people, as the recent Welfare Reform Bill claims to have done, the consultation must include formal consultation, and this needs to be supported in law to cover national and local policy.

Any panel involved in such a consultation needs to be announced, together with each of the member’s interests in order that gaps in knowledge can be identified by the public.

Impact of funding on the right to independent living

The decision, announced in the CSR, to remove the mobility component of Disability Living Allowance for all people living in residential care

Sense Scotland has already submitted a detailed response related to the proposed changes to DLA, including the effect on people living in residential care. We believe that the proposals show at best a misguided assumption about the lives of disabled people, and at worst a blatant disregard for the value of disabled people’s lives. We would also refer the committee to the publication, to be published in May 2011, entitled: How am I going to put flowers on my dad’s grave?148, which contains many telling stories about the concerns relating to this measure.

DLA was intended to be about the additional costs of being disabled, and to mitigate some of these costs, but PIP does not have that focus, being rather about the ‘greatest need’. This approach has to increase inequality and reduce the opportunity for independent living.

Changes to the Independent Living Fund

148 How am I going to put flowers on my dad’s grave? Care home residents’ use of the mobility element of the Disability Living Allowance. Capability Scotland and Margaret Blackwood Housing Association. May 2011
The changes to this fund have resulted in numerous cuts in packages to school-leavers where local authorities had factored ILF income into their calculations regarding funding for support. Sense Scotland is aware of a number of families whose lives have been turned upside down by the failure of expected supports to materialise, due to the local authority not picking up the assessed needs which were going to be met through ILF. This indicates both the direct impact of the cessation of ILF for new people, and the impact of local authorities failing to meet needs it had assessed as requiring support.

Young people are now going to be reliant on their families for support, rather than being in a position to ‘spread their wings’ and develop lives independent of their families, as non-disabled people would expect.

The changes to ILF are also having a negative impact on adults, and given the approach to cuts being implemented by local authorities, we have major concerns about the fund being handed over to be managed at a local level—where it will not be about entitlement, but about competing needs.

"The Big Society"

Sense Scotland values the input of volunteers, and many of them work for the people we support. We are all too aware of the massive levels of assistance already provided to the disabled people we support by unpaid carers—mostly family members. Many of these relatives are already at or beyond the limits which maintain a healthy family life, due to the level of assistance they provide. They would like a family life based on positive experiences, and similar opportunities to other families. Instead, they are often pushed to breaking point.

The people we support take time to get to know. To develop the unique communication methods used by each person can take months, if not years. We are aware that there are not many people who can commit that kind of time, consistency or patience on a voluntary basis. Even paid staff at colleges, in hospitals and in social work departments usually need the skills of our staff in order to communicate with the people we support. It would be unrealistic to expect them to develop the unique communication methods for each person we work with. Failure to recognise that fact results in generic support which does not include people, and will fall at the first hurdle if there is a reliance on voluntary support. Consistency, and a constant presence of human communication support is essential for people who have had major communication support needs due to complex conditions from birth. Natural supports may develop, but these will follow from a realistic understanding of the different needs of people. There cannot be a ‘one size fits all’ approach which assumes these supports will be available to, or appropriate for, everyone. We are currently seeing these assumptions in the application of eligibility criteria and implementation of budget cuts. People are paying a heavy price because of it.

Restrictions on local authority funding, social care budgets and benefits reassessments

We currently have experience of support costs which were agreed only 6 months ago, being cut by up to 45%. The language of independence is being used in the promotion of the ‘new way of doing things’ but these cuts to services which were well specified and already had economies of scale do not result in control and choice through Self Directed Support.
All of our service users who are not already receiving it will have to be reassessed for ESA. We believe the work capability assessment is not fit for purpose, is time and money consuming, causes distress and promotes inequality because of these factors—particularly when people often already have clear assessments of need carried out by responsible people who know them well. We expect the same of the PIP assessment, although we will provide comment on that when the consultation is published. Our point earlier about publicising panel members who are being consulted is borne out of this issue. We have tried, and failed, to find out who is being formally consulted in order that we can be satisfied that the disabled people we support will have their needs represented. Equality relies on consultations being comprehensive and inclusive.

**Increased focus on localisation and its potential impact on care provision, and specifically, on portability of care and mobility for disabled people.**

The current pressure on local authorities to cut the costs of support they pay for has seen an increase in cross-boundary disputes relating to payments. This leaves disabled people living away from what is considered their ‘home area’ in a stressful position, where they do not know if their support will continue to be available to them. This often has nothing to do with the fact that the support may be cheaper in the ‘home area’—as it is often just not available. However, despite this fact, we have seen a recent increase in local authorities refusing to pay the full top up costs for people living out of their area, whatever the ‘ordinary residence’ issues are, or the Scottish guidance says.

This lack of respect for individual needs and wishes would indicate that people would have more freedom of movement if the funding they required could be transferred with them wherever they chose, or had, to live. This would also support disabled people having more similar ability to move as that enjoyed by non-disabled people.

A further barrier to transferring funding is the lack of availability of suitable housing, or funds to adapt accommodation. This is compounded by an unwillingness to fund adaptations for people moving from an adapted house—yet non-disabled people have freedom of movement and choice over where they live—whether it’s a couple of streets away to be near family, or to a completely different local authority area. The recent decision by the Scottish Government to cut adaptations funding to Social Landlords compounds this difficulty, and reflects a lack of real commitment to equality and independence.

**What impact does funding have on the ability of the UK to secure the right to independent living protected by Article 19 of the UN Disability Rights Convention?**

Funding mechanisms ration what is available, and determine what are ‘eligible needs’—however generous the funds available may be. This means that for many people, the additional costs of being disabled are never fully met—as not all needs are considered ‘eligible’, or a standard cost is applied to meeting them. Availability in rural areas may be very different from urban areas.

Our other points in relation to this question are covered in earlier sections.

**How will recent policy and budgetary decisions impact on the ability of the UK to meet its obligation under Article 19 to protect the right of all persons to independent living?**
Our comments above illustrate that the obligations are not being met.

**Participation and consultation**

What steps should the Government take to meet its obligations under the Disability Rights Convention to involve disabled people in policy development and decision-making, including in budget decisions such as the Comprehensive Spending Review?

See our earlier comments—particularly about transparency.

Are the current arrangements for involvement of disabled people in policy development and decision-making working?

No. See our earlier comments. To these we would add the point that adjustments need to be made to timescales, venues and methods of consultation to be inclusive in consultations. Accessible document formats are not enough.

**Monitoring the effective implementation of the convention**

What steps should Government take to ensure that disabled people’s views are taken into account when drafting their reports to the UN under the UNCRPD?

The reporters and their advisers need to be identified, together with contact details for them, and a range of methods of gathering information.

Measures need to be identified which will identify the distance yet to be travelled towards equality, progress towards them, and diminishment of quality of life where that occurs.

The report needs to be circulated in draft to a wide range of stakeholders—disabled people, organisations led by disabled people, and providers, before it is signed off and submitted.

Any report needs to spell out the commitment to equal rights to an independent life for all, and measures which do not have that as their aim should be excluded.

As part of the national monitoring mechanism, what steps should the EHRC, NIHRC and SHRC take to ensure that the Convention is implemented effectively?

Scotland currently has a national outcomes framework, and if it continues after May 2011 there is no reason why it can’t be used as a general framework within which suitable indicators are reported on.

We are responding on behalf of the organisation Sense Scotland. Views reflected in the response have been expressed to us during one-to-one meetings, group meetings or have been directed to us in correspondence over the course of time and not specifically in relation to this consultation. We work with deafblind and disabled children, adults and their families and are happy for our views to be shared publicly.

*February 2011*
About Disability Wales

Disability Wales (DW) is the national association of Disabled People’s Organisations in Wales, striving to achieve rights, equality and independence for all disabled people.

We are an independent, not for profit organisation established in 1972 which is run and controlled by disabled people and their organisations. Our wider membership includes a range of other national and local disability organisations, trades unions and public and voluntary sector bodies.

DW’s core role is to reflect the views of Disabled People’s Organisations to government with the aim of informing and influencing policy.

We work primarily with the Welsh Government but also with government bodies at local, UK and European level. DW co-ordinates the Coalition on Charging Cymru which has campaigned for more than ten years for the abolition of community care charging.

We are involved with several other All Wales networks which take a strategic approach to development of Direct Payments. DW is also represented on the Council of the Wales Alliance for Citizen Directed Support.

DW’s policy development is underpinned by the Social Model of Disability (SMD) which recognises that people are disabled more by poor design, inaccessible services and other people’s attitudes than by their impairment or health condition. We are recognised as the lead organisation in Wales in promoting the understanding, adoption and implementation of the SMD. The Welsh Assembly Government adopted the SMD in 2002.

Background to Independent Living in Wales

“Independent Living enables us as disabled people to achieve our own goals and live our own lives in the way that we choose for ourselves” (Disability Wales, 2010)

Independent Living has long been a central focus of DW’s work. In 2008 the Welsh Assembly Government awarded funding to DW for the new role of Policy Officer (Independent Living).

In April 2010 to March 2011 DW ran a campaign for “Independent Living NOW!” The campaign principles received unanimous cross-party support in a debate in the National Assembly for Wales on 12 May 2010.

The campaign called for a National Strategy on Independent Living in Wales. A petition in support of a National Strategy was signed by over 700 people and is being considered by the National Assembly’s Petitions Committee.
In March 2011 DW published a Manifesto for Independent Living ahead of the May 2011 Assembly election. The Manifesto highlights six “Calls to Action” which disabled people in Wales have prioritised as key to making Independent Living a reality in Wales.

Whilst the Welsh Government have stated that their preferred approach to making change happen on the ground is to impose specific duties on public bodies under the new Equality Act 2010, DW’s view is that the priorities highlighted in the Manifesto, and others necessary for Independent Living, will not be achieved without a National Delivery Strategy for Independent Living.

Following the ‘Yes’ vote in the recent referendum on increased powers for the Welsh Assembly, DW is exploring the potential for reinforcing a National Delivery Strategy with new legislation to secure disabled people’s right to Independent Living.

**Citizen Directed Support**

Provision of personalised, outcome focused social care and support services is vital to achieving Independent Living for many disabled people in Wales.

The Welsh Government has not followed the top down approach to personalisation, based on the In Control model, that has been adopted in England.

Instead, the Wales Alliance for Citizen Directed Support (WACDS), of which DW is a Council member, is developing a model that is more suited to the Welsh context. This is based on three core principles: choice and control, change and community.

The model supports local innovation and provision of a range of options for service users, including Direct Payments and traditional service delivery for those who want it. The model also emphasises the importance of co-operative approaches to service provision, building social capital and community development using mechanisms such as Time Banking.

The Alliance includes disabled people, representative organisations, service providers and about half of the 22 Welsh local authorities.

Publication of the Welsh Government’s paper on Sustainable Social Services (March 2011), which is broadly supportive of Citizen Centred Services, has opened up discussion on how to implement personalisation in Wales.

Although the Welsh Government continues to support development of the Direct Payments Scheme, take up has been very low. The All Wales Direct Payments Survey 2008-09 shows that of 71,377 children and adults receiving local authority funded services, only 2,440 (3.42%) received a Direct Payment.

Whilst continuing to support efforts to improve the take up of Direct Payments, and despite reservations about people being left with inadequate access to services if CDS is not implemented in line with the WACDS core principles, DW would like to see the transfer of control to disabled people extended further through implementation of CDS.
Written Evidence submitted by Disability Wales (IL 39)

**Citizen Directed Support and Independent Living**

DW supports the statement by Independent Living in Scotland (ILiS) that:

“For independent living to be a reality, disabled people need access to certain basic rights. Self Directed Support (SDS) is one of these rights. For some disabled people it is an essential link in the chain of rights needed to ensure they are free to live their life in the way they choose, to be in control of it and to do this with dignity.

To this end, controlling your own support [...] are not outcomes in themselves, but are part of a process which leads to the real outcome of Independent Living.”

(ILiS Response to Draft Self Directed Support (SDS) Bill for Scotland, March 2011).

It is vital that this linkage between personalisation and the wider Independent Living agenda is recognised in the design and implementation of new systems of outcome focused, person centered care and support in Wales.

To this end, DW maintains that CDS should not be taken forward in isolation from wider policy development but as an integral part of a National Delivery Strategy on Independent Living in Wales.

**Response to specific questions**

**The right to independent living**

*Should the right to independent living continue to form the basis for Government policy on disability in the UK?*

Yes. Independent Living remains an effective framework for understanding and tackling the barriers that disabled people face which prevent them from having the same choices, opportunities and control of their lives as non-disabled people.

*Do existing policy statements, including the Independent Living Strategy, represent a coherent policy towards the implementation of the obligations in Article 19 of the UN Disability Rights Convention? Could current policy be improved? If so, how?*

As the JCHR note, in Wales there is no comparable policy to the Independent Living Strategy that has been implemented in England. DW continue to campaign for a National Delivery Strategy on Independent Living for Disabled People in Wales.

*What steps, if any, should the coalition Government, the Scottish Government or other public agencies take to better to meet the obligations in Article 19 and to secure the right to independent living for all disabled people in the UK?*

In developing a National Delivery Strategy on Independent Living the Welsh Government will need to consider whether new legislation is needed to secure the right to Independent Living for disabled people in Wales.

*If you consider changes to policies, practices or legislation in the UK are necessary, please explain.*
The Welsh Government has stated its commitment to improving public services, but without a coherent National Delivery Strategy on Independent Living—not only in social services but across all public services, and backed up by legislation if necessary—it is likely that disabled people in Wales will continue to experience poorer quality services than people in other parts of the UK.

**Impact of funding on the right to independent living**

The decision, announced in the CSR, to remove the mobility component of Disability Living Allowance for all people living in residential care

DW is concerned that the Coalition Government are still considering this proposal, despite strong evidence that it is flawed. DW is also deeply disappointed that the Coalition Government failed to take notice of the deep criticism of DLA reform which many disabled people and organisations voiced in the consultation.

**Changes to the Independent Living Fund**

DW is deeply concerned about the impact of ILF funding coming to an end on the 2000+ current recipients in Wales, as well as on potential future beneficiaries. ILF enables many disabled people to gain and maintain a decent quality of life. The ILF, as its website states, “is dedicated to delivering financial support to disabled people and advancing standards of independent living.” Loss of this funding will be devastating for many people. For example, in one case that we are aware of, a fiercely independent young man of 28 whose ILF application was blocked by the introduction of new criteria, is forced to continue living at home with his parents. DW has raised these concerns with the Welsh Government and hopes to see the new Assembly finding ways to mitigate the effects of the ILF closure.

"The Big Society"

The impact of cuts on the third sector in Wales is already becoming evident. For instance, DW was very disappointed to learn that Denbighshire Disability Forum was forced to close in April 2011 due to a cut to its local authority funding.

**Restrictions on local authority funding, social care budgets and benefits reassessments**

DW is currently collecting case studies of people who have been affected by the “double whammy” of cuts to both public services and welfare benefits. A very bleak picture is emerging across Wales which, with the highest proportion of disabled people in the UK, is experiencing a disproportionate impact.

**Increased focus on localisation and its potential impact on care provision, and specifically, on portability of care and mobility for disabled people**

DW welcomes the Welsh Government’s commitment in Sustainable Social Services to developing portable assessments and national eligibility criteria for adult social care. It seems likely that time banking and the Welsh tradition of mutuality will be called upon to inspire new co-operative models of care and support.
What impact does funding have on the ability of the UK to secure the right to independent living protected by Article 19 of the UN Disability Rights Convention?

If consideration is given to the long term potential savings that can result from Independent Living (as evidenced in The Costs and Benefits of Independent Living, Office for Disability Issues, 2007), rather than to the initial set up costs of new services, then implementing Independent Living can make a positive contribution to the efficiencies and savings agenda.

How will recent policy and budgetary decisions impact on the ability of the UK to meet its obligation under Article 19 to protect the right of all persons to independent living?

The pace and depth of public service and welfare benefits cuts that have been implemented by the Coalition Government is a serious threat to disabled people’s right to Independent Living. In this regard, DW is supporting the disabled people’s national day of action in London on 11 May 2011 in protest against the cuts.

Participation and consultation

What steps should the Government take to meet its obligations under the Disability Rights Convention to involve disabled people in policy development and decision-making, including in budget decisions such as the Comprehensive Spending Review?

The Social Services Improvement Agency’s ‘Getting Engaged’ project (http://ow.ly/4vaSL) identified a substantial number of participation and involvement notable practice examples in Wales.

However, DW regularly represents disabled people in a wide range of Welsh Government stakeholder groups and, generally speaking, at local authority level there is a woeful lack of meaningful engagement with disabled people and Disabled People’s Organisations (DPOs).

The recently introduced Wales Specific Duties under the Equality Act 2010 require public bodies to engage with citizens on a pan-equality basis. DW wish to see the Welsh Government making a strong commitment to developing and supporting local and national DPOs to enable them to represent disabled people’s views effectively and contribute productively to policy development.

Are the current arrangements for involvement of disabled people in policy development and decision-making working?

The Disability Equality Duty (DED) required public bodies to engage with disabled people. Despite inconsistent implementation across Wales, in some areas significant progress was achieved. Although the Wales Specific Duties under the Equality Act 2010 continue to require engagement with people who have “protected characteristics”, DW is concerned that the ground gained by disabled people under the DED will be lost.

National Principles for Public Engagement in Wales have been developed: http://ow.ly/4xw9w. Again, there needs to be a much stronger commitment to enabling disabled people’s involvement in policy development, decision making and budget decisions before any significant improvement can be achieved. This commitment would need to
include provision of information in accessible formats and accessible meetings for all impairment groups.

**Monitoring the effective implementation of the Convention**

*What steps should Government take to ensure that disabled people’s views are taken into account when drafting their reports to the UN under the UNCRPD?*

The Government should use the National Principles for Public Engagement, referred to above, and proactively involve DPOs in gathering evidence that reflects disabled people’s views and experience.

*As part of the national monitoring mechanism, what steps should the EHRC, NIHRC and SHRC take to ensure that the Convention is implemented effectively?*

It is essential that the national reports present an objective and independent perspective, are widely publicised and are made freely available.

Consideration should be given to introducing new legislation to secure disabled people’s right to Independent Living.

DW would also like to draw the Committee’s attention to the sections on The Promotion of Independent Living, Choice and Control, and Cost Effectiveness (pp135-143) in *Community Care and the Law, Fourth Edition* (Clements L, and Thompson P, Legal Action Group 2007).

27 April 2011
Disability Wales (DW) submitted written evidence to the Joint Committee on Human Rights Inquiry into Implementation of the Right to Independent Living, and also gave oral evidence to the Committee on 24 May 2011.

In April 2010 DW had launched a campaign called Independent Living NOW! This highlighted the lack of a National Strategy on Independent Living in Wales. We raised a petition in support of a strategy on the National Assembly’s website and also collected signatures on paper. Over 700 people signed the petition but the Welsh Government’s initial response was to suggest that Independent Living could be achieved through the Public Sector Equality Duties under the Equality Act 2010.

Whilst recognising that the Equality Duties can make an important contribution to implementation of Independent Living at a local level, DW maintained that this should be reinforced by a cross departmental strategy. DW used the Petitions Committee process to make this case. The JCHR’s inquiry undoubtedly strengthened our position.

On 11 October 2011 Jane Hutt AM, Minister for Finance and Leader of the House (whose portfolio includes Equalities) gave oral evidence to the Petitions Committee. The Minister took this opportunity to announce that in response to DW’s petition, the Welsh Government will develop a Framework for Action on Independent Living, which she will champion. The Minister announced this publically at DW’s AGM on 19 October 2011.

The Welsh Government moved quickly to appoint a senior civil servant, Carys Evans, to lead an Independent Living project. DW have subsequently had several meetings with Ms Evans and on 1 December 2011 facilitated a Round Table meeting of national disability organisations on behalf of the Government.

This resulted in broad support for the six “Calls to Action” identified in DW’s Manifesto for Independent Living. Working groups are now being established to “achieve a shared understanding, to note current progress and constraints and identify opportunities for further progress”. The first of these working group meetings are scheduled to take place in week commencing 23 January 2012. The Welsh Government will publish an ‘Independent Living Project’ bulletin early in the new year.

The Framework for Action on Independent Living is due to be published in summer 2012. It will “set out the action to be taken to promote the rights of disabled people to live independently and exercise the same choices as other citizens. It will contribute to the Welsh Government’s Strategic Equality Plan and support its efforts to mitigate the effects of the UK Government’s welfare reform plans.”

DW are delighted that the Welsh Government have responded positively to our case for a strategic approach to implementation of the right to Independent Living.

It seems likely that the opportunity to present evidence to the JCHR Inquiry, which enabled us to highlight the situation in Wales in comparison to the rest of the UK, had a significant influence on the Welsh Government’s decision to develop a Framework for Action on Independent Living.
Additional Written Evidence submitted by Disability Wales (IL 39A)
Overview and context

“My Motability car has changed my life. When my mum and other relatives now see me they can see how happy I am. I have freedom because of my car to do what other people can do. Before, I was not happy; I would sit at home watching other people in the home going in and out as they liked. I could only dream about that kind of freedom. Please don’t take my car away from me.” Steven Colley, care home resident, Essex

Executive summary

We welcome the government’s commitment to promoting social justice for disabled people and the focus that has been given to increasing independence, participation and employment opportunities.

However, we are gravely concerned that the removal of the mobility component of Disability Living Allowance (DLA) for those living in residential care will undermine the realisation of these ambitions. It may also greatly reduce the independence, autonomy and opportunities of this group of people.

The government has proposed the change primarily based on an assumption of ‘double funding’, with all the needs of the individual provided for by their local-authority-funded package of support. If this was the case, the assumption that these needs should be met by the provider would be a perfectly reasonable one. However, this is simply wrong.

If the government goes ahead with this proposal, it will have a significant and adverse impact on the everyday life of those affected. The possible outcome can only be one of two things: people will be forced to remain indoors and have a diminished quality of life; or social services will be forced to make up the difference in funding. Given the current climate, we do not expect local authorities to be able to do this.

The government’s proposal needs urgent reconsideration:

- The removal of the DLA mobility component from people living in residential care is based on an assumption of ‘double funding’. However, evidence shows that local authorities are not currently meeting mobility costs. It also makes clear that rather than removing ‘an overlap of public funds’ as the government has stated, this measure will simply transfer costs to already-stretched local authorities or will leave people without the vital support that they need.

- Many disabled adults living in residential care have all their income taken to pay for their care, and are left with just the £22 per week Personal Expenses Allowance (PEA). This is not intended to cover additional mobility costs. It is intended to cover personal costs such as clothes, toiletries and phone bills. Without the DLA mobility component, the PEA is not enough to cover additional mobility costs and people will be left without the money to meet basic mobility needs.
The resulting savings of £160 million are relatively small in contrast to the total of £81 billion in spending cuts the government plans to make by 2014/15. However, the impact on the 80,000 disabled people to be affected will be massive, with many left unable to afford to leave their home and denied the independence most people take for granted.

Background to this report

In the Comprehensive Spending Review on 20 October 2010 the Chancellor of the Exchequer announced the government’s proposal to remove the mobility component of DLA for people who live in local-authority-funded residential care. It has been estimated that 80,000 people who live in care homes will be affected by the move.

Following the government’s proposal to remove the mobility component of DLA for people who live in residential care, a number of organisations have expressed serious concerns about the impact of this on disabled adults and children.

Since the proposal was announced, a consortium of disability organisations has worked to gather evidence and information about the assumption of ‘double funding’ as justification for the proposed changes. The consortium has also spoken to individuals about the impact that withdrawing the DLA mobility component would have on their lives. This has particularly focused on adults living in residential care, although the removal of DLA mobility from children and young people in residential schools and colleges is also considered in this paper.

We believe that the argument at the heart of the government’s proposal based around the need to ‘remove an overlap of public funds’ is wrong. This is supported by the information collected and presented in this report.

Rather than removing ‘an overlap of public funds’ as the government has stated, this measure will simply transfer costs to already-stretched local authorities or will leave people without the vital support that they need.

This document provides a summary of information and evidence from:

- a survey of residential care home residents, including how individuals spend their mobility component of DLA and how this enables independence and participation
- a survey of 22 national providers of social care services that are members of the Voluntary Organisations Disability Group (VODG)
- knowledge and experience of individual organisations who provide residential care
  - ‘desk research’ and discussions by individual organisations with care home providers and representatives from local government.

About DLA

DLA is a non-contributory, non-means-tested and tax-free benefit that helps meet the extra costs associated with disability. It has two components: the care component and the mobility component. It is described by the Department for Work and Pensions as providing:

“[...] a financial contribution towards the generality of extra costs experienced by [...] disabled people as a direct result of their disabilities [...] [DLA was] introduced as a
policy response to the evidence that disabled people and their families suffered greater disadvantage and poverty than their non-disabled peers.”

The mobility component of DLA

The mobility component of DLA provides support to people who need help getting around. There are two rates to the mobility component of DLA—the lower rate at £18.95 a week and the higher rate at £49.85 a week.

The higher rate is relevant to people who have physical and sensory difficulties in walking. Some people with a severe learning disability are able to get the higher rate of the mobility component of DLA, although there are strict conditions. The lower rate of mobility applies to those who can walk but who need guidance or supervision from someone else to do so. This applies to people with physical disabilities as well as people with a learning disability.

The mobility component helps people to pay for things like accessible transport, or mobility aids such as an electric wheelchair. It makes a vital difference in ensuring that people can leave their home independently and participate in everyday activities that non-disabled people take for granted, like meeting friends, attending a leisure centre or getting to college. In some care homes there are schemes where people’s DLA mobility component is pooled and used to buy or lease a car which care staff can then use to take them out and about.

For disabled children and young people in school or college, DLA mobility allows them to keep active during the school holidays and enables family members to visit during term time and take them out on weekend day trips. Family carers often use the DLA mobility component to pay for adaptations to vehicles. This enables disabled children and young people to maintain contact with friends and family, and participate in leisure and other community activities.

The government’s justification for the proposal

1. What are the ‘assessed needs’ of the individual?

“Local authority contracts with care homes should cover services to meet all a resident’s assessed needs, including any assessed mobility needs, so an individual’s care support and mobility needs should be met by residential care providers from social care funding. This measure will remove an overlap of public funds while ensuring that resources continue to be targeted at disabled people with the greatest needs”.

Maria Miller MP, Minister for Disabled People, House of Commons (written answer, 2 November 2010)

The process

1. The community care assessment identifies an individual’s assessed needs.

2. The assessed needs are then matched against the different eligibility bands (critical, substantial, moderate, low) in line with Fair Access to Care Services (FACS) criteria.

149 Attendance Allowance, Disability Living Allowance and Carer’s Allowance, Retrospective equality impact assessment, September 2010
3. Based on the local authority’s policy around which bands are regarded as eligible for services, it is determined which needs will be met by the local authority. \[150\]

**What happens in practice**

It is the community care assessment that identifies an individual’s assessed needs. However, local authority services are designed to meet only needs that fall within a set eligibility framework. This identifies four bands of need: low, moderate, substantial and critical, and the majority of councils will only fund substantial and critical needs. Therefore, an individual may be eligible for DLA care and/or the mobility component but not be eligible for support according to local authority criteria.

Mobility needs tend only to be factored into care packages to meet specific needs identified in the community care assessment, such as going to a day centre. Local authorities do not tend to factor in the costs of individuals’ personal mobility or transport costs associated with visiting friends and family, going shopping or accessing local community and leisure facilities. The DLA mobility component enables disabled people to retain their independence in a way that local authority funding does not. Through meeting additional mobility costs it places control in the hands of the individual.

**The fundamental issue**

- In its interpretation of assessed need, a local authority does not usually include activities like going to the cinema, visiting a leisure facility or meeting with friends and family.

- We know from the evidence that often when funding for transport is included within an individual’s care package, this is only to cover the costs of travel that are directly related to their specific care needs (for example regular attendance at a day centre).

- The key question is about whether or not an individual’s assessed needs will meet the FACS criteria. While an individual’s personal care needs may be regarded as critical, this may not apply to an individual’s mobility or transport needs.

- We know that local authorities will only fund needs that are critical and substantial. The overwhelming majority of those with moderate and low needs are not provided for. DLA mobility is used to meet some of these needs that are not met by local authorities.

**Evidence: the community care assessment**

Comment from the mother of a young lady with profound and multiple learning disabilities living in residential care:

a) “There is nothing specific in Louise’s* care plan, but I distinctly remember from discussions with the social worker that the local authority was to take into account

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150 In 2007/08, 74% of local authorities set eligibility criteria at ‘substantial’ or ‘critical’ only—see Cutting the Cake Fairly: CSCI review of eligibility criteria for social care (October 2008)
Written Evidence submitted by Mencap and Leonard Cheshire Disability (IL 40)

Louise’s DLA mobility component when agreeing the fees with the care home provider. Louise contributes some of her DLA mobility to the home in order for them to support her to access the community and, in addition to this, we are able to use some of her mobility component to help us with transport costs associated with her disability when we take Louise on holiday. Being able to access the community is a core part of Louise’s care plan.”

*Name changed

The following is taken from an individual’s community care assessment form:

b) [Under finances section]: “Out of my DLA [mobility], I pay for my transport when I go out and/or when I access the community.”

**The care home provider perspective**

“In our experience, when a vulnerable adult is being assessed by a local authority for a care package, all of the benefits to which they are entitled are taken into account.”

RCHL

2. **What is the contractual position?**

“Local authorities’ contracts with care homes will cover services to meet a resident’s assessed needs. These will cover activities of daily living which may include providing access to doctors, dentists and local services such as libraries and banks. Local authorities should also take into account the resident’s emotional and social needs as part of the assessment. Maria Miller MP, Minister for Disabled People, House of Commons (written answer, 16 November 2010)

**The process**

1. The formal arrangements between a local authority and care home may or may not specifically address the transport needs of the individual.

2. Contracts tend to be costed against the eligible needs identified by the local authority through the community care assessment.

3. In many cases, when an individual is being assessed by a local authority for a care package all of the benefits to which they are entitled are taken into account.

**What happens in practice**

Whatever the formal arrangement, in practice, the provision of 24-hour residential care has by custom and practice covered personal care, food and limited activities in the home. It has not generally covered activities outside the home apart from day services. The former have only been provided as extras making use of the individual’s limited money, including the DLA mobility component.

**The fundamental issue**

- The arrangements between a local authority and care home may or may not specifically address the mobility needs of the individual. Contracts will tend to be
costed against the needs identified by the local authority through the community care assessment.

- Therefore unless an individual is assessed by the local authority as having mobility needs and these needs meet their eligibility criteria, providers receive no funding to meet these needs.

- For the most part, as noted above, this is very unlikely to include mobility costs above and beyond the essential needs of the individual as determined by the community care assessment and related eligibility criteria.

- With increased pressures on local government, many authorities have had to scrutinise their service specifications to ensure value for money, seeking to identify what is non-essential expenditure.

**Evidence: extracts from service specifications provided by care homes**

a) The following is included within an existing Adult Services Residential Care Contract:

   “Activities for which contractor may charge resident (which are in addition to the services provided under the contract and not included in the daily charge):

   - Holidays
   - **Contribution towards transport (from mobility allowance)**”

   The local authority contract clearly states that the provider is entitled to charge the resident a contribution towards transport from their mobility allowance. **The local authority is therefore not providing for this need.**

b) The following is taken from a *Framework Agreement for the Provision of Long and Short Term Residential Personal Care*:

   “The Provider may charge the Service User for any facility not included in the Services such as the provision of hairdressing, chiropody, dry cleaning services or outings (“Extras”) provided that these have been agreed with the Service User.

   “The Service User shall be liable for any charge made for Extras and the Provider shall be responsible for recovering any charges direct from the Service User. **The Purchaser shall have no liability for payment or recovery of such charges.**”

   **The contract states that the provider may charge for any provision, including ‘outings’, that is the responsibility of the service user and not the (local authority) purchaser.**

c) The following is taken from an *Agreement for Provision of Accommodation with Personal or Nursing Care*:

   “The Schedule 2 shall specify any arrangements by the Council for the Resident to attend specialist facilities outside the Home […] Where a resident wishes to engage in activities in addition to those specified […] the Provider shall not be responsible for meeting any resulting additional costs.
“A Resident can be asked to contribute up to a maximum contribution of 50% of his/her Mobility Allowance towards the cost of communal transport arranged by the Provider […] A Resident who chooses not to contribute […] can be excluded from the use of communal transport.

The individual would, in such circumstances, be expected to pay for any transport direct e.g. by using taxis or by being charged a fee per journey for the use of communal transport.”

The local authority provides for one aspect of the transport needs of the individual where this is to attend specialist facilities outside the home. **Activities above and beyond this are the responsibility of the service user, to be funded by their mobility allowance** whether this is paid for directly or as a contribution towards the cost of communal transport arranged by the provider.

**The care home provider perspective**

“Even where the local authority has costed transport into a care package, which is not the case for many of the people who use our services, this is for specific identified care needs, for example, regular attendance at a day service. Individual care packages do not include funding for activities like accessing volunteering opportunities, going shopping or to the hairdressers, going to the cinema or out with friends or visiting family.” **Scope**

### 3. Is the proposal aligning the rules for people who are placed in residential care by the NHS?

“The arrangements are further confused by different funding streams […] For example, NHS-funded individuals in residential care do not receive the DLA mobility component, while those funded by local authorities do. If we want to be fair—not only to disabled people, but to taxpayers—we have to tackle the gaps and overlaps and ensure that everyone gets access to the mobility they need”. **Maria Miller MP, Minister for Disabled People, Westminster Hall (debate, 30 November 2010)**

“This measure will end the anomaly whereby two state-funded residents with similar needs who are placed in the same care home can be treated differently according to whether they are funded through the NHS or local authority”. **Maria Miller MP, Minister for Disabled People, in response to representations made by MPs**

**The process**

The above statements, made by the Minister for Disabled People, are not correct and the situation is far more complicated than implied:

1. Where an individual is funded by NHS continuing care, it is correct that they will not be eligible for DLA mobility. This is because they are regarded as patients under related guidance and regulations, i.e. the person is seen as a patient where the NHS is providing nursing services, and these nursing needs are more than incidental and ancillary to other care needs. In these cases, the NHS is providing a round-the-clock, all-encompassing package of care and support.
2. Where someone is part-funded by the NHS and the local authority (whether or not the service is commissioned by the NHS, the local authority or jointly), they are not regarded as a patient and are therefore eligible for the DLA mobility component.

3. There are fundamental differences in the situation of those individuals funded by the NHS and those funded by the local authority. Individuals whose placement is funded by NHS continuing care are not asked to contribute to the cost of their support. Those who are local authority funded are subject to financial assessment and required to make a contribution towards the cost of care. Given the differences between these two situations, it is simply not the case that the removal of DLA mobility from local authority-funded residents will end an anomaly and align the rules with those in NHS funded care.

What happens in practice

In residential care homes, it is unusual for disabled people to receive NHS continuing care and therefore not receive the DLA mobility component. People in residential care are not patients but residents. If some nursing care is provided, but this is ancillary to the main purposes of the home, the individual remains eligible for the DLA mobility component.

There are some homes that are dual registered (residential and nursing homes) where there could be a small number of people who are fully funded by the NHS. Therefore there could be a minority of cases where in the same care home some residents are getting the mobility component of DLA and some are not.

The fundamental issue

- From discussions with providers, we know that residents who are part NHS funded are still receiving the mobility component of DLA.

- The assumption that the measure will end an anomaly ‘whereby two state-funded residents with similar needs who are placed in the same care home can be treated differently according to whether they are funded through the NHS or local authority’ is inaccurate in the vast majority of cases, as noted above.

- Therefore, to try to tackle this limited anomaly, where a very small minority are not getting the mobility component of DLA, by removing it for the majority, is wrong. A fairer way would be to ensure that all residents are receiving the mobility component of DLA on the basis that they are not hospital patients.

4. What is the impact on disabled children in residential schools?

“The spending review announced that the mobility component of DLA would be removed from adults in residential care and children in residential special schools”.
Maria Miller MP, Minister for Disabled People, House of Commons (written answer, 24 November 2010)

Similarly, the justification given by government for the removal of the mobility component of DLA from children and young people in residential special schools or colleges is that of double funding—i.e transport is provided by the facility (school or college) themselves. However the evidence, again, suggests that this is not the case. Even where transport is
provided by the education provider, it is often restricted to provision at the start and end of term. No extra provision is factored in for visits at weekends or for the child when they are at home during the holidays.

The evidence: the education provider perspective

“The college currently requests a contribution towards the cost of transport. This payment contributes towards the cost of transport for activities outside of the curriculum. This includes, but is not limited to, visiting leisure facilities (for example, swimming pool and cinema), outings during the evenings and weekends (such as a trip to the coast), going shopping for personal items and accessing local groups such as youth clubs. The alternative would be to use public transport. This would be difficult as the college is not on a bus route […] The activities carried out in the students’ free time are chosen by the students and if we were unable to request a contribution to the cost of transport from the DLA mobility component, our students’ choices would be severely restricted.” Specialist residential college

Survey of care home providers

The following provides a summary of evidence from 22 national providers of social care services that are members of the Voluntary Organisations Disability Group (VODG). The organisations surveyed for this briefing provide residential care services to people with a range of different impairments, many of whom have multiple and complex support needs. The following key points were raised:

- Half of the social care providers receive no contribution towards the costs of transport as part of service users’ social care packages. Of those that do receive funding for transport needs from local authorities, fee levels only cover travel costs deemed necessary for meeting people’s assessed care needs.

- None of the social care providers surveyed receive a state contribution towards the costs of personal transport, such as visiting family, accessing work, volunteering or education, and participating in leisure activities or community activities.

- Social care providers face considerable difficulty in getting local authorities to contribute towards transport costs and given the current financial pressures they do not believe it will be possible to force local authorities to fund the additional costs of personal transport, especially if these are not considered part of their statutory obligations.

Comments from care home providers

“In all of our registered homes the DLA mobility component is a significant part of the budget, designed to cover the cost of providing necessary vehicles and transport for service users. Inclusion of this item within core fees has been under severe attack from commissioners now for some years”. Elizabeth Fitzroy Support

“We make provision within our cost base for that proportion of the vehicle costs necessarily incurred in delivery of people’s basic residential care service. The fees do not, therefore, include any contribution to the costs of residents’ personal, social and
leisure travel. Any personal or leisure use beyond these essentials has to be funded by people’s DLA mobility”. The Brandon Trust

“We support 941 people with a learning disability in residential care homes. Most of them are in receipt of disability mobility. In most cases, the local authority funders make no provision in the care contracts for the areas the mobility component is intended to cover”. Mencap

Results from the survey of residential care home users

Since the launch in mid-November, we have had around 100 responses to the survey to date. The survey remains open. All of the quotations in this section are from survey respondents.

How do people spend their mobility component of DLA?

We asked people to tell us (a) how they spend their mobility component of DLA and (b) what this allows them to do.

100% of respondents used their DLA mobility component to support them to get out and about. This included using it on taxis where they could not travel independently, on accessible transport and on mobility aids.

People either spent their DLA mobility component themselves or had an arrangement with their care home in place to support them to do this.

Over 50% of respondents told us that they had an arrangement with their care home whereby some or all of their mobility component was given directly to their care homes. In these cases, just over 40% of respondents said that the care home used the money towards a Motability car and 21% said the money contributed towards petrol costs to care staff to give them lifts.

“A mini-bus. I give them my mobility allowance and they pay for any transport I need. I like to go out a lot during the day and in the evenings, and I go on holiday”.

For those people who spent their DLA mobility component allowance themselves, the following top four ways were identified:

- Petrol money to care staff who give me lifts
- Money for taxis
- Petrol money to friends and family to give me lifts
- Motability car

What are people able to do as a result of their mobility component of DLA?

Respondents described a range of activities that enabled them to take part in community life. These included:

151 The online survey was hosted by Mencap, Scope and Leonard Cheshire Disability.
going to the leisure centre
• going to a music or art group
• going to the cinema or theatre
• going out with friends
• attending regular medical appointments
• visiting family and friends
• attending a college course
• volunteering.

“I go to big family gatherings like birthdays and weddings, and for a holiday or short break”.

“I go to London to see a show on the train with friends from the care home”.

**What impact will the removal of the mobility component of DLA have?**

Of those who responded to this question, over 80% felt that they would see much less of their family and friends. 73% said that they would lose their independence.

Many respondents described great anxiety about the possibility of losing this money, as the following quotations demonstrate:

I won’t be able to go on holiday. I will only be able to visit my parents when other family can collect me. My parents are very frail and I use a taxi to visit them sometimes. I won’t be able to go out as I won’t be able to afford the taxi or petrol money.

Without it, I would be severely depressed like I used to be [...] My independence is my most prized possession.

“My independence is very important to me and a very important part of my care. Less independence would affect my confidence”.

“I would be totally isolated and not be able to get out, to be part of my community and enjoy the things that I like doing”.

“If I and the other residents don’t get this money, there will be no transport for me and I will be stuck in my room all day watching TV”.

“There would obviously be a reduction in [my daughter’s] community presence and participation”.

**What would people tell the government about how they feel?**

We asked people to tell us what they would say to the government about they feel about these cuts.

“I look forward to going out—it keeps my spirits up. Otherwise I get very low”.

“I would urge them to rethink their decision and [tell them] that I feel betrayed”.
“The government needs to listen to the people [...] I would ask you to come and see us and see what it is like to live the life we have and then say how it feels to have their independence taken away and not to have any social interaction”.

“Please look at other options and ways as this would be very dramatic on our lives and quality of life”.

“I will tell them that I am very upset as they have taken away my small means of Independence”.

**Case studies**

**David**

David lives in a residential care home. He has been assessed for the higher rate of DLA and he receives the mobility component. His DLA package is divided between expenses to the provider for transport, and petrol money to his parents to take him home at weekends or on short holidays.

The home provides transport to enable David to travel to a gym, a dance class and a highly successful Riding for the Disabled centre. Psychologists and other medical professionals have emphasised repeatedly the critical importance of providing outlets for David's energy because he thrives with an active lifestyle.

David’s parents are worried about the possible axing of the mobility allowance and the effect this could have on his wellbeing if his opportunities for physical activity and external stimuli are restricted. They are particularly worried that this will culminate in aggression and self-harm, which he is prone to if bored and frustrated.

They know that if the situation arises, David will begin to exhibit what is labelled as challenging behaviour, which threatens to negate all the positive things that happen when he is enabled to get out and about.

*Name has been changed.*

**Steven**

I have been told that I might lose my Motability car and I am very worried. So, I wanted to tell you what it means to me, how it has changed my life and how it has given me more freedom to access the community locally and beyond.

I live in a home with six other people who have daily routines of going out into the community with the support of a staff member. They can all access the community by buses or walk, but I cannot.

I cannot use one of my arms and this makes my posture unsteady on one side. I cannot walk very far. I cannot use buses because I cannot stand and I am not good with large crowds pushing together in a small space as a bus would have. I may get agitated because of the confined space and lots of people pushing together on a bus.

I also have to wear an incontinence pad so travelling by bus or even in a taxi would present a problem for me and my dignity. With the amount of time it takes travelling and waiting for
Written Evidence submitted by Mencap and Leonard Cheshire Disability (IL 40)

buses or a taxi, I would be at risk. I get tired quickly when walking too far due to my disability posture. It would make me very unhappy. I also sometimes need help with my incontinence while out in the community.

When I got my Motability car it opened the door to a new world for me. I could go out when I like—to do my shopping, go to shows, watch films at the cinema and go and watch my local football team. I can now attend my Friday social club and this year I was able to book a holiday in Yarmouth for a week, and while I was on holiday I visited different places. I couldn’t have done this without my car.

My car has changed my life. When my mum and other relatives now see me they can see how happy I am. I have freedom because of my mobility car to do what other people can do. Before I was not happy; I would sit at home watching other people in the home going in and out as they liked. I could only dream about that kind of freedom. Please don’t take my car away from me.

*Steven Colley, care home resident, Essex*

**Impact on the rights of disabled people**

**Rights of disabled adults**

Article 20 (Personal Mobility) of the *UN Convention on the Rights of Persons with Disabilities* commits signatories to:

“[… ] take effective measures to ensure personal mobility with the greatest possible independence for persons with disabilities, including by:

a) facilitating the personal mobility of persons with disabilities in the manner and at the time of their choice, and at affordable cost

b) facilitating access by persons with disabilities to quality mobility aids, devices, assistive technologies and forms of live assistance and intermediaries, including by making them available at affordable cost.”

**Removing the DLA mobility component from disabled people living in residential care jeopardises this right.**

**Rights of disabled children**

The withdrawal of the DLA mobility component represents a significant erosion of the rights of disabled children. The *UN Convention on the Rights of the Child* Article 31:

“1. States Parties recognize the right of the child to rest and leisure, to engage in play and recreational activities appropriate to the age of the child and to participate freely in cultural life and the arts.

“2. States Parties shall respect and promote the right of the child to participate fully in cultural and artistic life and shall encourage the provision of appropriate and equal opportunities for cultural, artistic, recreational and leisure activity.”
However, if the mobility component is withdrawn from children in residential schools they may be denied these rights.

**Disability Equality Duty**

The Disability Discrimination Act 1995 (as amended in 2005) requires public authorities (including the government) to have due regard for the need to:

— promote equality of opportunity between disabled people and other people
— eliminate discrimination that is unlawful under the Disability Discrimination Act
— eliminate harassment of disabled people that is related to their disability
— promote positive attitudes towards disabled people
— encourage participation by disabled people in public life
— take steps to take account of disabled people’s disabilities, even if this requires more favourable treatment than others.

The decision to remove DLA mobility will reduce equality of opportunity and restrict participation in family, social and cultural life. Furthermore, the decision comes without measures to mitigate the fact that the government is more likely to be in breach of the Disability Equality Duty.

**Conclusion**

The assumption behind the proposal to remove the mobility component of DLA from those living in residential care is wrong.

It is based on the belief that people living in residential care situations have all of their needs provided for by the package of support bought by the local authority (in a similar way to hospital patients) and do not therefore need any additional money other than a Personal Expense Allowance to cover things like buying toiletries.

As the evidence presented in this report demonstrates, this is incorrect. The reality is that an individual’s package of support does not provide for all aspects of an individual’s life. It only funds basic care.

As a result, removing the mobility component of DLA will significantly restrict the ability of those in residential care to play an active role in their local community, be independent and maintain relationships with family and friends.

Activities that will be threatened by the removal of the DLA Mobility component include access to work and volunteering, access to friends and family, the ability to maintain relationships with a partner, access to community activities, access to healthcare services and access to leisure activities such as swimming, shopping and going to the cinema. Limiting people’s ability to do these things goes against the concepts of choice and independence, and goes against the principles of the government’s personalisation agenda.
The implications of this change, even for people who currently receive some local authority funding for mobility costs, are extremely significant and in the current climate we do not expect local authorities to step in to cover these additional costs. In the long term, the impact on individuals is likely to result in higher costs to the state, due to consequent effects on disabled people’s wellbeing and health, and the increased likelihood of a crisis.

Implementing this proposal will mean one of two things for care home residents. Those affected will either have a diminished quality of life with restricted options available to them, or social services will be forced to make up the difference in funding. In the current climate this is unrealistic. Ultimately, the impact on disabled people will be devastating.

**We therefore strongly urge the government to reverse this decision in light of the overwhelming evidence and strength of feeling regarding this measure.**

20 April 2011

Written Evidence submitted by the Mental Health Foundation (IL 41)

1. The Mental Health Foundation is the leading UK charity working in mental health and learning disabilities, bringing together research, service development and policy. It incorporates the Foundation for People with Learning Disabilities (FPLD).

2. We are very pleased that the Joint Committee is conducting this inquiry, as many disabled people and their families are very worried about the cumulative impact on them of a range of Government and local policies and actions.

The right to independent living

3. We supported the Independent Living Strategy when it was published in 2008 and strongly support the view that the right to independent living should continue to form the basis for Government policy in the UK.

4. However, we do have some continuing concerns about whether policy specific to different groups is sufficiently joined up. For example, there are separate strategies for people with learning disabilities, people on the autistic spectrum, people with dementia and for mental health (including people with mental health problems). The recent Green Paper for England “Support and aspiration: A new approach to special educational needs and disability” contains many welcome proposals for improving support for disabled children; again, this needs to join up clearly with a coherent policy for all disabled adults. Whilst specific attention is undoubtedly required to each of these groups to ensure that the particular barriers they face are tackled, it can sometimes feel as though different groups are being set up to compete with each other, instead of all disabled people feeling part of a common movement. We accept that some of this arises from divisions within the disability movement itself, but it would be helpful if Government policy set a clear direction for all disabled people, within which specific needs are clearly addressed. Ideally we would like to see a common position on this across all four countries of the UK, co-ordinated by the national focal point in Government (the Office for Disability Issues), so that disabled people are able to move freely across boundaries, confident that their right to independent living will be respected and supported wherever they choose to live in the UK. However, we
recognise that each of the four countries has its own health and social care competencies, so that aligning policy and practice across the UK on how the Convention obligations are delivered may not be practical.

5. Further, we remain concerned that policy in respect of disabled people eligible for NHS Continuing Healthcare (CHC) funding is not securely linked to the right to independent living. We are pleased that the CHC good practice guidance for England does emphasise the importance of personalised support, but we are aware that practice in the field remains variable and we would like to see policy in this area strengthened in all four countries with an explicit link to the Convention.

Mental capacity

6. Our research and development work over the last few years on issues of mental capacity convinces us that the Mental Capacity Act is a vital element of policy in relation to independent living. Good understanding of the principles and their application to practice is required throughout the range of services that are needed to make a reality of independent living, especially in housing, health and social care, and financial services such as banking and insurance. Whilst we know that many organisations have offered their staff training on implementation of the Mental Capacity Act, we are concerned that the quality of practice remains variable. We have evidence of this from the data from an on-line tool we developed for health and social care staff to audit their assessments of mental capacity; we also hear anecdotally (particularly from family carers of people with learning disabilities) about continuing concerns relating to capacity and consent in health care. The Care Quality Commission’s recent report, „The operation of the Deprivation of Liberty Safeguards in England, 2009/10”, showed that “In some care homes and hospitals a lack of awareness and training among managers and staff was evident. Some councils and PCTs had not progressed as well as others in setting up the mechanisms needed to deal properly with applications.”

7. Our Dementia Choices project was set up to explore self-directed support for people living with dementia, their families and friends, and staff who support them. Self-directed support, including direct payments and individual budgets, enables people living with dementia (and their carers) to live as independently as possible and to have more freedom and choice about the social care services they receive. Throughout the project we found that there was a very low level of awareness and understanding of self-directed support among people living with dementia and their family carers. We also found that a wide variety of social care workers at a local level needed practical information about how self-directed support can work for people living with dementia. If self-directed support is going to help people living with dementia to live independently, then it is important that all practitioners (not just those in local social care services) understand self-directed support and can discuss it confidently with people living with dementia and their family carers.

8. Under new powers introduced in the Mental Health Act 2007, some mental health patients in England and Wales can be discharged from hospital under a Community Treatment Order, compelling them to continue to take medication while living in the community, and also adding other restrictions as considered appropriate. This Order can be imposed even if the patient has the capacity to make their own decisions about their treatment. This is discriminatory relative to patients with physical health problems, who may choose not to take medication even if that decision could have a serious health consequence. We would like to see a change to the legislation so that only patients whose ability to make decisions about the provision of medical treatment is significantly impaired
can be made subject to an Order. This would put England and Wales in line with Scotland, which has such a safeguard in its own mental health legislation.

**Impact of funding on the right to independent living**

9. We welcome the Joint Committee’s focus on recent developments that may affect implementation of the right to independent living.

**Disability Living Allowance (DLA)**

10. We opposed the Government’s view that the mobility component of DLA should be removed from people in residential care and were pleased to hear in late March that this issue would now be reconsidered as part of the overall review of DLA. Considerable distress was caused to disabled people and their families before that announcement was made.

11. In principle we welcome the concept of a “Personal Independence Payment” (PIP) to replace DLA. This should be based on a clear statement about the contribution it is expected to make to quality of life, so that phrases such as “necessary to everyday life” are not open to widely differing interpretations. We would like to see much greater clarity about the complementary roles of the PIP and social care, which should include the specific issue of responsibility for funding mobility support for people in residential care.

**Independent Living Funds (ILF)**

12. We appreciate that the Independent Living Funds have been administered by a non-governmental body that has had to manage within its allocated budget, although we were very concerned at the way the budget pressures were managed. We also appreciate that the Funds grew in a piecemeal fashion in response to past pressure from the disability movement and thus did not form part of a truly coherent policy response to the right to independent living. What they did demonstrate was the value that disabled people and their families attach to the freedom to organise their own support, using a clear allocation of funding. Thus the ILF laid the ground for personal budgets and personal health budgets. However, ILF money could be used for a wider range of support for independent living. We think that the option of a cash benefit for disabled people, possibly in the form of a disability pension focused on support for independent living and subsuming the current artificially divided range of benefits and service entitlement, is worthy of serious consideration.

**“Big Society”**

13. Many of the concepts at the heart of the “big society” debate resonate strongly with values espoused by the disability movement: citizenship, empowerment, self-help, connection with your local community. However, there are three interlinked concerns that we hear from disabled people and their families:

- a perception that “big society” rhetoric is no more than a cynical cover-up for massive cuts in public spending, with family carers in particular feeling that it means increased reliance on them

- a concern that the concept could be interpreted as implying a return to a view of disabled people as passive objects of charity
• an acute anxiety that profoundly disabled people and their families may be increasingly expected to rely on a patchwork of volunteer support rather than being able to expect reliable, publicly funded services.

14. Our experience of supporting personalisation in some areas over a period of several years convinces us that there is much more that can be done to support disabled people and their families to take control of their own planning and support. For example, we established “Get a Plan” in Cornwall to build capacity amongst people with learning disabilities, their families and supporters for person centred planning and circles of support. We do this by offering training, mentoring and supports for people in Cornwall around person centred planning and personalisation. This approach is proving both popular and successful in helping people to plan and put plans into action. However, public sector funding continues to be required both for the “Get a Plan” service and for the individuals concerned.

15. Our research on “community connecting” over the past five years has shown that skilled and time-limited interventions by paid connectors can help by marrying people’s skills, talents and aspirations to opportunities in their communities. Such connecting fills a gap that often exists between person centred planning and the achievement of good outcomes for people, particularly people with the highest support needs. The emphasis is less on supporting people to be “in the community” or to do activities, and more about them building relationships based on reciprocity—what do people have to offer and what can be offered in return.

16. Connectors work with and alongside paid support workers, families and people’s circles of support and the service may be characterised as “brokerage plus” in recognition of the fact that the usual brokerage models do not provide the level of depth and level of intensity required.

17. The potential outcomes are significant. People using the service and their families can see an improved quality of life and increased options, paid support staff learn new ways of working with the community, and there are long-term savings to be made as “natural supports” diminish the need for specialised services. We also see that connecting works best when it can be supported through a person’s individual or personal budget where the person and their families have control over how they arrange their support. Again, public funding continues to be required both for the individual and for the connecting service.

**Personal budgets**

18. We do know, however, that people with mental health problems can miss out on the potential benefits of personal budgets. The 2008 evaluation of the Individual Budgets Pilot Programme (IBSEN) showed that many mental health service users had not liked services available under conventional arrangements, and saw a personal budget as an opportunity to access more appropriate support. However, it also found that relatively few mental health service users were offered a personal budget and that, when they were, they had a smaller budget to use on home care, personal care and day care. One factor appeared to be that local authority staff were reluctant to trust mental health patients with personal budgets.

19. We also know that professionals’ concerns (including risk) and assumptions can mean that people with dementia are not always allowed the same choices about their care as others might be. We obviously want good risk management to be exercised (allowing people to live independently and self-manage their condition is not necessarily a good thing if they
become isolated and have no support or engagement with family or professional support staff), but we also know that there is often a poor understanding of people’s ability to make choices for themselves and live independently.

**Social care funding**

20. According to a report in Community Care (18.4.11), the Association of Directors of Adult Social Services has completed a survey of councils in England that shows councils are making about £1bn worth of cuts in social care services this year—and this is only the first of three or four years in which very significant savings will be required. The survey findings bear out what we have heard anecdotally from people with learning disabilities, family carers, service providers and commissioners. Examples we have heard about include:

- disabled people being excluded from services by tightened eligibility criteria
- people in receipt of services having their hours of support cut
- an increase in people being told they will have to live with several other people whether they like it or not
- small voluntary organisations (such as a well respected self advocacy organisation for people with learning disabilities) losing all their grant and contract funding and having to close (this has a significant adverse impact on “Big Society” aspirations)
- service providers having significant cuts in the hourly rate for support imposed as „non-negotiable“, with a significant rise in reported examples of adversarial behaviour between commissioners and providers
- loss of commissioning posts and, in some cases, a return to generic care management teams—both representing a significant loss of expertise just at a time when knowledgeable, creative commissioning is most needed.

The cumulative impact represents a serious risk to support for independent living.

21. We note the recent court ruling in Birmingham that a decision by the council to raise its eligibility threshold for care from ’substantial’ to ’critical’ was unlawful. As reported (Community Care, 21 April 2011), in an interim judgement Mr Justice Walker ruled that the council had failed to pay due regard to the impact of its plans on disabled people during the decision-making process, contravening the Disability Discrimination Act. He indicated the council would need to review its plans. Up to 5,000 people in Birmingham could have had all or parts of their social care packages withdrawn under the plans. The tension in local authorities arising from meeting statutory duties while implementing necessary savings needs to be acknowledged in the JCHR’s inquiry.

22. Alongside reductions in social care, we are also hearing of reductions in NHS services at the same time as major changes are taking place in NHS systems and structures. As one consequence of reductions in social care is likely to be increased demand on NHS services, this is of particular concern to disabled people and their families. For example, there is good evidence that reductions in support for people whose behaviour challenges families and services leads to a downward spiral that can rapidly result in a need for admission to inpatient care.
Welfare benefits

23. We believe that disabled people and their families will welcome in principle a reformed welfare benefits system that is simpler and that deals effectively with the 'benefit traps' that bedevil the current system. Our research shows that two-thirds of people with learning disabilities want to work, yet fewer than 7% of those known to social services have a job. The vast majority of people with a mental health problem who are out of work also want to work, but employment rates for people with a mental health condition are low, with an overall rate of around 21 per cent, compared to around 74 per cent for the overall working age population and in the region of 47 per cent for all people declaring a disability as defined by the Disability Discrimination Act. Research shows that employment rates for those with a more serious mental health condition are considerably lower and have fallen steadily over four decades. One of the barriers to employment for people with learning disabilities and people with mental health problems is fear of what will happen to the complex web of benefits on which they and their families rely.

24. Whilst it is important to retain the principle that a benefit is awarded to an individual, it is also important to consider the impact on a household. The Government is thinking about this from the perspective of capping the total benefits payable to a household. We are concerned that many disabled people live in households that have more than one disabled member. For example, parents may be caring for two adult disabled sons/daughters; a disabled parent may also have a disabled child, or a disabled couple may be living together. We know of a growing number of families in which an older person with learning disabilities is becoming a carer for their much older parent(s). In these situations it is not uncommon to find that the disabled members of the household do not individually meet the increasingly stringent criteria for social care, yet the household circumstances taken as a whole are more complex than would be realised if one looked at each individual in isolation. Using DLA or combined housing benefit entitlements can enable a family to stay together, to manage and to avoid much more expensive state intervention.

25. Housing concerns loom large for many disabled people who have great difficulty in finding and affording suitable accommodation. Shared ownership was one way for some disabled people to get on the housing ladder and enjoy secure tenure, but changes in Support for Mortgage Interest and FSA rules have already called a halt to successful schemes and some existing shared owners will be forced out of their homes.

26. More work is needed to ensure that people with mental health problems and people with learning disabilities benefit from the Employment Support Allowance (ESA) and that the assessment process does not trigger unnecessary stress or anxiety. Also, it is important to ensure that the assessments themselves are fair, thorough and carried out by health professionals who have an in-depth understanding of the nature of learning disability or mental health problems, so that people are not prematurely assessed as ready for work and placed on Job Seekers Allowance (JSA). On 23 March 2011 the Disability Benefits Consortium and Disability Alliance published their report "Benefiting disabled people?", which highlighted the ways in which these welfare reforms will affect people with a physical or learning disability or a mental health problem. The report found that 43% of respondents who had been for a medical assessment for ESA said that it made their condition worse because of the stress that it caused and, additionally, half of the respondents did not agree with their assessment outcome, with half of these people appealing against it. Since then, statistics have been released that show 40% of people who appealed against their decisions from the Working Capability Assessment (WCA) pilot schemes, initiated by the government
in Burnley and Aberdeen, had them overturned on appeal. This high percentage gives us grave cause for concern that many initial assessments being made are simply wrong.

27. One way in which these concerns can be addressed is by ensuring that all assessments are carried out by well-informed healthcare professionals, who have a thorough understanding of learning disability or mental health problems and the potential variations that each individual can experience as a result of their condition. This will enable the assessment to more accurately measure the impact that an individual’s learning disability or mental health problems has on their ability to work, thus preventing disputable decisions being made based on a poorly informed assessment. The assessment itself needs to be fair and sensitive to those with a learning disability or mental health problem in order to prevent inaccurate decisions being made.

28. We are eager to see that people with learning disabilities and people with mental health problems receive the best possible support in order to access suitable work opportunities. Further figures from the government’s WCA trials showed that 38% of people claiming Incapacity Benefit have the potential to work when given the right support. We were pleased to have the chance to submit evidence to the Sayce Review of specialist disability employment programmes. It is critical that such support is closely integrated with welfare rights, health and social care. In accordance with other social policy developments, support should be self directed as far as possible, local, and able to flex between low level, short term support to for some and intense, long term and specialist for others. We think an updated system should assume (and expect) economic activity at some level for everyone – provided they are given appropriate support and that even very modest work (such as an hour a week for someone who is profoundly disabled) is recognised and encouraged.

29. An updated system needs to recognise that many people with learning disabilities or more serious mental health problems have not been encouraged and supported to work. The system needs to support people who have missed out on the early expectations and experiences of work that most young people have; it needs to enable them to pursue a sustained journey to work. We are hopeful that the Work-Related Activity Groups, initiated by the Government to support people who are diagnosed as unwell but able to work in the near future, will enable people with learning disabilities and people with mental health problems to get additional help to find and keep work. However, it is vital that this is done collaboratively with each individual, and that there is no threat of sanctions, such as a loss or reduction of benefit, if people genuinely engaged in the process are slow to make progress towards work.

**Participation, consultation and monitoring effective implementation of the Convention**

30. In England Learning Disability Partnership Boards have offered a valuable means for people with learning disabilities and family carers to influence local policy and practice. At a national level representatives have joined forces through the National Forum and the National Valuing Families Forum. In turn those groups have been represented on the Minister’s Programme Board and on disability groups such as Equality 2025. This structure has not been matched across the UK or for other disability groups and is unlikely to continue in its present form for people with learning disabilities with the ending of implementation support for “Valuing People Now”. Partnership Boards, if no longer mandatory, may well disappear as a consequence of reduced council spending. Reduced, time-limited funding has been agreed for the National Forum and the National Valuing
Families Forum. As noted above, the funding for local disabled people’s groups is under threat and it is not clear how the new structures proposed in England (such as Health and Wellbeing Boards) will secure adequate representation from across the disability movement.

**Recommendations**

31. Arising from the points made above, we conclude with the following recommendations:

- the Government should bring disability policy together into a coherent statement that sets out ambitions/outcomes for all, but allows for differential action to take account of differing needs for support to achieve outcomes
- the equality impact assessments of all Government policy should take account of different groups of disabled people (including people eligible for CHC)
- the Government should take account of the impact of policy implementation that may have unintended consequences for disabled people (e.g. cuts in frontline social care were not intended by policy, but are real)
- mental health legislation should include a requirement that people may only be placed under a Community Treatment Order if they have impaired decision-making capability
- the funding of local organisations that represent the voices of disabled people should be protected
- the allocation of personal budgets for social care and health care should be carefully monitored to ensure no group of disabled people is disadvantaged in terms of access to such budgets.

27 April 2011
The Social Care Institute for Excellence is an independent charity which aims to improve social care by identifying and spreading knowledge about good practice to the social care workforce, and supporting the delivery of transformed, personalised social care services. We aim to reach and influence practitioners, managers and the sector leadership who have responsibility for service delivery in adults’ and children’s services. We recognise the central role of people who use services, children, young people, their families and their carers, and we aim to ensure their experience and expertise is reflected in all aspects of our work.

Should the right to independent living continue to form the basis for Government policy on disability in the UK?

1) Yes. Independent living is defined in the Independent Living Strategy as disabled people having choice and control over the assistance and/or equipment needed to go about their daily lives; and having equal access to housing, transport and mobility, health, employment and education and training opportunities. We believe that this is a fundamental human right for disabled people, which should underpin all legislation and policy.

Do existing policy statements, including the Independent Living Strategy, represent a coherent policy towards the implementation of the obligations in Article 19 of the UN Disability Rights Convention? Could current policy be improved? If so, how?

2) The Independent Living Strategy is an important element of a body of recent policy documents and initiatives promoting the independent living of disabled people. Some of these, such as the Vision for Adult Social Care; the new social care partnership agreement “Think Local, Act Personal”; the refreshed Carers’ Strategy; and the NHS White Paper address independent living for disabled people generally. These are backed by policies aimed at more specific groups of disabled people or relevant issues, such as Valuing People Now; No Health without Mental Health; the National Dementia Strategy; the new transition proposals in the SEN and disability green paper; and the Fulfilling and Rewarding Lives strategy for people with autism.

3) Together, these policies represent a largely coherent and consistent expression of the position that disabled people do have a right to independent living, and that this right needs to be promoted.

4) That disabled people do not enjoy choice, control and equality, therefore, in the terms of the definition cited above, is not a failure of policy documentation. The Independent Living Strategy acknowledges that there is a “gap between national policy and people’s real experiences”, and the gap will not be filled by more or different policies. It will be filled by the assiduous day-to-day application of the policies by public, voluntary and private organisations, and the individuals within them.

5) Making the right to independent living legally enforceable at an individual level, so that each disabled person has a clear entitlement to independent living and the services required to support it, would build on the body of policy work in a useful way. Clear delivery structures and sufficient funds would also be of benefit.
What steps, if any, should the coalition Government, the Scottish Government or other public agencies take better to meet the obligations in Article 19 and to secure the right to independent living for all disabled people in the UK?

6) As indicated above, there has been progress at a national policy level but issues remain about making these policies a reality at a level local.

7) There are particular issues around older people not being given the same options to live independently as younger disabled people.

8) Ensuring the continued progress of personalisation policies seems to be a key step in meeting Article 19.

9) One national policy that does need to be addressed is the proposed closure of the Independent Living Fund. The Government needs to show how it plans to replace the support for individuals that is currently funded through the ILF.

10) The Government also needs to show how it will ensure that cuts in public expenditure (including those to benefits such as Disability Living Allowance) do not have a negative impact on independent living.

If you consider changes to policies, practices or legislation in the UK are necessary, please explain.

11) Detailed above.

What impact does funding have on the ability of the UK to secure the right to independent living protected by Article 19 of the UN Disability Rights Convention?

12) The impact of funding on the right to independent living is seen at the level of national government (GB, England, devolved administrations) and local authorities. Central government sets overall tax and public expenditure levels; runs the benefits system; decides levels of and eligibility for pensions, credits, employment-related, housing and disability benefits; decides overall funding allocations to the devolved administrations, and the funding and distribution formulae for local government in England; decides and manages funding for the NHS. Decisions at this macro-level affect disabled people’s incomes, and the availability of a range of state-funded resources and services to support independent living.

13) Local authorities set their budgets in the context of public funding, Council and other local tax levels and user charges (see below). They are required to assess and publish, jointly with the NHS, the care and health needs of their populations; determine which levels of the national “Fair Access to Care” eligibility criteria will qualify for funding; assess the needs for care and support of individuals, applying the FACS criteria and taking into account the sustainability of support provided by caring family and friends; supervise the local economy of commissioning, including the workings of LA and joint LA/NHS commissioning, self-funding and use of personal budgets and direct payments; and shape the local market in provision to meet current, emerging and future needs. So at local level, funding affects the right of groups and individuals to independent living through decisions on rationing, priority-setting, commissioning and market-shaping. There may be
different outcomes for different people both within and between local authorities.

14) Unlike the NHS, adult social care is both needs-tested through FACS criteria and means-tested, and both central and local government determine charging policy and practice. Charging for residential care, including the personal needs allowance or “pocket-money”, is set nationally. People with more than £23,250 in capital, including the value of their home if a spouse or partner no longer lives there, are likely to be charged the full cost, and may have to top up the difference between the home’s fees and what the local authority will meet. Both the level of the personal needs allowance, and the speed at which charges erode their capital, can impact on disabled people’s financial ability to access the same mainstream services as the general population, and may place them at increased risk of isolation and exclusion from the community.

15) Local authorities have a good deal of discretion in deciding whether, whom and how much to charge for services to people living at home. Department of Health Guidance (Fair Charging for Home Care, 2003, and Fairer Charging for People Using Personal Budgets, 2010) sets a broad framework, stating that charges should be “reasonable”, that they should be applied fairly between individuals, and should not operate in ways that oblige people to live where they do not wish to live. Financial assessment for these charges disregards earnings, so as not to deter people from working, and excludes the value of the person’s house, but people with over £23,250 savings can be required to meet the full cost of their services. Local home care charging policies can therefore impact on disabled people’s financial scope for equal access to mainstream services and facilities, and place them at increased risk of isolation and exclusion from the community.

How will recent policy and budgetary decisions impact on the ability of the UK to meet its obligation under Article 19 to protect the right of all persons to independent living?

16) Within the comprehensive DWP programme to restructure the benefits system, there will be winners and losers. Based on statements so far, those older disabled people in receipt of the state pension should benefit from higher flat-rate payments, and therefore be marginally better able to access community services and facilities. People in work, however, including disabled people, are likely to be making higher pension contributions, and will be affected by policies to equalise and raise the state pension age.

17) A key component of these benefit changes, however, is the determination to reduce substantially the numbers of working-age people claiming Incapacity Benefit. This involves changing the procedures and criteria for assessing people’s fitness for work, providing new forms of support to help disabled people into employment, and crucially, transferring people found “fit to work” from Employment and Support Allowance (ESA) onto the lower-level Job-seekers Allowance (JSA), with sanctions for those judged to be failing to take up suitable jobs. This is expected to result in savings of some £104m annually.

18) 38% of ESA recipients, the largest single group, are people with mental and behavioural disorders. Data shows that around 30% of customers who are disallowed ESA do not claim another out-of-work benefit. This may be because they move into work, but reliable data is not available. DWP notes evidence that disabled JSA customers and those with a health condition stay on JSA for longer than the average jobseeker; and that people moving from incapacity benefits to JSA flow off JSA slower than current disabled JSA recipients or those...
with a health condition. Leaders of disability groups, including the Chief Executive of Radar who is leading a government-appointed review of specialist disability employment programmes, have recently warned that the new capability assessment is “extremely stringent”, raising concerns that people “might miss out on the help they need [...] It is not the right approach just to make it tougher for disabled people to get the support they need”.

19) In the housing field, the June 2010 budget introduced lower limits on levels of housing benefit and local housing allowance. The rates for Local Housing Allowance are being reduced and capped across the country, and qualifying conditions tightened up. The anticipated result in many areas is a significant cut in the proportion of private rented property available to low-income households. The shared accommodation rate which currently applies to single people under 25 living in privately rented accommodation will be extended to people aged under 35, meaning that single people under 35 will no longer receive Housing Benefit based on one bedroom self-contained accommodation. These changes will apply to disabled people among others claiming housing benefit and local housing allowance, and may affect where they are able to live as well as their overall income levels. There will be help for disabled people towards the cost of an extra bedroom if they need an overnight carer.

20) The government proposes to reform Disability Living Allowance (DLA), a benefit to cover the extra costs people incur as a result of disability, and replace it with Personal Independence Payments (PIP), with a daily living component and a mobility component, each with a standard and enhanced rate. Its stated aim is to create a benefit that is simpler to administer and easier to understand, is fair, and supports disabled people who face the greatest challenges to remaining independent and leading full, active lives. It has stated that Personal Independence Payment will remain a non-mean-tested and non-taxable cash benefit which people can spend in a way that best suits them. It will however be subject to a new process for assessing and reviewing each person’s need for PIP, with a view to targeting support at individuals who require the most assistance to live full, active and independent lives, eliminating allocation of the allowance on an indefinite basis, and reducing the cost by 20%. The aim of targeting is, by definition, to reduce the number of disabled people receiving help towards disability-related expenditure. A proposal announced in the budget to disqualify 80,000 working age adults in residential care from receiving the mobility element of DLA is subject to further review.

21) In any assessment of the impact of policy and budget decisions on the right to independent living, these diverse benefits changes need to be put alongside the effects of local authority budget reductions on social care provision to disabled people, and the consequences of the NHS commitment to making £20bn efficiency savings. The results are seen in very restricted FACS eligibility criteria in a number of LAs, amounting in some cases to excluding all but those with critical levels of need; reassessing, in some cases drastically, individual levels of need for community care support, leading to sharp reductions in their direct payment or personal budget; freezing or cutting fee levels to providers of residential, nursing home and domiciliary care; a marked increase in means-tested charges for home care in some LAs; limited breaks and other help for relatives and friends providing informal support; increased disputes between NHS and LAs over funding responsibility for people with high-level and/or complex needs. ADASS estimates that councils have reduced adult social care budgets by £1bn for 2011/12.

What steps should the Government take to meet its obligations under the Disability Rights Convention to involve disabled people in policy development
and decision-making, including in budget decisions such as the Comprehensive Spending Review?

22) The Convention recognises the importance of working with disabled people’s organisations as a basis for involving disabled people in decision making at a national level. The Office of Disability Issues plays a central role in facilitating this involvement and this should be continued and developed.

23) Again there is a disparity between national policy and what is happening at a local level. While there is a policy requirement for every local authority to support disabled people’s organisations/user-led organisations, many such organisations are facing cuts in their funding. Without coordinated action there is a question mark about whether there will be organisations in place to support the involvement required by the Convention.

Are the current arrangements for involvement of disabled people in policy development and decision-making working?

24) Probably just about at present—the ODI has a useful co-ordinating role for this but we have to be concerned that many of the local organisations that provide the grass-roots input are facing major cuts and this is likely to change the situation.

What steps should Government take to ensure that disabled people’s views are taken into account when drafting their reports to the UN under the UNCRPD?

25) There should be open calls for evidence from disabled people and ULOs—it would be good practice to commission disabled people’s organisations/user-led organisations to work on the reports. The UK Council of Disabled People has set up a project to monitor the Convention (http://www.disabilityrightswatchuk.org/index2.php) and this is an initiative to be supported so it can play a role in producing reports for the UN.

26) There should be opportunities for disabled people to comment on draft reports.

As part of the national monitoring mechanism, what steps should the EHRC, IHRC and SHRC take to ensure that the Convention is implemented effectively?

No response to this question.

9 May 2011
Supplementary Written Evidence submitted by the Social Care Institute for Excellence (IL 42A)

Some witnesses have told us that it is service providers’ attitudes, and the way resources are used, that are more important than the level of resources available. Would you agree and do you have any examples of this?

1) Although additional resources for adult social care over the current Spending Review period, including from the NHS, are welcome, SCIE believes that the scale, speed and front-loading of overall local authority budget reductions have put adult social care, the largest controllable block of council spending, under very severe pressure. Effects include:

- management pre-occupation with effecting budget reductions, sometimes to the exclusion of a focus on service improvement or quality assurance
- rushed decision-making, as seen in examples of overly-speedy implementation of changes to eligibility criteria, and wider challenges to the adequacy of consultation processes, leading to a spate of judicial reviews
- front-line staff having to operate tighter eligibility criteria and turn more people away
- fee freezes or cuts imposed on residential and home care providers
- targets, such as having 30% of users on personal budgets by 2011, being met whilst doubts remain about the “authenticity” of some personal budgets from the user perspective
- an environment largely unconducive to innovation

2) In this climate it would be difficult to argue that the level of resources available was not a major factor in the overall coverage and quality of social care. Nonetheless, SCIE believes that:

- The workforce (paid, voluntary and carers) and their relationships with disabled people are one of social care’s greatest assets, and their understanding, knowledge, skills, attitudes and values are a critical element in the promotion of personalisation and independent living
- The sector must maintain and increase investment in staff development and training to equip the workforce to work in more flexible, creative and enabling ways
- Practice experience suggests the quality of social work support is a key determinant in whether people with complex needs get a institutional response, or a flexible one, which may carry greater risk but also greater opportunities
- A common element in successful independent living for people, especially those with complex needs, is a positive attitude to risk-taking among professionals, and this needs to be focused upon.
Supplementary Written Evidence submitted by the Social Care Institute for Excellence (IL 42A)

3) We would therefore agree that attitudes and values are central to the promotion of independent living, as is the effective use of all the resources used in social care. Some ways resources can or could be used more effectively include:

- Extra investment in early intervention work. Currently, the ability to invest in services that promote independent living, and at the same time therefore reduce reliance on expensive institutional options, is hampered by the difficulties, including double-running costs, of transferring resources from one service type to another.

- Working more closely with carers. Our work on autism shows how wearying people still find dealing with, and navigating around, services. This makes it more likely that people will be placed into care. We need to make people’s engagement with services easier, and this means integration and flexibility. Supporting carers to continue to care is what people want, on the whole, and is cost-effective.

- Integration around joint assessments and joint commissioning by health and social care, and often involving education and housing can lead to a more effective use of resources.

- Telecare and other preventative services are increasing rapidly (167,000 new users last year) and have the potential to promote independent living.

- Involving user-led organisations and peer support in service design and delivery can lead to better use of resources and improve the outcomes which services can achieve.

**SCIE would also like to add detail to its answer as to the benefits of additional legislative support for the promotion of the right to independent living.**

4) SCIE was not arguing for additional human rights or disability rights legislation. Rather, we were recommending the forthcoming Bill to reform the law on adult social care in England and Wales should incorporate the provisions of the UN Convention on the Rights of Disabled People, to which the UK is already committed.

5) The Law Commission has proposed that the statute should “set out a single overarching principle that adult social care must promote or contribute to the well-being of the individual” (Recommendation 5).

6) Its report further recommends that “Community care services (however named) should be defined in the statute as any of the following provided in accordance with the well-being principle:

(1) residential accommodation;

(2) community and home-based services;

(3) advice, social work, counselling and advocacy services; or

(4) financial or any other assistance.
The statute should set out the following list of outcomes to which the wellbeing principle must be directed:

(1) health and emotional well-being;
(2) protection from harm;
(3) education, training and recreation;
(4) the contribution made to society; and
(5) securing rights and entitlelments.” (Recommendation 28)

SCIE’s suggestion is that “independent living”, defined in accordance with the UN Convention, could be added to the second list.

7) SCIE hopes that this clarification is useful, and that the further submission will be of benefit to the important work of the committee.

9 September 2011
1. Introduction

The parliamentary Joint Committee of Human Rights is conducting an inquiry into the implementation of the right to independent living for disabled people, as guaranteed by Article 19, UN Convention on the Rights of Persons with Disabilities. The committee is inviting evidence, by 29 April 2011, focused in particular around a number of questions.

2. Focus of Inclusion London’s evidence:

Inclusion London is not covering all the questions and points raised by the JCHR. The areas we are covering are as follows:

- Right to Independent Living and government policy
- Steps to be taken to meet the obligations in Article 19 and Independent Living Strategy
- Changes to the Independent Living Fund
- Restrictions in eligibility and levels of DLA
- Impact of the restrictions on local authority funding, social care budgets and benefits reassessments
- Localism
- Big Society
- Participation and Consultation
- Impact of funding on right to independent living
- Impact of recent policy and budgetary decisions
- Involvement of disabled people in policy development and decision-making working
- Monitoring

3. Background evidence

Inclusion London is extremely concerned that disabled people are being disproportionately hit by the current government policies to the extent that the report, ‘All in this together? The impact of spending cuts on Deaf and disabled people in London, an evidence base on Deaf and disabled Londoners and the impact of past and future policies’, was commissioned by Inclusion London and researched by the Office Public Management. This evidence base identifies key discriminatory barriers faced by disabled people in London and how these result in inequality, greater poverty, exclusion from employment, education, social participation and other aspects of life. Much of the evidence relates to independent living and the negative impact that current government policy will have in this regard. The report can be found at:

www.inclusionlondon.co.uk/domains/inclusionlondon.co.uk/local/media/downloads/Spending_cuts_and_evidence_base_report_Inclusion_London_final_copy_290311_1.doc

4. Response to JCHR Questions
4.1 Should the right to independent living continue to form the basis for Government policy on disability in the UK?

As a signatory to the UN Convention on the Rights of Persons with Disabilities it is extremely important that the rights of the Convention are integral to government policy. The prominence given to the right to independent living in the Convention reflects the historic and ongoing denial of this right to disabled people internationally, and certainly including in the UK. It is extremely important that the right to independent living as stated in Article 19 of the Disability Rights Convention forms the basis for Government policy on disability in the UK.

4.2 What steps should be taken to better meet the obligations in Article 19?

The rights in UNCRPD should be fully integrated into UK law.

The Independent Living Strategy put forward a 5 year cross departmental strategy to improve disabled people’s experience and life chances. This identified the need for legislation to better support independent living rights, for the barriers that charging represents to independent living to be addressed, for an improved supply of accessible and affordable housing and a number of other key steps. These need to be taken forward.

The specific duties of the Public Sector Equality Duty should be sufficient to encourage proactive good equality practice and guide public authorities in implementing the public sector duty. This would help to meet rights enshrined in Article 19. For example, the government proposes to strip down the specific duties so that there would only be a requirement to set one equality objective across all local authorities’ functions and all equality groups, in a four year period and the proposals do not sufficiently link objective-setting to meeting the general duty obligations. We believe this will lead many public authorities, particularly when under pressure to make spending cuts, to omit steps to meet the needs of disabled people and specifically steps to deliver independent living. The specific duties need to be increased, need to be adequate and specifically the number and level of equality objectives that a public authority sets need to be linked to the organisation’s performance of the general duty. The duties need to include an obligation to take steps to reach objectives that are established. The specific duties also need to allow for transparency – for example so that there is a requirement to publish regular data in relation to service functions and an explicit requirement to conduct equality impact assessments.

4.3 Changes to the Independent Living Fund

This government’s decision to close the Independent Living Fund (without a proper formal consultation) to new applicants and entirely by 2015 is a staggeringly brutal decision: saying that the sixth largest economy in the world can no longer afford to fund the support that disabled people. This will make meeting Article 19 harder. We call for the reinstatement of a properly resourced ILF.

4.4 DLA cuts

DLA was introduced to address the extra costs that disability presents to the individual. Its planned replacement ‘Personal Independence Payment’ is not based on the same principle. A cruder assessment is planned, with lower eligibility, a narrower range of recipients and benefit levels. All this is intended to cut the budget and recipients by a fifth. These changes
Written Evidence submitted by Inclusion London (IL 43)

will restrict not advance independent living. One specific change will be particularly savage in this regard: removal or reduction in the mobility component of Disability Living Allowance (DLA) for people living in residential care. Government has stalled on plans to cut this but is still considering the cut. Such a cut would clearly breach Article 19. The government has claimed wrongly that people living in residential care have all of their needs provided for by the local authority’s package of support, when in fact only basic care is funded. The effect of the loss of the mobility component will be to incarcerate disabled people in residential ‘homes’.

These changes ignore the fact that the figures for the number of DLA claimants in the context of the estimated 6.7 million disabled people of working age indicate that there is an underclaiming for DLA: the Pensions Select Committee highlighted the need for a campaign to raise awareness of DLA because it recognised that disabled people need to be lifted out of poverty. There is a low level of fraud, (1.9%\(^{152}\)). The assessment process is already rigorous, (only about 50% of claimants are successful and in 2008 40% of appeals were turned down\(^{153}\)). Inclusion London made a number of other relevant points in its consultation response: http://www.inclusionlondon.co.uk/inclusion-londons-dla-reform-response

4.5 Restrictions on local authority funding, social care budgets and benefits reassessments

Local authority funding cuts and independent living: The impact of cuts already taking place include,

- Disabled people becoming more isolated and impoverished due to the closure of local Deaf and disabled people’s voluntary and community organizations which provide support to access services and benefits. In the last month Inclusion London has heard of 11 such organizations closing or struggling due to such cuts.

- Many facilities such as day centres run by local authorities closing. See on London borough’s proposal here: http://www.haringey.gov.uk/adult_social care_consultation_fact_sheet.pdf

- Local authority (LA) staff redundancies, which have a greater impact on disabled people than non-disabled people because of the greater likelihood of disabled employees to be working in the public sector\(^{154}\).

- LA staff redundancies which may increase waiting times for social care assessments and other services such as occupational therapists, during which disabled people’s conditions can deteriorate and the number of falls increase.

Social Care: Many disabled people are not receiving the support needed because many local authorities are raising the bar on eligibility and only providing (or planning to provide)

\(^{152}\) www.parliament.uk/briefingpapers/commons/lib/research/briefings/snsp-05749.pdf


\(^{154}\) http://www.inclusionlondon.co.uk/all-in-this-together
social care to those assessed as having the highest level of need, (critical). This will reduce support to other disabled people and not only cut across the right to independent living but will reduce the possibility of preventing disabled people from deteriorating to a critical level of need by providing support at an earlier stage. In addition care charges are escalating wildly in many areas so that in reality disabled people will be priced out.

**Benefits reassessments:** We are extremely concerned at the reduction or potential ending in benefit support to many disabled people as a result of the extension of the much criticized Work Capability Assessment to all existing claimants of Incapacity Benefits. The crude functional focus of this test ignores the barriers that exist in reality to independent living and results in direct harmful stress to many disabled people and to many being denied benefits which support independent living. Our wider views are at [www.inclusionlondon.co.uk/Welfare-Reform-Bill-info-paper](http://www.inclusionlondon.co.uk/Welfare-Reform-Bill-info-paper). We oppose the extension of the WCA to all new claimants and the aim of cutting the number of recipients via this test, harsh sanctions and tighter eligibility, and the cuts in the value of the benefit as this will all reduce the income and increase the barriers to independent living for disabled people.

**Benefits in General:** Disabled people are twice as likely to claim welfare benefits as non disabled people\(^\text{155}\) so cuts will have a disproportionately negative impact.

**Housing Benefit and ESA:** The impact of reassessments for Incapacity Benefit is compounded by the tightening of the eligibility criteria for other benefits. The cap on Housing Benefit in particular will disproportionally impact on disabled people because a higher proportion of disabled people live in social housing and are four times more likely to claim Housing Benefit than non-disabled people\(^\text{156}\). Disabled people in London are likely to be the hardest hit by the Housing Benefit cap because rents are higher in London than many other areas in the UK.

The tightening of criteria and sanctions for Employment Seekers Allowance (ESA) will hit disabled people disproportionately hard as disabled people are more likely to be unemployed\(^\text{157}\), for a variety of reasons including discriminatory attitudes of employers. These income cuts will radically restrict the potential for independent living and for equal social participation.

### 4.6 Localism

With fewer services being provided by statutory bodies a post code lottery for services and in charging for them is likely to be intensified. This will restrict disabled people’s movement from one area of the country to another. The impact of housing benefit caps will create a pressure to move from inner London, possibly to areas where services for disabled people are worse: thus creating a double whammy against independent living. Localism, at its best should provide a range of services in response to local need, but with cuts in services in both

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\(^{155}\) [http://www.inclusionlondon.co.uk/all-in-this-together](http://www.inclusionlondon.co.uk/all-in-this-together)

\(^{156}\) [http://www.inclusionlondon.co.uk/all-in-this-together](http://www.inclusionlondon.co.uk/all-in-this-together)

\(^{157}\) [http://www.inclusionlondon.co.uk/all-in-this-together](http://www.inclusionlondon.co.uk/all-in-this-together)
the statutory and voluntary sector and reduced enforcement of equality legislation, it is likely to result in less choice and control for disabled people.

This variability of provision applies to door-to-door transport services for disabled people, where changes are occurring in London already, due to the cuts in local authority funding e.g. taxi card ‘double swiping’ is being removed in some boroughs and not others. Taxi card, dial-a-ride and the freedom pass make a crucial contribution to independent living and go some way to offset the inaccessibility of the transport system in London (which has become worse as a result to delays in plans to make the Tube accessible, a slower timetable for bus stop accessibility and sharply rising ticket prices).

4.7 Big Society

In order that disabled people can be independent services should be professional, reliable and well resourced. There is no way that large scale professional services can be provided by the voluntary sector. We are also very concerned that statutory sector provision is being weakened and passed to the voluntary sector at a time that the voluntary sector’s funding is under threat or being cut already. Leaving many disabled people without support at a local level which will result in a loss of independence, more poverty and isolation. Also increasing the reliance on volunteers could impact on the professionalism, reliability and quality of a service.

4.8 Participation and Consultation

Inclusion London is very concerned at the government’s determination to weaken the specific duties to the Equality Act 2010. The latest policy review paper (published March 2011) contradicts the approach government set out in January, two months before, and would mean that public bodies had no obligation to involve or ‘engage’ disabled people when setting equality objectives or to publish details about the results of such involvement. We believe such changes will reduce the likelihood of public authorities undertaking engagement and this will undermine the design and delivery of services and practices to best support independent living. These changes breach the Convention’s commitment that disabled people ‘be actively involved in decision-making processes about policies and programmes, including those directly concerning them’.

4.9 Impact of funding

Funding (or the lack of it) has a huge impact on disabled people’s lives and whether independent living becomes more of a reality. Cuts in funding are impacting on: information and support to access services, welfare benefits and concessions provided by voluntary and community organizations; provision of personal care; provision of door-to-door transport and accessible public transport; access to welfare benefits and equipment; consultation with disabled people regarding policies and service planning; access to affordable and accessible housing; the street environment; transport systems; access to justice; access to cultural and leisure activities. Funding or the lack of it impacts on almost all areas of disabled people’s lives.

4.10 The Impact of recent policy and budgetary decisions
We have set out already a number of ways in which current policy and budgetary decisions are negatively affecting disabled people. These cover all areas of life and the impact is cumulative. Examples include:

- Loss of support provided by DDPO’s, due local authority funding cuts, leading to less access to services, welfare benefits and concessions.
- Loss of disabled people’s income due to tightening of eligibility criteria of welfare benefits.
- Reduction in mobility due to restrictions in the funding and criteria of door-to-door transport and Blue Badges. The number of tube stations that will have building works to ensure step free access has been reduced.
- Restricted access to justice, through planned cuts in Legal Aid which would mean that disabled people will have no support to challenge unjust decisions about welfare benefits, housing, employment etc.
- Education policy, where the government proposes to move away from mainstreaming disabled people’s education and return to special schools. In other words to further exclude disabled children into what will inevitably be badly resourced facilities with low expectations. The Green paper also suggests the use of personal budgets but with narrower criteria leaving many disabled people without the support they need. Parents/carers wishing to challenge decisions will not have access to legal aid.
- Cuts to budgets and equipment that will be funded through Access to Work. Larger companies are being asked to contribute more to the costs of equipment, which could act as a disincentive to employing disabled people.
- In addition to these changes there are major concerns about the proposals in the Health and Social Care Bill, which we will not detail here.

These cuts will restrict independent living not support it.

4.11 Involvement of disabled people in policy development and decision-making

Involvement of disabled people in policy development and decision making is crucial for disabled people’s independence, choice and control. It is important that both central and local government continue to consult with disabled people. When consultations are carried out it is important that the governments own consultation criteria should be followed particularly:

- The duration of a consultation should last 12 week or longer. This criteria is often ignored.

158 Support and aspiration: A new approach to special educational needs and disability [http://www.education.gov.uk/publications/standard/publicationDetail/Page1/CM%208027]
• All consultations are accessible, (i.e. that consultation documents are produced in accessible formats e.g. Braille, audio, large print and easy read).

• Legislation requires all public bodies to involve disabled people and to be transparent and efficient about publishing the results.

If disabled people are to be at the heart of decision making it is important that public offices are accessible to disabled people, including the positions of local Councillors and Members of Parliament. At present the cost is prohibitive and not covered by Access to Work.

4.12 Monitoring

The EHRC should be resourced to monitor the Convention and should fully consult with disabled people and disabled people’s organizations as part of this process. However the planned government budget cuts to the EHRC, with a 68% cut and more than 200 staff cuts in a short timescale will greatly undermine the work the Commission will be able to do on all fronts, including monitoring the Convention. The government should not proceed with its cuts in funding and the commission should not proceed with proposed staff cuts. We believe these cuts will undermine the ability to meet the requirements of Article 33.

28 April 2011
Should the right to independent living continue to form the basis for Government policy on disability in the UK?

1. In my view, the answer to this is yes, provided all parts of government actually understand what independent living means in practice when they formulate policy. The concept of independent living is not yet well embedded in UK society, so all government departments should be very clear in the way in which they define independent living, which should follow the definitions and concepts used by the UK Disability Movement. There is a huge danger that the concept of independent living could be seriously weakened by being quoted often but not rigorously defined or applied, and at present the UK media is insufficiently informed to provide effective journalistic scrutiny in this area.

What steps, if any, should the coalition Government, the Scottish Government or other public agencies take better to meet the obligations in Article 19 and to secure the right to independent living for all disabled people in the UK?

2. The government should undertake a public information/awareness-raising exercise, to educate the general population about disability equality and the concept of independent living. This would have many benefits, including: reducing negative attitudes to disabled people (with a possible knock-on effect of reducing disability hate crime), encouraging employers to have a positive attitude to the ability of disabled people to work (with the right support), encouraging the general public to view disabled people as equals, combating the still-widespread view that disabled and older people have to be 'dependent' and 'cared for', enabling employees in the public sector, including the NHS and local government, and service providers in the private sector, to understand the needs and wishes of disabled people better, and many other benefits. Above all, such an exercise, if done well, should gradually increase the proportion of the population who understand what disability equality and independent living mean and why they are important in 21st century society.

3. Disabled people will never be able to exercise the same choices as other people while the government continues to allow local authorities to charge so much for independent living support (social care) that they are expected to live in relative poverty or arguably even actual poverty. Non-disabled people do not have to pay all their income (bar the basic income support level plus 25%) and all their capital above a certain amount, simply to undertake such activities as washing, dressing, going to the loo, eating and drinking, as many disabled people have to. This means that disabled people have much less choice than other people about how they spend their money, the standard of living they enjoy and their ability to achieve economic independence, for example, by saving for a deposit on a home or making provision for their future. Disabled people will never experience anything approaching equality if they are expected to pay to undertake basic functions of life and thereby end up subject to a huge marginal tax rate compared to non-disabled people. The current situation, under the Dept of Health guidance on charging for social care services and the need of local authorities to charge the maximum allowable under that guidance due to lack of funding, is that only the very poorest disabled people have a ‘right’ to independent living; all other disabled people have to pay an enormous proportion of their income and capital and sacrifice their financial security and standard of living to pay for the ‘right’. That is not equality.
4. Even for those disabled people who are sufficiently poor to be eligible for independent living support via social services, there is no nationally agreed set of activities with which they have a right to be supported. Fair Access to Care Services criteria allow local authorities to deny disabled people support if they are short of public funds, so resulting in many disabled people missing out on independent living support.

5. It is becoming clear that the personalisation agenda is to a certain extent failing to build on the learning around independent living achieved with direct payments and personal assistance use. As reablement and personal budgets are rolled out for disabled people, including those disabled as a result of the aging process, it appears that the steps taken towards independent living are being undermined, as many local authority employees either have insufficient understanding of independent living or insufficient resources to help service users achieve it. (see Peter Beresford’s article in the May 2011 issue of Disability Now, page 14). There is a serious danger that whilst younger disabled people who are accustomed to direct payments and personal assistance use are able to continue to benefit (subject to funding restrictions of course), older people have to make do with personal budgets which may deliver services with some choice and control but do not truly deliver independent living. This is primarily a training issue but is also a resource issue. A major exercise needs to be undertaken to train and equip local authority staff and others in relation to what independent living means before it’s too late and a generation of service users are denied the autonomy and independence achieved by disabled people over the last 20 years or so.

6. The NHS and/or social care services need to provide the equipment that disabled people actually need to live independent lives. Although Disability Living Allowance is supposed to meet the extra costs of disability, most disabled people could spend their DLA many times over on the equipment they need to live independently but which the eligibility criteria for health and social care do not allow them to have. The criteria for equipment provision should be flexible enough to enable disabled people to be provided with the equipment, or a cash payment in lieu, that they need to maximise both their health and their independence. For example, the criteria for getting a powered wheelchair from the NHS are so strict as to imply that disabled people are not expected to go out of their own homes, and the criteria for getting equipment such as specialist seating at home are so strict as to prevent people being provided with such equipment to maximise their health and minimise the likelihood of more costly medical interventions at a later stage. In both these examples I speak from personal experience.

**What changes to policies, practices or legislation are necessary?**

7. The FACS criteria should be replaced by a national set of criteria for independent living support which is the same for every local authority area. This support should be available to all disabled people who need support to achieve independent living, regardless of economic status.

8. The Dilnot commission should consider care charging first and foremost as a human rights issue. This was a notable absence in the commission’s call for evidence and did not inspire confidence in the commission’s understanding of the human rights issues around independent living support.

9. Criteria for equipment provision, including wheelchair provision, should reflect the need to promote both optimal health outcomes and independence, and the artificial divide between health and social care should be removed.
10. Lifetime Homes criteria should be mandatory and incorporated into both Part M of the Building Regulations and planning law. The requirement for an appropriate proportion of wheelchair accessible housing should be included in planning requirements country-wide, not just in London, and should apply to both affordable and private housing.

Recent developments

11. Removal of mobility component of DLA for all people living in residential care—this proposal seeks to reduce the independence of people living in residential care and is fundamentally ill-conceived from a human rights perspective. The issue of duplication of provision can be dealt with by ensuring that the mobility needs of each resident are dealt with in the same way as if they were living at home, ie by the provision of DLA mobility component if they meet the criteria. This is preferable as it provides the greatest opportunity for independence by enabling the resident to use the Motability scheme in the same way as they would if they lived in their own home or with their family, including to purchase their own powered wheelchair or scooter or to lease a car for their own benefit through Motability.

12. The Big Society—to the extent that this implies that the needs of disabled people should be met from ‘charity’ or ‘by volunteers’, this risks taking us back several decades and undoing all the hard work and campaigning by disabled people since the 1970s. Having disabled people’s needs met by volunteers or by charity is totally inconsistent with the concept of independent living. Disabled people have no more wish to be objects of charity than any other member of society.

13. There may be a role for the ‘big society’ if it is taken to mean that disabled people have the right to independent living support to play their full part in society and in their community. There may also be a role for the ‘big society’ in relation to encouraging all kinds of organisation, including the voluntary sector, to provide services to support independent living. However, this already happens and the development of personal budgets implies the development of a marketplace in which all providers can provide services to those in receipt of a personal budget to purchase services which meet their particular needs.

14. Restrictions on local authority funding, social care budgets and benefits reassessments—these issues are undoubtedly going to affect the right to independent living. We have already seen, in Kingston, a decision to increase charges for domiciliary social care, ie independent living support (see paragraph 3 above) in a way which will seriously affect the ability of disabled people, particularly those with high value care packages who have tried to take the responsible course of saving for their future, to exercise their right to independent living. In other local authority areas independent living support is being denied to people who do not meet the higher levels of the FACS criteria due to the need to save money.

15. The Work Capability Assessment for Employment and Support Allowance has had seriously detrimental outcomes for many disabled people who have been found fit for work but are in fact not able to work, and the extent of the hardship faced will only increase as all incapacity benefit claimants are subjected to the WCA over the next few months. Disabled people have to have access to a reasonable level of income to be able to exercise any right to independent living, and putting them onto the lower-paying JSA when they are not able to engage in work-related activity undermines their ability to live independently. In some cases it is likely that disabled people will be denied essential income if they are not capable of
engaging in work related activity and therefore fail to meet the conditions even for receiving JSA (when in fact if they had been properly assessed under the WCA they would be eligible for ESA). Whilst the aim of supporting disabled people into work is laudable, resources would be better targeted on dealing with the barriers to employment presented by employer attitudes and inflexible working practices, and on enabling disabled people to look after themselves and their families if they are in reality unable to work, which many are. In addition, tightening eligibility criteria and reduced independent living support are likely to result in disabled people failing to receive the support they need to work anyway.

16. Disabled people are very fearful of the proposals to replace DLA with PIP. The government says it expects to save 20% of the current expenditure on DLA and that it is committed to protect those in the greatest need. However, this is likely to mean that those with moderate but significant extra expenses arising from their impairment will be entitled to less or no support through PIP. The government’s stated intention to take account of adaptations and equipment available to disabled people when assessing eligibility for PIP runs the risk of making unwarranted and unrealistic assumptions about the fitness for purpose and/or availability of such adaptations and equipment, particularly bearing in mind that many disabled people have to supplement publicly funded equipment with equipment they buy themselves because publicly funded equipment is often unsuitable or of inferior quality.

17. **Increased focus on localisation**—whilst the government favours localisation for some justifiable reasons, it is utterly inappropriate for the human rights of disabled people, including the right to independent living, to be subject to the whim of local electorates and politicians. Disabled people should have the right to appropriate support wherever in the country they live, otherwise they also lose the right to live wherever they choose, as they can’t move to another area if they have no assurance their needs will be met at their destination. It can take several months following a move to another local authority area for support to be put in place, and there is no guarantee before moving that the support will be equivalent to that provided in the area the disabled person has left.

18. **Impact of funding on the ability of the UK to secure the right to independent living**—this issue has been covered in the above paragraphs. Independent living support costs money and if funding is not available the support cannot be provided. Human rights should not be dependent on ability to pay.

**Participation and consultation**

19. **Involving disabled people in policy development and decision-making**— the government purports to be involving disabled people but it is extremely unclear the extent to which it is actually listening to what disabled people are saying. Before making budget decisions such as the CSR, the government should consult with disabled people, especially those individuals known to have a sound grasp of the issues (so not restricted to the Equality 2025 group), and make full disclosure of the outcomes of this consultation along with the decision, including explaining how it has taken account of the views of disabled people expressed during the consultation. To identify and consult with disabled people with a good grasp of the issues, the government should contact local Centres for Independent Living and organisations of disabled people, as well as academics in the field of Disability Studies.

20. **Current arrangements for involvement of disabled people**—the current arrangements are not working. Whilst the government does consult, eg on the proposals for the reform of DLA, there is no transparency in relation to what is said in consultation and
how this has influenced the development of policy. The government must demonstrate that it is not just consulting but that it is listening to what disabled people say in response to the consultation, and must be prepared to change its mind in response to a well-argued case that proposals are likely to cause harm and detriment to disabled people. Government should not rely on assurances that those most severely disabled will be protected, because this does nothing to protect those who are disabled and face higher costs but are not ‘severely’ disabled.

**Monitoring the effective implementation of the Convention**

21. The government should consult widely on its first periodic report, as it did on the proposals to replace DLA. It should consult all local Centres for Independent Living, all organisations of disabled people, leading activists in the field and academics in Disability Studies departments at universities. This should allow it to hear the views of a large number of disabled people, as organisations can pass details of the consultation to their members. The government should NOT rely on the ODI, the Equality 2025 group or the various equalities and human rights commissions to draft their report.

22. **National monitoring mechanism**—the EHRC, NIHRC and SHRC should liaise with all Centres for Independent Living and Disabled People’s Organisations, as well as academics engaged in emancipatory research, to monitor what is happening in all areas of the UK. It should direct its attention to issues of poverty, benefit levels and assessment procedures, social care funding/charging and the delivery of social care services in its monitoring.

27 April 2011
Written Evidence submitted by Disabled People Against Cuts (DPAC) (IL 45)

Disabled People Against Cuts is a pan-impairment user-led disabled people’s campaigning group set up to campaign against the many cuts to benefits and care funding which are now facing disabled people.

We have well over 2,000 supporters and many of their views and experiences, in particular living in fear, are reflected in our submission to the committee. Our recent virtual on-line campaign to coincide with the TUC march on March 26th had more than half a million viewings over the week of and weekend of the march.

Recommendations we would like to see in the committee’s report

- We would welcome the committee recommending that disabled people’s human rights must be upheld by any changes to legislation, and that any legislation that fails to encompass these rights is unlawful.

- We would hope that the committee will recommend that the Independent Living Fund will not be abolished in 2015 and that it is reopened to new applicants forthwith, together with an adequate level of funding being made available to support disabled people to live independently.

- We would further like to see the committee recommending that local authority social care budgets must be ring-fenced as we feel this is also essential. There should also be no increases in charges for care funding.

- A programme of urgently building more, accessible and affordable social housing is a further necessity to enable independent living. This must be accompanied by the reversal of proposed changes to Housing Benefit and Local Housing Allowance until such time as there is an adequate supply of suitable social housing available for disabled people.

Should the right to independent living continue to form the basis for Government policy on disability in the UK?

What do we mean by IL?

*Independent Living does not mean that we want to do everything by ourselves and do not need anybody or that we want to live in isolation.*

*Independent Living means that we demand the same choices and control in our every-day lives that our non-disabled brothers and sisters, neighbours and friends take for granted. We want to grow up in our families, go to the neighbourhood school, use the same bus as our neighbours, work in jobs that are in line with our education and interests, and start families of our own.*

http://www.independentliving.org/def.html

Without the right to live independently in the community like non-disabled people disabled people will continue to be excluded from society, to face gross inequalities and to have their human rights under article 19 of the UNCRPD denied. UNCRPD upholds the principle that
disabled people including disabled women and children must be able to exercise human rights on an equal basis to non-disabled people. As the UK has ratified the convention both current and new UK legislation should uphold disabled people’s convention rights. However at the moment disabled people are having their human rights stripped away from them one after another.

The proposed cuts by the coalition will result in further erosion of disabled people’s human rights and rights to live independently. This includes in many cases a drastic reduction in income, negative reforms of the current systems of welfare to cuts to social housing, adaptations, housing benefits, and loss public sector jobs. All of these changes will negatively affect disabled people including disabled children and their families disproportionately.

Do existing policy statements, including the Independent Living Strategy, represent a coherent policy towards the implementation of the obligations in Article 19 of the UN Disability Rights Convention? Could current policy be improved? If so, how?

While the existing policy statements sound coherent as they stand the reality of what is happening in practice is very different and far from what is intended in the substance. In no way are the stated policy objectives being met.

The Independent Living Strategy is meaningless when support for disabled people for personal care as basic as going to the toilet is withdrawn and replaced by packs of incontinence pads and waterproof sheets when the service user in not incontinent (Kensington and Chelsea council). This is degrading and dehumanising but has been justified as a money saving exercise.

In many cases personalisation has not meant an improvement in choice and control over their lives for disabled people but rather a rationalisation of services and a reduction in care funding allocated and/or a huge increase in charges which disabled people have to pay towards the care provided. (Warwickshire and Dudley councils). We have been informed by a social worker that disabled people are no longer considered to need access to bathing facilities and that being able to strip wash is now considered adequate. (Birmingham City council)

Further cuts which local government are making to their budgets has resulted in many local authorities tightening their eligibility criteria for social care which leaves an ever increasing number of disabled people isolated in their own homes without the level of support they need to be included in society.

There is no point therefore in central government putting forward independent living strategies which are meaningless without the necessary financial commitment to implement them at a local level. There must be a full commitment to uphold and fund our human rights including provision of fully accessible and affordable housing, inclusive design, new building of social housing, and enough resources to provide adaptations and aids where they are needed.

There must be as a minimum an adequate level of community support resources to support disabled people not only to live in the community securely and in adequate comfort, but to be fully included in society. At the moment all the legislative changes proposed and cuts to services are resulting in moving further away rather than moving closer to this.
The plans to close the Independent Living Fund from 2015 to save money and not provide anything to replace it with are totally unsatisfactory. Disabled people’s access to equality and human rights cannot be dependent on funding issues alone and there must be a financial commitment made and kept to meet disabled people’s human rights under UNCRPD. Cuts to legal aid funding which will restrict disabled people’s ability to challenge any cuts and human rights abuses further mean that for disabled people to be assured of their convention rights there must be a system of monitoring and sanctions for those who do not adhere to these principles.

**What steps, if any, should the coalition Government, the Scottish Government or other public agencies take better to meet the obligations in Article 19 and to secure the right to independent living for all disabled people in the UK?**

There is little point in ministers saying they wish to support those in greatest need when their actions prove these words meaningless. Disabled people and the disabled people’s movement have been fighting the same battles for over 30 years, yet rather than independent living being a closer reality it is now being threatened with extinction. There is no commitment on the part of the current government to support or fund this. If the right to independent living is lost then disabled people’s right to equality and human rights will be set back 30 years.

When similar changes were made to independent living funding in Norway the changes led to a large increase in the numbers of disabled people admitted to hospital for a long time and massive increases in costs to the state. Part of the Independent Living Strategy is to provide preventative services to disabled people to prevent this but in reality these too do not exist.

Article 19 stresses that people should be able to choose where and with whom they live with the support necessary to meet their needs. However much of the proposed legislation is severely eroding this. In particular disabled peoples’ human rights under Article 19 are being seriously undermined through caps on housing benefit in social housing, removal of the security of tenure from social housing, increases in social housing rents, planned removal of housing benefit payment for all rooms in a property from 2013 so that the full rent disabled tenants pay for social housing properties will no longer be covered. This is already the case for those living in the private rented sector.

Changes to Local Housing Allowance for those unable to get social housing and who rent in the private rented sector will further prevent convention rights under Article 19 being met. These changes include limiting the amount of LHA available to the 30th percentile rate will make it much more difficult, if not impossible, for someone who has additional housing needs such as a requirement for a larger property to turn a wheelchair in, or a person who needs extra space for equipment to find anywhere suitable to rent at a price they can afford. Disabled children still have no right to funding for an extra, separate bedroom to meet their needs regardless of the severity of their impairment.

Supported housing schemes are also under threat of being lost due to lack of funding.

The other important aspect of independent living however is the provision of the right level of support which is now in severe danger of ceasing to exist in many cases.
If you consider changes to policies, practices or legislation in the UK are necessary, please explain.

From what has already been said previously I think there is an urgent need for changes to policies, practices, and legislation. Eligibility criteria and access to care funding should be the standardised and provided adequately in all local authorities. Whether or not disabled people can access the homes and care and support funding they need to live independently should not be a postcode lottery.

Impact of funding on the right to independent living

The Committee would particularly welcome evidence on these recent developments:

The decision, announced in the CSR, to remove the mobility component of Disability Living Allowance for all people living in residential care

Changes to the Independent Living Fund

The removal of the mobility component of Disability Living Allowance announced in the CSR will impact negatively on the quality of life for those living in residential homes. Those people who currently receive only about £22 a week to meet all non-mobility needs will lose the major part of their income affecting their capacity to purchase mobility aids, and pay for transport to be any part of the community at all. In numerous cases losing the mobility component of DLA will deny such residents a right to family life as they will no longer be able to afford to travel to see relatives.

If mobility allowance is removed from those who are spending their mobility component on mobility aids such as a wheelchair or scooter do we assume these items will be taken away from them when they lose entitlement to mobility allowance. We do not feel the full consequences of this proposed policy change has been properly or sensibly thought through.

The closure of the Independent Living fund is one of the most obvious and vicious attacks by the government in undermining the principles of independent living. While it has been agreed that 23,000 ‘severely disabled’ people will stay on the scheme until 2015 there are no plans after that date for this funding to be replaced in any other way.

We have yet to see how the planned abolition of DLA including the higher rate - a marker for continued entitlement to ILF will affect existing claimants. Further, Adult Social Care in many areas have raised eligibility thresholds while increasing charges, leading to cases already where disabled people although pre-existing ILF claimants now fail to reach the qualifying threshold and therefore have lost their entitlement too. (Nottingham City council, Buckinghamshire council)

Young disabled people are already being denied the opportunity to go to university due to the closure of Independent Living Fund to new applicants and lack of alternative support funding from social services. This will obviously have a very negative effect on their life chances overall.

"the Big Society"
Restrictions on local authority funding, social care budgets and benefits reassessments

Many local authorities have raised their charges for care, and some disabled people are now paying for their care (up to £50 per week) for the first time ever. Social workers are saying that disabled people will be lucky if they reach the qualifying criteria. Benefit reassessments are causing the most severe emotional and financial destruction.

The threat of the loss of care funding which would lead to an inability to continue to live independently means that large numbers of disabled people are living in fear of their care packages being re-assessed. We believe that in a civilised society people should not have to live in fear just because they are, or become, disabled.

Increased focus on localisation and its potential impact on care provision, and specifically, on portability of care and mobility for disabled people

Care provision should be the same regardless of where someone lives and in order to be treated on equal terms to non-disabled people it is essential that disabled people should be able to move and take their care package with them.

What impact does funding have on the ability of the UK to secure the right to independent living protected by Article 19 of the UN Disability Rights Convention?

The cuts proposed by the coalition government mean that the UK will utterly and totally fail to meet the convention rights guaranteed in Article 19 of the UNCRPD.

How will recent policy and budgetary decisions impact on the ability of the UK to meet its obligation under Article 19 to protect the right of all persons to independent living?

There will be no right to independent living at all.

Participation and consultation

What steps should the Government take to meet its obligations under the Disability Rights Convention to involve disabled people in policy development and decision-making, including in budget decisions such as the Comprehensive Spending Review?

Governments should include all user led disability organisations. While the current practice is to engage with charities they put forward views FOR disabled people not the views OF disabled people, and only user led organisations and disabled people can do this. In particular the National Centre for Independent Living is a long standing user-led organisation which sees the impacts of the cuts and proposed cuts.

Meetings across the country would also be useful so that the views of a sample of local CILs can be included and they can also be involved with meeting ministers. Responses to written consultations seem to be being ignored and it is not clear how much or how often points raised within them are taken on board.
A government with a commitment to disabled people should accept that disabled peoples’ views represent the expert views on living in a disabling society.

**Are the current arrangements for involvement of disabled people in policy development and decision-making working?**

No the proposed cuts shows this is not the case. The governments’ misinformation eg. that DLA was a benefit that prevents disabled people from working was a major error repeated by the media. Whether the government still incorrectly believe this is unclear, however it shows they have a serious lack of understanding about disability and disability issues.

There is growing concern that paper consultations are worthless, eg. the implementation of the Universal Credit was announced on the morning that the consultation on this closed. This gives the impression that responding to government consultations is pointless and what is said will be ignored anyhow.

Disabled people resent token consultations and want on-going involvement, to be listened to seriously and to be accepted as the experts on disability, disabling barriers and disabling policies.

One clear example is the Work Capability Assessment (WCA) for entitlement to ESA carried out at an additional massive cost to the tax payer by ATOS. Despite the fact that with representation 70% of those refused ESA win at appeal, despite the Harrington report, complaints by DPOs and CABs we are still hearing stories of individuals being declared ‘fit for work’ and placed into the work ready group when they have terminal illness, months to live, severe mental health conditions, and/or need 24 hour support. Nobody is asking the relatives of those who have committed suicide through the loss of benefits, nor those who threaten to why they feel they need to take this action.

**Monitoring the effective implementation of the Convention**

**What steps should Government take to ensure that disabled people’s views are taken into account when drafting their reports to the UN under the UNCRPD?**

There are already a range of groups involved in this for England: UKDPC, EHRC, and Disability Rights Watch. Local user-led organisations run and controlled by disabled people should also be encouraged to provide input into this through shadow reports detailing real life examples. Local groups should also be given the support and funding to establish a baseline measurement of where their area is in satisfying the key articles of the convention.

This would be of use in the intervening years until the next monitoring report is due in helping to of identify the impact of the cuts, the impact on independent living, and measurement of those things that may have improved. (although with current policies and practices this latter is unlikely to happen).

Most importantly ministers and others involved in making policy decisions should consult more widely with disabled people themselves. In particular the voices of those who are most disenfranchised and rarely are able to attend public consultations should be listened to. Those individuals who are least likely to get involved in reporting any failures to meet their convention rights should be actively sought out and their views noted and acted upon.
Often what such people experience is outside of the experience of those groups of disabled people such as Equality 2025 who do advise the government at present. Members of Equality 2025 are disabled people who have managed to negotiate the many barriers disabled people face relatively successfully but they often do not represent the views of those who have not.

**As part of the national monitoring mechanism, what steps should the EHRC, NIHRC and SHRC take to ensure that the Convention is implemented effectively?**

The EHRC, NIHRC, and SHRC should be a completely independent body not responsible to government in any way. It should have much stronger powers to enforce the convention. EHRC is currently viewed as weak in using its enforcement and other powers and this could be further undermined if the proposed cuts to staffing levels goes ahead. Sanctions for breaking the convention should be imposed at both national and local levels.
Introduction

1. NAAPS is the UK network for family-based and small-scale ways of supporting adults to live independently and to contribute to their families and communities. Our members are Shared Lives carers and workers, Homeshare programmes and micro-enterprises.

2. We help our members to work together to survive, thrive and influence decision makers, providing support, training, events, resources, research and campaigning. Our social enterprise, Community Catalysts, employs ‘fixers’ in local areas who identify very small 'micro-enterprises', offer them tailored support and advice, connect them with each other, and help the council to avoid inadvertently regulating them out of existence.

3. Our members’ work is characterised by a number of features which are at the heart of implementing independent living. Our members’ interventions:

   • are built upon family and community relationships, mixing paid and unpaid contributions;
   • focus on choice, inclusion and independent (or more accurately, inter-dependent) living;
   • find new, sometimes state-free solutions to problems traditionally tackled by a statutory service;
   • require the state to step back, create space or operate differently.

4. The given definition of independent living as being about “disabled people having the same level of choice, control and freedom in their daily lives as any other person”, does not mention the importance of relationships and a sense of belonging. Our members’ services attempt to achieve these things as well as independence.

5. There are 10,000 Shared Lives carers in the UK (and growing) and tens of thousands of micro-enterprises (many operating below the radar of councils). Here are some case studies:

Alison, Mark and Neil—a pub solves a drink problem

6. Alison and Mark run a pub in a seaside town. Neil, who has a learning disability, spent a lot of time drinking in pubs around the town, and gradually spent more and more time at Alison’s pub. Alison and Neil were concerned about his drinking, his behaviour and increasingly, his safety. He even began sleeping rough on their doorstep. Alison and Mark approached the council and were told about Shared Lives. They put themselves through the recruitment, training and approval procedures and became registered Shared Lives carers.

7. For the first time, Neil now looks people in the eye. He takes care of his appearance and has control over his drinking; people say they can now understand his speech. He has achieved long-held ambitions like going to Wembley. Neil says “Now I know what I wanted:
what I wanted was a family”. Alison says “His behaviour has changed completely. He brings a whole new dimension to our lives, we get as much pleasure as he does in our ‘family’. We are even thinking of getting out of the pub trade to become full time carers”.

**DanceSyndrome— finding a way to make a real contribution**

8. Jenny has a passion for dancing. She also happens to have Down’s Syndrome. With support from her Mum and her personal assistant paid for through a personal budget, Jenny has established a social enterprise to take dance into the homes of people with a disability to increase their health and wellbeing. Jenny is currently undertaking training designed for people with a learning disability to develop their skills as dance leaders. She is now working with a number of other dancers, disabled and non-disabled. The support of Jenny’s Mum and family is crucial to sustaining the enterprise.

**John and Shared Lives**

9. John had lived in residential care for most of his life and lost touch with his family. His happiest memories were of early childhood growing up on a farm. Through Shared Lives, he was matched with a farming family and lives as part of that family on a permanent basis. He has been able to use his newly acquired farming skills to get work with a neighbouring farmer, is part of the neighbourhood watch scheme and gave a star performance in this year’s village pantomime. He feels a sense of belonging for the first time, as well as experiencing a more independent life.

10. More case studies and articles are available on request and at:

10.1 [www.naaps.org.uk](http://www.naaps.org.uk) and [www.communitycatalysts.co.uk](http://www.communitycatalysts.co.uk)


10.6 Our blog: [http://alexfoxblog.wordpress.com](http://alexfoxblog.wordpress.com)

**Our responses to your questions**

**11. Impact of personal budgets and Direct Payments**

11.1 Personalisation is about people having more choices, more control, more opportunity to contribute. Changing the way the money moves around (through introducing personal budgets and encouraging people to take them as Direct Payments) is only one part of making this happen. People who don’t want control of the money still want control of their lives. Having control of the money makes no difference without ensuring that there is a growing choice of small support providers, not a diminishing group of cut-price care supermarkets.
11.2 Some councils have tried to impose unnecessary and damaging rules to restrict people’s use of personal budgets or Direct Payments, or have told people they can only have a Direct Payment if their allocation is at least a minimum amount. Some allocate Direct Payments based on hourly rates for employing personal assistants, which is not necessarily the most creative and effective use of the money for everyone. None of these rules are lawful or good practice. The point of giving people a payment rather than the service it would traditionally have paid for is to enable them to widen their choices, not to find new ways of restricting them.

12. From independence to inter-dependence

12.1 There is a perception in some quarters that independent living is always about living on your own. How many of us really aspire to this? It should be a choice available to everyone, but forced on no one. A group of young disabled adults who had been brought up together in care and had little contact with their families had to fight to stay in their shared accommodation, because the council’s new policy was everyone to live in their own place, in the name of personalisation. Furthermore, most care and support has always been, and will remain, delivered by unpaid family carers: their role and the importance of family relationships is central to genuine personalisation. We all live inter-dependently, within complex webs of relationships and most of us crave a sense of belonging. Those are hard things to achieve just through better service provision; they require much wider attitude changes and more accessible and inclusive communities.

12.2 Our members’ services, particularly the Shared Lives services, enable people who need support to live the life of their choice in an ordinary family household in the heart of their community. Shared Lives carers and people who use Shared Lives are matched for compatibility in recognition of the fact that both must feel positive about the arrangement for it to be a real relationship, rather than a professional/client interaction. Both parties are expected to be able to contribute something positive to the relationship. This is all part of ensuring that people are able to achieve a sense of belonging, which is as important to many people as a sense of independence.

12.3 The focus on social care being delivered by individual Personal Assistants (PAs), employed by individual budget holders, has some drawbacks for some people. Whilst some people wish to be employers of those who support them, others are not looking for an employer/employee relationship. There is also evidence from Europe (see Prof Caroline Glendinning’s work for JRF) about the potential for exploitation or risks to independence on both sides in employer/ PA relationships. These arrangements may have little in the way of back up when the PA is sick, on holiday or turns out not to be suitable. Micro-enterprises, which sometimes involve small groups of PAs grouping together to form partnerships, can retain the empowerment and personalisation whilst introducing more back up, peer support and sickness cover. They also do not necessarily require the people who use the service to take on the responsibilities and liabilities of becoming an employer.

12.4 One final frontier of personalisation is recognition that adults with learning disabilities are increasingly likely to be parents with children of their own. As a society we have become more accepting of disabled people having sexual relationships and forming partnerships, but not of their right to have children. NAAPS works with CHANGE and Homestart to campaign on this issue. Shared Lives is proving an affordable way of providing support and accommodation to parents and their children, which safeguards children whilst helping parents to gain parenting skills and become good enough parents.
13. The impact of cuts

13.1 Shared Lives (see case study above), by providing much more space for flexibility and creativity than that found in traditional professional/client transactions, is not only able to provide a much more tailored and responsive service which promotes independence, but also one at a much lower cost than alternatives. People with complex disabilities and health issues can nevertheless be supported with much less intrusive and professionalised interventions, partly because for some individuals, some of their perceived problems (such as ‘challenging behaviour’), arise from their interaction with a service which does not meet their needs.

13.2 For instance, ‘Alan’ is a 22-year-old young man in South Tyneside with a diagnosis of Asperger’s Syndrome. Following a breakdown within his family home and then in a residential placement, his behaviour deteriorated and he began to drink to excess despite the best efforts of a number of expensive ‘out of area’ placements. Some health professionals felt that Alan’s support needs could not be met in a family home, but potential Shared Lives carers were identified and the matching process commenced. Alan has now been supported within the scheme for three months without any incidents. He has stated that he is “very happy and wants to stay with his carers for the rest of his life”. He has begun accessing community education classes and leisure centres and is also contemplating a work experience placement. The saving to the Local Authority by providing support within the Shared Lives Scheme rather than the Residential Care Home is £49,000 per annum (£965 per week).

13.3 When people are given the space within which they can operate more creatively, they will often contribute more of their own, unpaid, time and resources. Richard Jones, President of the Association of Directors of Adult Social Services, when talking about Shared Lives said, “You can’t specify love in a contract”.

14. The impact of ideas about Big Society upon disabled people and independent living.

14.1 The Big Society concept is being launched at a time of public service cuts, so it is understandable that in the minds of many people, “smaller government” and “shrinking public services” are conflated. It is our view that it would be a great pity if the debate about cuts precluded a sensible discussion of where the state should draw back, move sideways, or indeed step forwards to intervene in ways it has not previously.

14.2 We support the drive to empower communities and individuals who use services. We advocate the involvement of people who use services in designing services, using outcomes as a starting point. Where existing services are not able to deliver outcomes, individuals, families and community groups should be supported to devise their own micro-enterprises and to share in their ownership. Having ownership of a new service, which has been specifically designed with you in mind, is potentially much more empowering than simply being given the opportunity to have your say on an existing service, in which you have no ownership.

14.3 The ‘DanceSyndrome’ example above is an example where statutory funding, which might previously have been used to fund a service indefinitely, has been used creatively to
help the individual to establish a new enterprise. This is not yet an income-generating enterprise, which would have the potential to reduce the amount of state support needed by the individual in the long term, because current benefits rules make the risk of taking up income untenable for someone who is likely to have long term support needs. But it does promote independence in other obvious ways.

14.4 There remain many barriers to disabled people forming and owning their own services and enterprises, including regulatory barriers and outdated commissioning practices. The former are being addressed by ourselves working with government departments as part of commitments made in the Chancellor’s growth review. The latter remain intractable in many areas, with councils promoting personal budget uptake on the one hand, whilst on the other, failing to ensure that people have a choice of small and large providers from which to purchase a greater range of care, and the option to pool budgets and create their own service where no suitable service exists.
This submission to the Joint Commission on Human Rights inquiry into the implementation of the right of disabled people to independent living has been made by Housing Options and the National Development Team for Inclusion (NDTi). This response focuses on the rights of people with learning disabilities to live independently.

Housing Options is a national charity that enables people with learning disabilities, families and the organisations that support them to make informed choices about getting housing and support by providing information and advice about housing and support options, welfare benefits and the legal framework that support all of the components of living independently. Housing Options has been central to developing national policy and good practice guidance around independent living for people with learning disabilities.

The NDTi is a not for profit organisation concerned with promoting inclusion and equality for people who are at risk of exclusion and who need support to lead a full life. We have a particular interest in issues around age, disability and health. In undertaking this work, we particularly aim to:

- Shape and influence policy and public debate
- Enable a stronger voice of people to be heard
- Support services to work differently so that they promote inclusive lives
- Support communities to be welcoming and inclusive

NDTi has a wide remit of activity covering a range of different groups – this response is specifically based on our experience of the lives of people with learning difficulties.

1. Policy changes needed to support the rights to independent living

- A clear entitlement to funding for housing and social care
- The freedom to move to other local authorities – better policy around the issue of ordinary residence

1.1 A clear entitlement to funding for housing and social care

“We believe that the right to independent living should continue to form the basis of government policy in the UK”

We see policies across housing and social care already support the right for people with learning disabilities to live independently but these are less developed in a clear entitlement to the housing and social care needed to make independent living a reality rather than just a right. Delivery and practice does not always follow policy and professionals still retain power and control over disabled peoples lives. Often, the process of getting the housing and
support necessary to live independently is very complicated and relies heavily on local political will and leadership at any given time.

We believe in the principles of localism and devolving power but this, combined with the removal of national performance indicators and the lack of clear entitlement to housing and social care presents a ‘postcode lottery’ situation for disabled people that is clearly unacceptable. We believe that the rights to live independently need to be enshrined in delivery and practice with clear national entitlements to housing and support.

1.2 The freedom to move to other local authorities – better policy around the issue of ordinary residence

Despite some efforts to improve procedural aspects of the current position, in recent years the Ordinary Residence rules have operated in a way which hinders the implementation of Government policy which itself reflects the changing preferences of people with learning disabilities.

In particular, moves towards the implementation of the personalisation agenda will be seriously restricted for many people unless changes are made. It is not simply a case of improving administrative cooperation between the Local Authorities involved. A more fundamental shift is needed along the lines set out in the recent Law Commission proposals i.e. to give Local Authorities the duty to pay for services for people not ordinarily resident in that Authority.

In its recently published guide ‘Feeling Settled’—a guide to changing services from residential care to supported living for people with learning disabilities the NDTI authors note that:

“Ordinary Residence issues can represent the most significant barrier to progress […]”

And highlights the reality on the ground that increasing people’s rights, choice and control can be seriously hindered by the existing position.

This position is not fundamentally altered by the recent guidance produced by DH in April 2011.

Changing services from residential care to supported living can:

- Offer people the opportunity to exercise their rights as citizens notably the right to a tenancy and to increased personal income
- Offer people greater choice and control over where they live, with whom and how they are supported
- Be part of moves towards greater personalisation of social care services
- Allow for greater flexibility and choice in services provided
- Enable the best of the resources available.
Working within Ordinary Residence restrictions can seriously hinder progress in this direction and there are many personal stories that offer moving accounts of the impact this can have on the quality of people’s lives.

In 2007 the Voluntary Organisations Disability Group document ‘No Place Like Home’ set out a persuasive case for change. Two of its three recommendations remain relevant following the issue of recent DH guidance:

- Establish and enforce the principle that a person should receive appropriate social care and support from the authority where they are currently living, or wish to live, regardless of circumstances;

- Put in place a framework for the transfer of funds between authorities so that the issue of ordinary residence can no longer be used as a basis for refusing to provide care and support.

This is a situation where without additional cost to the taxpayer, changing the approach to Ordinary Residence can greatly improve the choice and control of many people using services that are not suited to their needs and preferences. When services are operating within such tight financial constraints, opportunities should be taken to deploy the resources available to greatest effect. As they apply at present, the Ordinary Residence rules are wasting money and not delivering policies which will improve the quality of lives of the people involved.

2. Restrictions on local authority funding, social care budgets and benefits reassessments

The following outlines our response to specific changes to welfare benefits and budgets that we believe will hinder the ability of people with learning disabilities to live independently;

2.1 Removal of the mobility component of DLA from people living in residential care

The Disability Living Allowance mobility component is an entitlement because people with disabilities need extra help to go out, get to work or college and generally take part in their communities. For people with disabilities living in residential care, this is no different. What is often different for people living in residential care is that their DLA mobility is usually held by the care home provider and used to fund shared transport and so they have less control over how their DLA is used.

Housing Options believes that the residential care model is already restrictive on disabled peoples rights to live independently and we advocate for a range of housing and support models that enable people to live independently and have choice and control over their lives. We actively support residential care providers to change their model of care and develop supported living models. That said, we feel that the removal of the DLA mobility component for people living in registered care homes is an additional restriction on what are already restricted lives.

2.2 Changes to the Independent Living Fund
The changes to the Independent Living Fund (ILF) blatantly discriminates against people with learning disabilities in that the criteria has changed to those working for 16 hours a week or more. The ILF already had a restrictive criteria that was clearly geared towards physically disabled people in that the criteria to be in receipt of high rate care component of the Disability Living Allowance. The requirement of both criteria together is highly likely to rule out most people with learning disabilities from being eligible for ILF.

The ILF has had much lower take up from people with learning disabilities than other disabled groups nationally but it has been a valuable source of funding for those with people with learning disabilities that have higher support needs whose only alternative would have been to go into residential care without the fund.

The ILF, as a discretionary and restrictive fund is outdated and unfair to some groups of disabled people, particularly as we are moving towards personalisation and a funding system that is fair, transparent and with less bureaucracy and complexity.

2.3 The reduction in local funding for social care

The last 10 years has seen a major shift away from placing people with learning disabilities in institutions and care homes towards enabling more ordinary housing options and therefore more ordinary and equal lives.

Local authorities across the country are having varied reactions to having to make budget cuts. Some are raising eligibility criteria for social care. Others are cutting frontline services that are not seen as essential such as advocacy and community support. A strong message from across the country is that local authorities believe that they cannot afford to give personal budgets and will only be able to offer what they believe are the less expensive traditional services. We believe that some of this reaction is based on flawed assumptions about affordability and a lack of imagination and creativity in enabling people to live independently, but local authorities have the power to make the decisions that they believe are right.

Some decisions to cut social care budgets and voluntary sector services are being made by councils who have a good track record of supporting people with learning disabilities to live independently but believe they have no choice to cut back all but the most essential services because funding from central government has been cut back so drastically.

Not only do some local budget cuts conflict with the rights of disabled people to live independently but they are also likely to cost councils and the state more in the medium to long term. The cost of ‘warehousing’ people with learning disabilities has been expensive both in monetary terms and in the cost to many thousands of individuals in the ability to lead an equal and independent life. Institutions have made people with learning disabilities more dependent and less able to do things for themselves and live a more independent life.

Raising eligibility criteria simply creates a crisis led response to social care and encourages disabled people to exaggerate their needs just to get often very simple needs met. It discourages a preventative and low level approach to meeting needs which if we disinvest in, will only cost local authorities more in the long term.

We are still undoing the impact of institutionalisation and that in itself it is an expensive task. A major threat from these cuts is that we undo years of hard work to support people
with learning disabilities to live more independently and return to the false economy of crisis led ‘warehousing’ provision.

3. Restrictions on funding and welfare benefits related to housing

- Reduced spending on social housing,
- Changes to Support for Mortgage Interest.
- Changes to Local Housing Allowance

3.1 Reduced spending on social housing

Spending on social housing will be cut by 60% and an increase in social housing rents is expected to fund new development. It is not yet clear whether this rent restructuring will make up the shortfall in funding for new development. Decisions about funding on social housing will be made locally and whether or not people with learning disabilities get social housing will be dependent on whether the adult social services department has good leadership, a strong enough voice and can present the case for more housing for people with learning disabilities against other competing priorities.

When in the past we have experienced a relatively good economic climate with higher public sector spending, local leadership to enable people with learning disabilities to live independently has varied greatly across the country, from pockets of good practice to mainly mediocre and poor leadership. Despite independent living being enshrined in the rights of people with learning disabilities and that there has been funding available, the facts are that the majority of people with learning disabilities live in residential care or the family home because of the lack of local leadership and knowledge about independent living rights and options. This is likely to get worse with the removal of national performance indicators and the reliance on local leadership to increase the capacity for independent living.

3.2 Changes to Support for Mortgage Interest

Buying a home and funding an interest only mortgage through Income Support has now become virtually impossible for disabled people following a reduction in the levels of interest the DWP will pay (6.08% to 3.63%). This change has coincided with new FSA guidance to lenders and at present all mortgage products aimed at people with disabilities have been taken off the market. The Homes and Communities agency are currently actively promoting the Home Ownership for People with Long term Disabilities (HOLD) product through the affordable housing programme yet housing associations are unlikely to bid for funding for this type of housing if disabled buyers cannot get a mortgage.

3.3 Changes to Local Housing Allowance

Renting from a private or non registered social landlord will be restricted because of changes to Local Housing Allowance that bring the rates down to the lowest 30th percentile of local rents. This will have a particular effect on people with learning disabilities needing to live in areas of higher cost housing in London and the Southeast. It will also impact on people who require housing that is outside of the ordinary such as having more space, or who need to live close to family or friends to get support to live independently. A sum for discretionary housing payments will be made available to local authorities to make up the
Written Evidence submitted by the Housing Options & National Development Team For Inclusion (NDTi) (IL 47)

rent shortfall for existing and new customers but these payments are discretionary and cannot be guaranteed for a long term. The allowance to reflect the need for an extra room when overnight care is a welcome development but despite this positive move, the option of privately rented housing for some people with learning disabilities too insecure and/or expensive to contemplate.

4. Conclusion

There are four major budget cuts and welfare benefit changes that will have a combined impact of severely restricting the opportunities of people with learning disabilities to live independently;

- The reduction in local funding for social care
- Reduced spending on social housing
- Changes to Support for Mortgage Interest
- Changes to Local Housing Allowance

The three main housing sources—public sector, private sector and home ownership could effectively be cut off as housing choices to many people with learning disabilities and will also be unlikely to deliver the intended result of making government savings.

Pressures on local authority social care budgets are likely to restrict the choices that people with learning disabilities should be able to make to get the support they need to live independently.

The combined impact on the restrictions to housing and social care for people with learning disabilities makes the right to independent living meaningless if there are not the resources and equitable systems in place to actually enable people with learning disabilities to live independently.

We believe that people with learning disabilities should have a transparent, fair and equitable entitlement to funding for housing and support based on individual needs that enables people to make real choices about where they live, who they live with (if anyone) and how they are supported. We believe that entitlements to housing and support for people with learning disabilities should not rely solely on changeable local leadership and politics.
The group feel that the timescales for responses are too tight. People will not know how the public sector cuts will have an impact on services by the end of April 2011.

The group feel that there will be the following impact:

- Public sector cuts will have an impact
- There will be fewer people who meet the Fair Access to Care Criteria
- There will be less housing support
- Fewer people will receive a Person Centred Plan
This response is made on behalf of the Lothian Centre for Inclusive Living (LCiL), a user controlled disabled people’s organisation, based in Edinburgh, that supports disabled people to access Independent Living and to have choice, control and dignity over their own lives.

**Background**

LCiL was established in 1991 by a group of disabled people living in residential care who wanted to live in the community and to have control over their own support. LCiL provides a range of practical and emotional services to support disabled people living in Edinburgh, Lothian and across Scotland to access Independent Living. For further information on LCiL, please see attached booklet: ‘Whose Choice Is It Anyway?’.

LCiL is an active member of the Independent Living Movement in Scotland and promotes full equality and social justice for disabled people.

At a time when disabled people are facing unprecedented cuts to benefits and services, when local authorities are restricting eligibility of care and when the Independent Living Fund is facing closure, disabled people are facing increased poverty, social exclusion and increasing barriers to Independent Living and to being able to participate in society. It is as a time like this that it is crucial that we should all continue to promote and champion the rights of disabled people to access Independent Living.

It is in this context that LCiL supports the UK Joint Committee on Human Rights: Inquiry into the Implementation of the Right of Disabled People to Independent Living

**1.0 The Principles of Independent Living**

Independent Living means “disabled people of all ages having the same freedom, choice, dignity and control as other citizens at home, at work, and in the community. It does not mean living by yourself, or fending for yourself. It means rights to practical assistance and support to participate in society and live an ordinary life”.

The principles of independent living, i.e. freedom, choice, dignity and control, do not only relate to the specific services and provisions for disabled people, but to the whole of disabled people’s interactions with society; its organisations, facilities and structures; and every aspect of their quality and equality of life:

- Full access to our environment
- Fully accessible transport
- Technical aids and equipment
- Accessible and adapted housing
- Personal assistance
• Inclusive education and training
• An income, including income within the state-benefit system for those unable to work
• Equal opportunities for employment
• Accessible and readily available information
• Advocacy and working towards self-advocacy
• Counselling, including peer counselling
• Accessible and inclusive healthcare provision
• Communication and appropriate support for communication
• Civic participation

Source: Independent Living in Scotland (ILiS)

2.0 The Impact of the announcement of the Closure of the Independent Living Fund (ILF)

LCiL supports a number of disabled people living in Lothian who receive funding through ILF. For those who received ILF it is an essential tool to enable them to participate in things like employment, education, leisure and social activities.

ILF is awarded to disabled people with the highest support needs. With continued restrictions to social work budgets and community care packages, ILF has been essential in ensuring that disabled people with the highest needs can continue to receive support that is more than just ‘life and limb’ support (eg: ‘help with bathing, eating and toileting’).

LCiL disagrees with the Government’s decision to close the ILF and believes that this decision will result in disabled people with high support needs becoming further excluded from the mainstream of society.

3.0 The decision, announced in the Comprehensive Spending Review, to remove the mobility component of Disability Living Allowance for all people living in residential care

According to the Disability Alliance, the decision to remove the Mobility Component of Disability Living Allowance (DLA) for all people living in residential care will effect 80,000 disabled people.

For those living in residential care the DLA Mobility component may be their only means of income and they may not be entitled to any other welfare benefits.

Removing the DLA Mobility component may also take away their only means of paying for transport costs to visit places like their doctor’s surgery, the library, the shops and to visit family or friends. For many disabled people living in residential care, the removal of DLA...
Mobility will only increase their further exclusion from society and create further barriers to accessing transport and independent living.

4.0 Restrictions on local authority funding, social care budgets and benefits reassessments

4.1 Restrictions on Local Authority Funding

In our own area, here in Lothian, local authorities have already restricted eligibility criteria to those assessed as being in Critical or Substantial need. Those with Moderate or Low Needs are not provided with any support from social work services.

Here is one Local Authority’s definition of Moderate and Low Needs:

‘Disabled people can be identified as having Moderate needs if, for example, they have an impairment or condition which is likely to get worse. They may need help with some personal care tasks, such as dressing and undressing and bathing. They may also need help with shopping and cleaning. Disabled people can be identified as having a Low needs if, for example, they are living at home and can walk around the home but have limited mobility when walking outdoors. They may also need help to get in and out of the bath.’

From the above definition of Moderate and Low needs it is evident that many disabled people who need help on a daily or weekly basis with personal care, mobility, shopping and housework are being refused support. This situation is being replicated not just in local authorities in our own area, but across the UK as local authorities continue to restrict eligibility criteria only to those in Critical or Substantial need.

LCiL believes that there needs to be further investment in community care services and personalisation, otherwise thousands of disabled people will be left without support until they reach a crisis situation. If as a society we believe that Community Care is about enabling disabled people to work, live, socialise, volunteer, participate and have the same choices as everyone else in society, then we need to continue to invest in community care services, rather than restricting budgets.

4.2 Restrictions on Welfare Benefits

The Government has announced £18 billion of cuts to the welfare budget with £9 billion of cuts directly impacting on disabled people. This, along with the announcements to cut the budget and caseload for Disability Living Allowance (DLA) by 20%, is pushing hundreds of thousands of disabled people into further poverty.

These draconian cuts could set back the Independent Living agenda by years as disabled people find that they are facing continual reassessment, appeals, exclusion from essential disability benefits, losing essential income and the means to pay for support and transport costs.

The Disability Alliance has said the following about the impact on disabled people of the Welfare Reform proposals:

‘Our main concern remains the abolition of working age Disability Living Allowance (DLA). We estimate over 750,000 disabled people will lose support as a result of this proposal—
which has been proposed to cut more than £2.1 billion from DLA support. The replacement benefit, the ‘Personal Independence Payment’ (PIP) will not provide the same levels of support as DLA. The PIP will axe the level of support which 643,000 disabled people currently receive but even this will not achieve the Government's cuts target. It will cost £675 million to run the new assessment process—paid for by cuts to disabled people’s direct support.

Currently, 643,000 disabled people receive the lower rate payment of care. Low rate care DLA is paid at £18.95 per week. Total payments amount to £634 million per year; this leaves a shortfall in meeting the cuts target of at least £366 million. The average DLA payment is £70 per week and using this figure we estimate a further 100,000 disabled people will lose support – a total of 743,000 people. The Government has also targeted 80,000 disabled care home residents for cuts to DLA mobility payments making a total number of disabled people likely to lose DLA support to over 823,000. This is a conservative estimate as we are excluding:

- children and older people who may be covered by the new assessment in due course; and
- the families/carers of the disabled people directly affected (losing access to Carer’s Allowance for example).’

5.0 The Big Society

LCiL believes that the Big Society can only be effective with proper investment in local groups and organisations to support local people to participate in their communities.

Disabled people’s organisations have a long history of enabling disabled people to participate in and become involved in their local organisations. The philosophy of much of the Disabled People’s Movement has been about disabled people’s organisations being user-led, enabling disabled people from local communities to be involved in policy making and service planning at a local level.

However, we are concerned that much of the current Government's policy on the Big Society is without substance or investment. Investment in public authorities, local government, the voluntary sector and the welfare state are all tools to enable participation in the Big Society. Lack of investment in local infrastructures and cutting funding to all of these areas will not be productive in enabling the Big Society to grow.
Introduction

The Scottish Government

1. In Scotland approximately 1 million people are disabled—20% of the population. Our approach to implementing the United Nations' Convention on the Rights of Disabled People (the Convention) is expected to complement and frame the Scottish Government's work to promote disability equality and independent living for all disabled people. The Scottish Government and partners have recognised disabled people as valued members of families, communities and workplaces, who make a positive contribution to the diversity of cultural and community life in Scotland and to the economic and social wellbeing of Scotland.

2. The Convention's commitment to disability equality and to disabled people's human rights has been supported at a strategic level in Scotland through the Common Purpose targets, National Outcomes and National Performance Framework. Equality is an integral part of the framework, which contains targets on participation, solidarity and cohesion, and a specific outcome 'to have tackled the significant inequalities in Scottish society.'

3. The Scottish Government has recognised the progress in policy and legislation as described in the annual disability equality report (December 2010). However we have been mindful of the continuing inequalities in Scotland's communities. Through a partnership with disabled people, the Government has sought to identify areas of policy and service delivery where more work is needed to ensure that disabled people can realise more choice, control, dignity and freedom, with a measurable impact on day to day lives.

Should the right to independent living continue to form the basis for Government policy on disability in the UK?

4. In 2008, in partnership with disabled people, the Scottish Government recognised independent living as the overarching commitment and high level policy framework for disability equality in Scotland. Scotland's commitment to independent living has been set out in a Shared Vision which was adopted in December 2009 by a partnership of Scottish Government, the Independent Living in Scotland (ILiS) Steering Group representing disabled people and their organisations, the Convention of Scottish Local Authorities (COSLA) and NHS Health Scotland.

5. Scotland's shared vision defined independent living in the following terms:

“Disabled people across Scotland will have equality of opportunity based on core principles of independent living: choice, control, freedom and dignity. It covers every aspect of an individual's life - maximising the opportunities for disabled people to

159 http://www.scotland.gov.uk/About/scotPerforms/outcomes/inequalities

160 http://www.scotland.gov.uk/PublicationS/2010/12/24082632/0

161 http://www.ilis.co.uk/independent-living/a-vision-for-independent-living-in-scotland/
participate fully in society and live an ordinary life— at work, at home and in the community”.

6. As the overarching commitment, the shared vision is intended to influence policy development and service delivery across national and local government and health boards. The Scottish Government has recognised that independent living is not something that can be achieved or promoted in isolation, but is cross-cutting and depends on a wide range of other policies and activities that affect disabled people’s independent access to daily living and are set out within other Articles of the Convention.

“For Independent Living to become a reality, people need to have access to housing, transport, new technology, education, jobs and leisure, and recreation in the community.” Self Directed Support, A National Strategy for Scotland.162

Do existing policy statements, including the Independent Living Strategy, represent a coherent policy towards the implementation of the obligations in Article 19 of the UN Disability Rights Convention? Could current policy be improved? If so, how?

7. The Scottish Government worked with disabled people to establish a Core Reference Group on Independent Living (CRG). The Group is a partnership of Scottish Government, disabled people, COSLA, NHS Health Scotland, the Association of Directors of Social Work and other public sector and disabled people's organisations. It is a cross-government group providing a framework and leadership which seeks to coordinate efforts across government and the wider public sector and to influence the culture and organisation of Scottish policy-making to help implement our combined approach to independent living in Scotland.

8. Scottish Government has funded the ILiS project of disabled people and their organisations (£372,000 from 2008–11 and a further £140,000 from 2011–12). The project team are employed by the Equality and Human Rights Commission (Scotland) and managed by a steering group of disabled people and their organisations. The ILiS project involves disabled people, across a wide spectrum of impairment types and their organisations, to strengthen and develop the Independent Living Movement in Scotland and to ensure disabled people have a strong voice in helping to shape the Government’s wider policy framework and public service delivery.

9. Further coherence has been added through joint funding of seconded posts with CoSLA and NHS. These posts are attached to the Scottish Government Equality Unit and contribute to a shared programme of work to develop local authorities and health boards perspectives and awareness.

10. The CRG’s approach was founded on a model of co-production where government and disabled people work together and benefit from each other’s respective knowledge and resources, to identify priorities and solutions.

11. The Scottish Government has recognised that access to self-directed support, including direct payments (cash payments to disabled people to enable them to arrange and buy their own community care and children's services) is fundamental to disabled people's experience

162 www.scotland.gov.uk/Publications/2010/11/05120810/0
of independent living. Disabled people have told us that support that is directed by disabled people themselves is the key to achieving real choice, control and freedom over how they live their lives.

12. In the year ending March 2010, 3678 people in Scotland had direct payments, an increase of 22% from the previous year. No data is currently available on self-directed support mechanisms other than direct payments. Scotland’s Self-directed Support Strategy 2010 seeks to radically increase the uptake of self-directed support, providing a range of options to give people more choice and as much control as they wish to take in designing and commissioning their care and support. Whilst initially focusing on health and social care, the future development of self-directed support will look at ways of giving people better access to education and employment. The Scottish Government has already consulted on a draft Self-directed Support Bill which aims to ensure that self-directed support becomes the mainstream approach to the delivery of personal support in Scotland.

13. As well as the core work on self-directed support, the Scottish Government and CRG partnership has carried out strategic activity to build capacity, awareness and commitment across the partnership and to increase the number of policy development areas where disabled people are participating as partners. Disabled people, as partners in the CRG, identified policy areas of Housing, Inclusive Communication, Portability of Care and access to Advocacy, and as key to independent living.

14. Housing: the Scottish Government has provided funding of 100,000 in 2010–11 and £90,000 in 2011–12 to a partnership of disabled people’s organisations to facilitate disabled people’s contribution to a national review of housing policy and develop an accessible housing register to give disabled people greater choice and control over suitably adapted accommodation to match their needs. Two local authority co-production pilots have also been given funding of £40,000 from Scottish Government to promote disabled people’s involvement in local policy development and strategic thinking. These pilots are expected to inform and develop local housing strategies to meet the needs of their specific communities.

15. Inclusive Communication: disabled people have been working with Government to create a new national statement of inclusive communication principles and indicators to measure progress. The document has been designed to be an information and self-assessment tool for public bodies and to offer a practical approach to delivering inclusive communication. Scottish Government have provided funding to Communication Forum Scotland to promote this work across the public sector. The document is expected to be included in the Public Service Improvement Framework (PSIF) guidance for 2011. PSIF is based on the European Foundation for Quality Management (EFQM) Excellence Model and was jointly developed by partners including Quality Scotland and Investors in People to create a culture of excellence within organisations. PSIF is currently used by 34 public, voluntary and arm’s length organisations across Scotland.

16. Portability of Care: disabled people have joined government and health boards to promote a human rights approach to portability of care in Scotland, where the barriers preventing disabled people from taking a package of care from one local authority area to another are at first minimised and eventually removed. This work has focused on local authority charging policies, guidance and eligibility criteria. On 6 April 2010, the Scottish Government issued revised guidance to local authorities on the recovery of expenditure on
accommodation and services under section 86 of the social work (Scotland) Act 1968—
Ordinary Residence 163

17. Advocacy: the Patient Rights (Scotland) Bill, 164 passed in February 2011, makes provision for the establishment of the Patient Advice and Support Service. The aim of the service is to raise awareness of patient’s rights and responsibilities and to provide advice and support. This will include advice in relation to other support services such as advocacy and will improve disabled people’s awareness of the availability and access to these services, so that they can exercise their full rights to independent living. Other statutory and policy routes to advocacy include the Mental Health (Care and Treatment) Scotland Act 2003, which gives everyone with a mental disorder a statutory right of access to independent advocacy; the Carers Strategy; 165 The same as you? 166, Scotland’s strategy on learning disability; and the CRG partnership’s new work on inclusive communication principles and indicators.

18. The Scottish Government has provided £40,000 to fund independent research to look at how effective our approach to independent living has been, how it can be improved and to identify future indicators of progress towards our shared vision.

What steps, if any, should the coalition Government, the Scottish Government or other public agencies take better to meet the obligations in Article 19 and to secure the right to independent living for all disabled people in the UK?

19. Not for Scottish Government during the Scottish Parliament election period

If you consider changes to policies, practices or legislation in the UK are necessary, please explain.

20. Not for Scottish Government during the Scottish Parliament election period

What impact does funding have on the ability of the UK to secure the right to independent living protected by Article 19 of the UN Disability Rights Convention?

How will recent policy and budgetary decisions impact on the ability of the UK to meet its obligation under Article 19 to protect the right of all persons to independent living?

21. The Scottish Government has recognised the significant issues which have arisen in relation to the UK’s current financial situation and the impact of measures to tackle the budget deficit on public expenditure. The link between disability and poverty is well known and disabled people across Scotland have expressed strong concerns that reduced spending on public services, combined with the impact of UK welfare reform, could leave disabled

164 http://www.scotland.gov.uk/Topics/Health/PatientRightsBill
165 http://www.scotland.gov.uk/Publications/2010/07/23153304/0
people facing greater barriers to independent living and to their ability to participate fully in society and contribute to the wider economy. Disability-related benefits, such as Disability Living Allowance and the provisions of the Independent Living Fund, have been essential in enabling many disabled people to be in employment and live independently in their own homes.

22. The Scottish Government recognised the severe pressures that are likely to face Scottish public services and public spending across the next 5 to 10 years when the demand for services is likely to increase sharply across the same period. Ministers expressed concern that the expected reductions in benefits for disabled people are likely have a disproportionate impact on Scotland's local authority services and spending. The Scottish Government's aim has been to ensure that spending decisions taken at national and local level support independent living as a key principle and do not inadvertently create additional barriers. To this end, the Scottish Government has worked closely with disabled people, COSLA and other key stakeholders to assess the potential impact of welfare reform decisions on Scotland.167

23. The Scottish Government has also worked closely with disabled people and COSLA to identify and promote ways of influencing budget decisions across the public sector as part of our commitment to independent living in Scotland. This partnership with disabled people has contributed to our understanding of the opportunities to reshape public services so that they support, rather than inhibit, independent living. Disabled people and their organisations, as members of the CRG, have made substantial and influential contributions to the work of Scotland's Independent Budget Review, which reported168 in July 2010 and to reviews undertaken by the Scottish Parliament Finance Committee in response to current economic circumstances, including its Report on Preventative Spending169 of January 2011.

What steps should the Government take to meet its obligations under the Disability Rights Convention to involve disabled people in policy development and decision-making, including in budget decisions such as the Comprehensive Spending Review?

Are the current arrangements for involvement of disabled people in policy development and decision-making working?

24. The Scottish Government has taken seriously its responsibilities to promote, champion and facilitate the direct involvement of disabled people in the development of policy across government. Working with disabled people to identify solutions has been an important part of our work on independent living, and will be crucial to its success. We have stated that enabling disabled people to be partners is not just the right thing to do in principle; it is practically sensible given the challenges that public services face. Making 'best use of resources' means drawing in the widest range of resources possible and direct involvement allows that to happen.

168 www.independentbudgetreview.org
25. Scottish Ministers have made a conscious decision to retain the funding level for equality work for the year 2011–12. In these very difficult economic times, this is a good indication of our continued commitment to ensuring that all the money that will be available to us is spent in the most efficient way possible, and where it will have the greatest impact on local communities. Capacity-building is already a significant part of our funding to disabled people's organisations. Our funding for disability equality (£1.9 million from 2008–11 and a further £866,000 from 2011–12) has helped to build a comprehensive framework through which disabled people can become more active and engaged in daily and public life and contribute directly to our overarching work on independent living and the development of policy.

26. The ILiS project is fully inclusive of disabled people across the widest range of impairment types and the 'Voice of Disabled People' is a standing item on the agenda of all meetings of the Independent Living CRG. ILiS has recruited and supported Independent Living Ambassadors to inspire other disabled people to take action and provided resources and information for the Movement and other disabled people.

27. Disabled people's engagement with the Scottish Government, through ILiS and our Policy and Engagement Officers' Network, has fostered disabled people's direct relationship with policy officials and increased the number of areas where disabled people are contributing to policy development from the start. This engagement framework has also provided opportunities to raise awareness of this UN Convention through events at which disabled people attended as audience members, and also contributed to as workshop participants, co-presenters and partners in our work on independent living.

As part of the national monitoring mechanism, what steps should the EHRC, NIHRC and SHRC take to ensure that the Convention is implemented effectively?

28. Not for Scottish Government

8 April 2011
Thank you for your letter of 25 October to Alex Neil about the Joint Committee’s enquiry into the Right to Independent Living.

Your letter relates to the Joint Committee’s sessions on 14 June with the various national human rights institutions across the UK, and to the session on 25 October with Ministers. On the former, the national human rights institutions referred to their perception that there are differences in how the right to independent living is interpreted in the different nations of the UK. That will be the case, of course, because we all start from a different base. In Scotland historically we have a legal system that is distinctively different from that in England or Wales; and we have our own legislation built up through the nineteenth and twentieth centuries on issues that are now devolved, including civil and criminal law, policing, education, housing, social care, healthcare, and transport etc.

This all reflects our needs in Scotland. In addition to this, the different nations have all been affected by wider developments over the years—changes in social and health care practice across the UK and, indeed, western Europe and Australia and New Zealand, higher public expectations of services provided by government, greater interest in equality issues, and of course the Universal Declaration of Human Rights and the UN Convention on the Rights of Persons with Disabilities.

This means that the great changes that have occurred in the last 20 or 30 years in health and social care—for example the closure of long stay hospitals for people with learning disabilities; the whole debate around medical and social models of care, resulting in increasing care at home and the move away from a medical model; and more recently the personalisation agenda—are common across the 4 nations of the UK. So while the interpretation may be different, I think you will find that we are all moving in the same direction, making changes that are conducive to, and support, independent living.

The issues raised with the Ministers for Housing and Local Government, for Disabled People, and for Care Services on 25 October were how the right to independent living is translated into action in housing, health and social care. Many of the issues that arose that day are relevant to Scotland, though in the context of our legislation, policies and practice. These matters are devolved, of course, as Maria Miller stated in her evidence on 25 October, and we are accountable to the Scottish Parliament for our responsibilities under UN Conventions in these areas.

The Memorandum Alex Neil sent to you on 8 April under the heading Protecting the Right of Disabled People to Independent Living remains relevant, and we do not wish to add anything further now. In closing, however, I would reiterate the point Alex Neil made then - this is that the Scottish Government recognises the Convention as an international benchmark for the human rights of disabled people against which states, including the UK, and therefore Scotland, will be measured.

16 November 2011
1. Introduction and Background

This response to the Inquiry has been prepared by Surrey Coalition of Disabled People and the 5 Empowerment Boards for people with physical and sensory impairments in Surrey.

The aim of the Surrey Coalition of Disabled People is to campaign and promote the rights of Disabled People to have equality of opportunity and to live independently. This means influencing the policies, strategies and services which impact on the lives of disabled people to make them better and more accessible for everyone.

The 5 Empowerment Boards are groups led by a majority of disabled people that work proactively within their local area in Surrey to design and shape services that they use or will do in the future. The Boards are chaired by disabled people, who encourage others to empower themselves to make a difference.

Those who contributed to this response were aware that the Independent Living Scrutiny Group had reviewed progress on implementing the Independent Living Strategy since 2008. However changes have not always been made for the better and alarmingly some people reported less choice and control. However it was noted that those in receipt of Individual budgets had seen some improvement.

When responding to this Consultation those present were aware that the UN Convention is not a legal requirement, however there is a duty on all Public Authorities to promote the rights of disabled residents. It was hoped that the Right To Control, which is currently a legal Right in trailblazer areas including Surrey, should increase the rights of disabled people as seen by those in receipt of an individual budget.

2. Our Consultation process

Our response to this Consultation comes on behalf of a diverse range of disabled people including those with physical, sensory ad cognitive impairments, people with learning difficulties and those with mental health issues. The response incorporates the views of those who attended a dedicated meeting held on 11th April 2011.

3. Response to the questions posed in the Call for Evidence

3.1. What steps, if any, should the Coalition Government, the Scottish Government or other public agencies take, better to meet the obligations in Article 19 and to secure the right to independent living for all disabled people in the UK?

The Government should create legislation which would ensure that public bodies received mandatory awareness training. Ignorance as to what Equality means could not then be used as an excuse for denying disabled people’s right to independent living. Disabled people should be involved in the development of all policies, as is now common practice within Surrey.
The diluted Equality Act now does not require Local Authorities to ensure Independent Living. The new Act only offers protection against discrimination. The term ‘reasonable adjustments’ is subjective and open to varying interpretation.

It is essential that private businesses meet all the requirements which prevent discrimination and ensure equal access including Disability Awareness. The Offices and Shops Act and the Health and Safety at Work Act equally apply.

All agreed that current legislation is weak, for example:—

— non enforcement of building regulations requiring buildings to meet accessibility standards.

— next generation of housing stock needs to be accessible. Legislation and agreements with the construction industry in this area has not been enforced effectively.

— Accessible housing needs to create space for care workers and any equipment required. Minimum standards should be developed. Disabled People must be involved in designing housing.

— As part of the ‘Big Society’ local small voluntary organisations will become more important to everyone, and especially disabled people. However many of these organisations are inaccessible to disabled people due to lack of funds. Additional funding should be made available to these organisations in order to make them accessible and able to include disabled people.

— Treat all disabled people as individuals. Local Authorities need to meet individual needs.

— Fewer assessments. More initiatives needed to prevent duplication, such as ‘Right to Control’.

3.2. What Impact does Funding have on the ability of the UK to secure the right to independent living protected by Article 19 of the UN Disability Rights Convention?

It is widely recognised that disabled people are more likely to be living in poverty than other groups. There have been swingeing cuts to all Local Authority budgets. This in turn affects all services provided by the Local Authority including Adult Social Care. Surrey County Council are trying to make savings through internal restructure etc but there is no doubt that funding cuts will impact on disabled people.

It is essential that Local Authorities continue to implement Self Directed Support which gives individuals control over their own funds. It was felt that the eligibility criteria for Adult Social Care services limits people’s rights to Independent Living, which is in turn limited by the amount of funding given by the Government to the Local Authority. The criteria for Social Care Support needs to support Independent Living. Currently there is no ‘right’ to this support.

There seems to be a human rights issue around how resources are allocated to individuals for their support. In between supported self-assessments and personalised services is the
critical decision making process that judges the amount of public funds a disabled person should have to meet their agreed outcomes. Disabled People have a right to this process being transparent and that the decisions should be taken by people familiar with their individual circumstances.

The modern day ‘parish boards’ in the form of panels consisting of service managers in Local Authorities seem to be thriving despite having always been legally dubious because of their remoteness from the individual under assessment. In the newly reformed benefits system, panels of medical ‘experts’ have already been criticised for their impersonal approach. One idea could be for applicants to be entitled to an advocate from a local Disabled Peoples Organisation who could be funded to support the panels and appeals hearings in their area.

In the age of ‘think local, act personal’ we ought to have a case for resource allocation processes being as informed by a disabled person’s own experience as possible.

The benefit of Disabled Peoples Organisations being involved in delivering Independent Living needs to be more widely recognised. Those living in Surrey have benefitted from the support given to user led organisations in Surrey. However despite the implementation of Self Directed Support as social care policy, it has yet to be fully accepted in the culture of practitioners.

Funding cuts and internal reorganisations (designed to save money) have had an impact on Adult Social Care Services in Surrey. There has been a loss in the continuity of care (e.g. Occupational Therapists relocating to different areas). It is clear that reductions in funding will effect front line staff despite the best efforts of individual Local Authorities only to reduce backroom staff.

The statement that ‘public services create dependency’ is misleading and offensive. Disabled People need public services and the use of these services have helped disabled people to be more independent. We are concerned that:

— Plans for a ‘Big Society’ may well mean that disabled people will be left to rely on support from the goodwill of friends, family and neighbours, thereby compromising our equality as citizens.

— There appears to be an emerging distinction between ‘deserving and ‘non deserving’ disabled people.

— Those with less obvious impairments may be discriminated against because they are not seen as ‘genuinely disabled people’.

— Advocacy is very important and there is a need for much greater provision of all kinds of advocacy.

— Cuts in Grants awarded to voluntary services will reduce the level of services available to disabled people and reduce the capacity of user led organisations.

With less money available, Local Authorities will have to award bigger contracts to fewer suppliers which will result in less choice.

Cuts in funding to Citizens Advice Bureaux has already reduced advice and support services, a significant concern given all the changes to welfare benefits.
More use should be made of IMCAs (Independent Mental Capacity Advocates) to support choice for people who lack capacity. It is recognised that older disabled people receive less choice and control than working age disabled people. Advocacy is needed for those in care homes to speak up for what they want. The effect on the independence of those living in care homes should they lose the mobility component of DLA. Disabled people are currently living in anxiety generated by rumour and policy proposals that have not been discussed with disabled people.

3.3. Are the current arrangements for involvement of Disabled People in policy development and decision making working?

What steps should Government take to ensure that disabled people's views are taken into account when drafting their reports to the UN under the UNCRPD?

All Disabled People should be treated and respected as adults, and have a right to be involved in policy development. Consultation should include disabled people from all communities, including Black and Minority Ethnic and Gypsy and Traveller communities. Information on Consultations must be accessible to disabled people. It has been noted that often Government do not give enough time for consultation, and sometimes do not consult at all BEFORE issuing policy, such as plans to remove DLA from residents in care homes.

Equality Impact Assessments (EIA’s) are useful if done properly. Therefore it is a concern that latest guidance on the Equality Act 2010 is removing this requirement. Government should follow this example of good practice and carry out EIA’s on all policy proposals before they are sent out for consultation. The Government needs to ensure it is transparent and ring fences services for disabled people which ensures equality and the right to independent living.

There should be a basic minimum level of support as defined by the UN Convention. This should be a National Model. ‘Cuts’ should not be used as an excuse by Local Authorities for not providing public services that are critical to disabled people’s equality. Duplication and repeat assessments are a waste of resources. Government should resource networks of disabled people to enable a two way communication between disabled people and the Government. Equality 2025 has been reduced in size and focused more on providing internal advice to Government. It is essential to have an independent body of disabled people to advise Government.

4. Conclusion

We have welcomed the opportunity to submit evidence to this Inquiry and hope that the Joint Committee of Human Rights will find our submission both helpful and constructive.

28 April 2011
Executive Summary

1. People with neuromuscular conditions are keen to live independent lives, and play a full role in society. However, they may need support to do so. All too often this support is not available. Consequently people’s independence, human rights, quality of life and health are compromised.

2. Without appropriate support, people with a neuromuscular condition can be prevented from engaging in forms of employment and social activities; as such they are prohibited from contributing to ‘the big society.’

3. There is a discrepancy between the kind of independent living facilitated by statutory support and that highlighted in Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). The Muscular Dystrophy Campaign call for the Government to rectify both the inadequacy and inequality of social care provision by providing Individual Budgets where requested which realistically reflect the resources required to achieve an adequate standard of independent living.

4. The postcode lottery of social care provision must not be allowed to continue. The Muscular Dystrophy Campaign would like to see a minimum standard set for the care arrangements that should be provided within each of the Fair Access to Care Services (FACS) bands, which all local authorities must meet, with the flexibility to go above this to meet exceptional need. Local authorities must be transparent and make public their internal policies regarding resource allocations within FACS bands.

5. The current economic situation cannot justify the rights of disabled people being compromised. The Muscular Dystrophy Campaign call for the Government to drop proposals to remove the mobility component of DLA for people living in residential care homes and schools. This essential assistance makes people eligible for a motability car or covers transport costs—giving people the ability to live independently. Contrary to the Government’s belief, mobility assistance is not always provided in residential care settings.

6. The Muscular Dystrophy Campaign believe that all local authorities should provide social care to people with a severe disability due to a neuromuscular condition.

7. Local authorities must ring fence budgets to provide adequate care arrangements in light of the closure of the Independent Living Fund to enable people to live independently in the way articulated by Article 19 of the UNCRPD.

8. Local authorities must ring fence budgets for Disabled Facilities Grants to provide people with the physical adaptations they require to live independently and protect their wider human rights.

Introduction
9. The Muscular Dystrophy Campaign represents the 71,000 people in the UK with muscular dystrophy or a related neuromuscular condition. There are more than 60 different types of muscular dystrophy and related neuromuscular conditions, many of which are low incidence, orphan conditions and indeed some are very rare and are regarded as ultra orphan. Neuromuscular conditions can be genetic or acquired and, with the exception of a couple of acquired conditions, there are no known effective treatments or cures.

10. Adequate social care and support is vital as part of multi-disciplinary management of a neuromuscular condition and to allow people affected by the condition to enjoy a high quality of life, facilitated through improvements in levels of health care.

11. Whilst some neuromuscular conditions, such as Duchenne Muscular Dystrophy, can be life shortening, advancements in care have meant that people are living longer, healthier lives. Statutory support has not reformed to meet this new demand. Young men, who previously would have died around 19 years of age are living into their thirties and as such there a greater population of people affected by Duchenne Muscular Dystrophy who wish to live independently.

Q1. Should the right to independent living continue to form the basis for Government policy on disability in the UK?

12. The right to independent living must be the cornerstone of any policy on disability in the UK to ensure equality of opportunities and enable people to live the life they choose, regardless of their disability. People with neuromuscular conditions are keen to live independent lives and play a full role in society; statutory support should enable them to do so.

13. We fully endorse Article 19 of the UNCRDP which iterates that:

States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

(a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;

(b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

(c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

However we wish to see this Article adequately implemented in policy on disability in the UK.
14. A right to independent living must underpin policies in order to facilitate essential human rights—such as the right to respect for a private and family life.

**Case study: Sarah Barber’s son has Becker Muscular Dystrophy**

“I saved my mobility component in order to allow me to purchase an adapted vehicle for my son Jonathan who has muscular dystrophy. Purchasing and maintaining adapted vehicles is essential to allow our child to participate in family outings and attend social activities such as wheelchair basketball.”

15. Independent living is essential for people to contribute to ‘the big society’ and to allow people to contribute fully and financially to society.

**Case study: Terrie Hume from Glasgow has Muscular Dystrophy**

“I have muscular dystrophy, live alone and work part-time. Without my motability car, I would be unable to work or go out at all. A part-time income would not stretch to transport costs; I would have to give up work and all other activities in my life.”

Q2. Do existing policy statements, including the Independent Living Strategy, represent a coherent policy towards the implementation of the obligations in Article 19 of the UN Disability Rights Convention? Could current policy be improved? If so, how?

And

Q3. What steps, if any, should the coalition Government, the Scottish Government or other public agencies take better to meet the obligations in Article 19 and to secure the right to independent living for all disabled people in the UK?

16. Existing policies on disability are incoherent and fail to deliver a realistic sense of independent living. There is an unacceptable postcode lottery in respect to social care arrangements. This jeopardises the equality principle embedded in Article 19 of the UN Disability Rights Convention (UNCRPD) which call for States to “recognise the equal right of persons with disabilities to live in the community with choices equal to others.”

17. Whilst all local authorities have to follow Department of Health guidance as set out in Fair Access to Care Services (FACS) which outlines an Eligibility Framework for all Adult Social Care Services, local authorities have the discretion to allocate care resources as they wish within this framework, leading to inequality in social care provision across the country.

18. Due to internal policies, it is practice that some local authorities are not providing 24 hour support in people’s home when requested, even though such policies are not legally binding. There is a lack of transparency and the Muscular Dystrophy Campaign call on all local authorities to make these policies available. They should make clear that these are not legally binding levels and should only be adhered to if a residential care setting would realistically meet the applicants needs- a decision made in conjunction with the applicant.
19. As shown in paragraphs 15 and 16 above, section a) of Article 19 of the UNCRDP cannot always come to fruition, which denies many people the chance of independent living.

Case study: Jon Hastie, 30 and Mike Moorwood, 27 who both have Duchenne Muscular Dystrophy, South East Coast

Jon Hastie is a 30 year old who has Duchenne Muscular Dystrophy. His condition is such that he now requires 24 hour care. His care arrangement from West Sussex would not permit him to contract this level of support in his own home; instead they said that his needs will be best met in a residential care home.

Jon is a very independent man—he is educated to PhD level, he runs his own independence and advice service and travels regularly. It would be a travesty and a huge cost to his quality of life to effectively force Jon into a residential care home. In this setting he would be unable to continue in employment or enjoy his private and social life.

Mike Moorwood, 27 who lives around 40 miles away in Surrey also has Duchenne Muscular Dystrophy and requires 24 hour support. He is supported by his local authority to live independently in his own home.

Surrey, is able to meet the cost for 24 hour care, approximately, £1200 per week. Mike currently received £900 per week from Social Services, plus £300 from ILF. Jon only receives £400 per week from West Sussex which is topped up by £300 from ILF. Jon therefore falls short by £500—a sum he cannot and should not have to meet.

West Sussex Continuing Health Care team originally rejected Jon’s application for support-stating his needs were not ‘intense, complex or unpredictable’. We have been working with the team who now provide the additional funds for Jon to remain in his own home.

Vital statutory support should not have to be fought for in this manner as many people lack the ability, confidence and support to appeal for the services they are entitled to.

20. This discrepancy is unacceptable and undermines the right of all people with disabilities to live independent lives. The Muscular Dystrophy Campaign would like to see a minimum standard set for care arrangements within each of the FACS bands, which all local authorities must meet, with the flexibility to go above this to meet exceptional need. Jon and Mike, from the above case study are clearly examples of such exceptional need.

21. Residential care homes are often a local authority’s default option for people requiring 24 hour specialist care, as they are deemed to be the cheaper care arrangement. However this view is based on unrealistic financial assessment of the total cost of providing this type of care in a residential setting. The cost of a high dependency residential care home—the type required by someone who requires 24 hour care is approximately £1,345 per week. Over 24 hour care contracted in someone’s own home is approximately £1,200 per week.

170 Unit cost of Health and Social Care, 2010 PSSRU. Pp: 97-99

171 The cost of 24 hour assistance deliver in a patient’s own home is approximated by Active Assistance, a UK based live in care agency. http://www.activeassistance.com/
one year the cost of providing 24 hour care in a person’s own home could save local authorities £7,540.

22. Additionally, policies on independent living for disabled people are incoherent as current statutory assistance does not permit the independence articulated in Article 19 in “facilitating full enjoyment by persons with disabilities of this right and their full inclusion and participation in the Community.” As such it prohibits Article 19 (b) which states that “Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community and to prevent isolation or segregation from the community”

23. All too often we hear of people who receive statutory support and live independently yet face a real financial struggle which prohibits any real notion of independent living. People struggle financially as social care services often redirect vital funds to cover care costs, compromising independence. This is unacceptable as it does not reflect a full notion of independence.

**Case study: Dan Farrant, 19 year old with Duchenne Muscular Dystrophy**

Dan is due to leave residential college in the summer, at which point he would like to live independently. It would be very difficult for him to return to the family home as although it is adapted for his needs, it is too small for him to have any kind of independence or privacy.

The family has been working with the local authority to explore residential options, including a unit for physically disabled adults, run by the Disabilities Trust where he would get high levels of care and support. His care needs would be met, food all supplied and access to art and crafts, IT club, etc and he would be free to access the community and also for people to drop in.

However the family has been advised that whilst he will still get his DLA—the care component would go to the Disability Trust. Additionally, he would be entitled to Income Support—approximately £90 a week, however he would be required to contribute £70 of this to his care package. Dan would therefore be left with £20 a week to live on for toiletries, clothing and a social life.

Dan could divert his DLA Mobility Component to cover some of his living costs—however by doing so he would not be able to afford a motability vehicle to enable him to leave the residential setting independently and engage in private activities with his friends and family. Additionally, with this fund at risk for people in residential care home settings—Dan could find himself in a situation where he is denied independent mobility and an adequate standard of independent living.

24. The Muscular Dystrophy Campaign would like to see local authorities accurately assess the costs of the full range of an individual’s needs to enable provision to accurately reflect these and therefore allowing adequate finances to enable independent living.

**Q6. How will recent policy and budgetary decisions impact on the ability of the UK to meet its obligation under Article 19 to protect the right of all persons to independent living?**

**DLA Mobility Component**
25. The Muscular Dystrophy Campaign strongly believe that the Government should reverse its plan to remove the mobility component of Disability Living Allowance (DLA) from many disabled people living in residential care homes and residential schools.

26. The Government argues that people who live in residential care accommodation or schools and are funded by the local authority should already have their mobility needs funded by the institution.

27. In reality the Muscular Dystrophy Campaign know that many care homes and schools do not provide these services and in the case of residential schools, are not obliged to provide transport costs during school holidays. We are therefore very concerned that the withdrawal of this benefit will mean disabled people in residential care or schools will be worse off and lose their Motability scheme car, or funding for prohibitively expensive accessible public transport. This is reinforced by the Joseph Rowntree Foundation, who, in 2001 found very variable practice in regards to local authorities supporting parents to see their children at residential school during term times—or indeed any time for those children on 52 week placements.

28. Furthermore it is the duty of the State to ensure this need is met: the Children Act 2004 duty calls for the Government to promote the welfare of children in residential schools and extends to supporting contact and relationships. Additionally it is ones human right to have a private and family life. By removing the mobility component of DLA from this group of people, many families will be unable to maintain close relationships with one another.

29. This proposal has driven 1,163 disabled people and their families to sign our petition which called on the Government to drop this policy. This petition was presented to the House of Commons by John Leech MP 15th March 2011.

Quotes from people affected by neuromuscular conditions regarding the loss of the mobility component of DLA:

“It allows me to have the independence to be an active participant in society, the wider community and with family activities. Due to the severity of my condition this is only possible with having a specialist adapted vehicle. My full DLA Mobility Component almost pays for the full running costs of such a vehicle.”

“My grandson receives this benefit—I cannot bear the thought he will lose his contact with the outside world and our family.”

“DLA higher rate mobility component allows me to drive a car under the motability scheme which means I’m able to continue working full time, without this I couldn’t work & would have to claim other benefits, meaning a bigger cost to the benefit system—would make no sense? I want to work & this enables me to do so!”

Personal Independence Payments (PIP)

30. The Muscular Dystrophy Campaign is concerned that the new PIP will include a new face to face assessment process. It is important that the health professionals carrying out the assessments have any experience in dealing with rare neuromuscular conditions so we therefore urge the Government to introduce exemptions for people with severely disabling neuromuscular condition. Without expert knowledge of neuromuscular conditions and the
limitations on one’s mobility, there is a risk that people will not receive the benefits to which they are entitled and will therefore not be provided with sufficient support to enable them to live independently.

31. If neuromuscular patients are included in such assessments, we recommend that greater weight is given to evidence provided by medical professionals, in particular neuromuscular care advisors, who have expertise in rare conditions so that the assessor can fully understand the impact of these complex, multi-system disorders and recommend adequate support to live independently.

32. A similar assessment process used to determine eligibility for the replacement benefit for Incapacity Benefit—Employment and Support Allowance—has been criticised for failing to correctly assess rare conditions.

**The Independent Living Fund (ILF)**

33. The £359m fund helps severely disabled people to stay in their own homes through the funding of personal assistants, who offer support for day to day living. Their help may include anything from assistance with washing and dressing to getting to and from work. For many severely disabled people, an assistant is required 24 hours a day in order for them to live independently.

34. The Government says that from 2015 it will be the responsibility of local authorities to pick up the shortfall in care funding left by the removal of the Independent Living Fund. However, many local authorities already rely on the fund to cover a shortfall in the available budget for care. With the recent announcement that local authority spending will see cuts as high as 27%\(^{172}\) over the next four years it is difficult to see how this will be possible.

35. The Muscular Dystrophy Campaign believe that with ILF being phased out, funds must be ring fenced within local authorities budgets to ensure that people receive a sufficient care package which enables them to live independently.

36. Without the means to cover the cost of assistance at home, many disabled people will now be at risk of losing their independence and may even be forced into residential care. In this setting they may also have to give up their job.

**Case study: Sarah Rose from East Sussex has Ullrich Congenital Muscular Dystrophy**

“ILF pick up the short fall [of my care arrangements] i.e. they provide that extra funding that social services won’t. This means I can pay my carers a good hourly rate which in turn allows me fund the type of care which allows me to go to the cinema, shopping, visit family, go to concerts/shows. If ILF is too be cut or become non existent and no alternative is put in place then I would have to reduce my hours. This could mean losing staff that then means I would have to choose between being house bound, jeopardising my health or go into care”

Helen Starbuck- Phelps, South West has Congenital Muscular Dystrophy

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172 Eric Pickles unveils biggest council cuts in recent times (December 2010)
http://www.guardian.co.uk/politics/2010/dec/13/eric-pickles-council-budget-cuts
“Losing the ILF will put a big question mark over my independence. The only option I have is to try to get more funding from direct payments, but with local authority budget cuts this seems almost impossible. Residential care is not for me at all—it would mean having my life taken away. The Coalition Government says it is working towards making disabled people independent and self-reliant. If that is truly the case then this move doesn’t make any sense. It will not only take away people’s quality of life but will make them more dependent on the state.”

Cuts to local authority budgets

37. The Muscular Dystrophy Campaign believe that all local authorities should provide social care to people with a severe disability due to a neuromuscular condition. With substantial cuts to local authorities, the Muscular Dystrophy Campaign is alarmed that many councils are down grading social care eligibility to “substantial and critical” and in some places “critical” only. This could deny people essential support to live independently.\(^\text{173}\)

38. The Muscular Dystrophy Campaign welcome the recent High Court Judgement which ruled that Birmingham City Council have failed in their duty to assess the impact that cuts to care packages will have on disabled people. It was also deemed that they had failed to come up with ways to avoid this impact and consequently contravened the Equality Act 2010.\(^\text{174}\) Local authorities across the country must ensure that impact assessments are completed and every effort is made to minimise the impact on people’s health and quality of life.

39. The cost of living for somebody with a neuromuscular condition is substantial and without adequate statutory support, many people cannot afford independent living. Even when a person is eligible for social care, the personal contribution is such that people cannot afford to enjoy such independence.

Case studies:

John and Mary McAnulty from Luton are in their late 60s, and are both affected by neuromuscular conditions, but have been told by social services that they have to pay the full cost of social care they receive: £13.50 an hour for 15 weeks.

Steve Ledbrook from Weston Super Mare is affected by Becker muscular dystrophy. His only income is from his disability benefits, but he was informed that he would have to pay up to £51.37 per week to receive social care support.

40. The means-test acts as a perverse incentive for continuing in employment, and saving for the future. This may actually increase, rather than decrease benefit dependency. We are

\(^{173}\) Community Care Councils to deny social care support to all but most needy (September 2010) http://www.communitycare.co.uk/Articles/2010/09/15/115321/councils-to-deny-social-care-support-to-all-but-most-needy.htm

concerned that spending cuts for local councils will further reduce eligibility and increase the contributions people are to pay towards their own care.

41. By supporting people to live independent lives, health outcomes can be improved and isolation reduced. People may be able to stay in their own homes for longer. Crucially, people with disabilities may be able to gain or retain employment, reducing dependency on out of work benefits, and increasing tax revenues.

42. The way social care is assessed prevents many people getting adequate social care support. Severely disabled children and adults may require continual supervision to prevent medical emergencies – such as the need for suction to clear airways. This does not fit easily into the criteria for social care support, but has a severe impact on family life – often preventing other members of the family from being in employment, or from being able to leave the home for essential chores or social activities. Therefore the assessment for social care assistance must be carried out by specialist professionals who can fully appreciate the limitations of a neuromuscular condition on ones life.

**Disabled Facilities Grants (DFG)**

43. The Muscular Dystrophy Campaign call for funding for DFG grants to be ring fenced in local authorities budgets. This will allow people to access the funds for such adaptations and prevent cash strapped councils diverting this money into other services.

**Case study: Danielle Wade, Limb Girdle Muscular Dystrophy, Ipswich**

Danielle is 25 and has Limb Girdle Muscular Dystrophy, a progressive, life limiting neuromuscular condition. As such her mobility is limited and she currently relies on her boyfriend for all her personal care, washing and daily needs.

Danielle is entitled to support to enable her to carry out such tasks herself to protect her independence, quality of life and levels of health. Danielle requires bathroom adaptations so that she can have a shower fitted or a walk in bath and a high level toilet. Without these adaptations her independent and quality of life are being directly compromised. Furthermore due to the progressive nature of her condition and her complex health needs, it is essential that she has access to washing and hygiene facilities to enable her to protect her health.

Despite this, Danielle was informed that they are unable to proceed with her application due to ‘the financial resources available’.

We have since worked with Danielle and the housing association involved and it has been decided that they will proceed with her case. This is yet another example where people must fight for the assistance which they are legally entitled to—something that some people do not have the ability, confidence or support to do.

44. Whilst we appreciate the current financial strain on local authorities, this cannot justify the council decision to refrain from providing people like Danielle with vital adaptations. Under section two of the Chronically Sick and Disabled Persons Act 1970, it is the local authorities’ obligation to ensure that the needs of vulnerable people are met.

**Specialist Equipment**
45. Too often children and adults with muscle disease in the UK are forced to wait several weeks, months and sometimes years to receive the wheelchairs they need—which are essential for their health, quality of life and independence.

46. A lack of funding and understanding of neuromuscular conditions amongst NHS decision makers often means that people with muscular dystrophy are denied the best wheelchair that suits their needs, therefore when they finally such equipment, it does not allow them the level of mobility, comfort and health to live independently.

Case study: Jack is a 13 year old with Duchenne Muscular Dystrophy

Jack waited 8 months for his new wheelchair. During that wait, with no working wheelchair, Jack was unable to attend school—a devastating his independence: isolating him from his friends and meaning that he misses months of his education. Jack’s father Terry contacted the Muscular Dystrophy Campaign after a wait of 6 months for just an appointment. After our first intervention, Jack was offered a wheelchair assessment appointment for the very next week.

However, despite the assurance of the Chief Executive of the Hospital Trust that Jack’s wheelchair would be now be ordered and with him as soon as possible, Jack’s father Terry contacted the charity again to say that not only had they not received the wheelchair, three months after the assessment, he had been informed that although the chair had now been delivered to Wheelchair Services, they would have to wait a further month for delivery. Once again we intervened again on Jack’s behalf and as such he received his wheel chair the next day.

In order for any notion of independent living to operate, the Muscular Dystrophy Campaign urge the Government to improve wheelchair services and not rely on able parents and charitable pressure to push for such vital services.

47. Often wait for specialist equipment is so that that it no longer meets people’s needs, in light of their progressive condition.

One patient said: “I have had no chance of trying another chair. I need a different type and shape of chair now, no-one is listening and it’s soul destroying.”

48. Many people are forced to pay for vital equipment out of their own pocket. The cost of such equipment can be crippling and it can be a case of people choosing between such equipment and the funds to live independently. Forcing people to make this choice is counterintuitive to the overall aim of independent living.

49. We call on the Government and Primary Care Trusts (PCTs) in England to ensure that all people with muscular dystrophy receive the right wheelchair for their condition to permit them to live independently.
The Independent Living Fund (ILF) welcomes the opportunity to respond to this call for evidence from the Joint Committee on Human Rights and hopes to play a positive role in assisting the Committee with this inquiry.

The ILF has provided the opportunity for our users to respond to this Inquiry by publishing the questions on our website and in our ‘Living’ magazine, as well as posing the questions at four recent regional meetings with users and social workers. We have received some contributions in writing that we have passed on to the Committee separately and in full.

Our submission is in two parts. The first part presents a response from the ILF with support from our advisory group of disabled people—on the future of the ILF—which the Committee has pointed up as an issue of direct interest. The second presents views from our users and partners that we have collected on the main questions posed by the Committee, and have presented without analysis or edit. We have a close relationship with our users and hold a responsibility to pass on their feedback.

Background

The ILF occupies a distinct place within disability support arrangements and adult social care, bridging the support provided by local authorities and the benefits system. The ILF is an Executive Non-Departmental Public Body of the Department for Work and Pensions, currently making cash payments through a discretionary trust with a board of trustees, to around 20,000 disabled people with complex and high support needs in all parts of the UK. Since 1988 we have pioneered direct payments and supported around 45,000 disabled people to remain living in the community as full citizens leading active lives.

The ILF administers around £350M of funding directly to its users with just over a 2% administration cost each year, enabling those with the severest impairments to lead the same lives in the community as the rest of us. The funding assists with meeting the cost of personal care and domestic assistance our users require to achieve independent living.

Our user satisfaction surveys show that 96% of our users expressed satisfaction with their award, 98% of our users are satisfied with their quality of life, 96% feel they have satisfactory choice and control over their own lives, 98% see themselves as able to live independently, and 92% (and growing) have been able to experience a wider range of activities through their awards.

In December 2010 a Written Ministerial Statement from Maria Miller, Minister for Disabled People, announced that funding for existing users would be protected for the life of this parliament and that the ILF is closed to new applicants. She also stated that following the outcome of the Dilnot Commission’s work there would be consultation aimed specifically at how to develop a new model to best support the ILF client group within any new arrangements for Adult Social Care.

Part One

Context for the ILF
The ILF has been a significant function of Government promoting independent living for disabled people in the UK over some 22 years.

The ILF occupies a unique position advancing independent living in tandem with the non-devolved DWP benefits system but on condition that there is matching funding from Local Authorities’ adult social care budgets within each country of the UK. An ILF award is effectively a “personal budget” combining funding from the ILF and half of the care component of DLA, from the relevant Local Authority and the person, to support the user to manage his or her affairs in order to achieve a fully inclusive life in the community.

The key strengths of the ILF model most valued by ILF users and our partner Local Authorities, are the ring fenced nature of the funding which is safe from local cost cutting initiatives, the award is portable without the risk of a ‘cliff edge’ effect often experienced where a user moves between Local Authorities, and the committed service that we provide with a dedicated case holder and visiting Assessors who know the case history and are able to provide an ongoing and high quality service.

However the number of ILF awards had always been demand led without time limit and could frequently last for a lifetime. In 2008 the previous administration took the decision to cash limit the fund. This considerably altered the operation of the funding model. Through a Written Ministerial Statement (WMS) on 13 December 2010, Maria Miller stated that the current ILF model is financially unsustainable and that the Coalition Government would consider the long-term future of the Fund. She also stated that the ILF is permanently closed to new applicants and stated that:

“We believe there is a strong and principled case for reform (of the ILF) and for the social care support needs of all disabled people to be delivered equitably as part of Local Authorities’ broader independent living strategies in line with local priorities and local accountability.”

The Trustees of the ILF understand the current position and its rationale and have worked in close collaboration with the Minister and with officials in the DWP to deliver effective support to users. We are aware that there are aspirations within DH for adult social care funding by Local Authorities to extend to meet the independent living needs of the most severely disabled people, and that the numbers of people with high support needs on HRDLA who might require special support of the kind that the ILF has provided considerably exceeds the number of people previously eligible for an ILF award under our specific eligibility criteria.

While ILF supports consistent quality and portability across the UK, there is some unfairness in that some Local Authorities make much greater use of ILF funding than do others. And while the ILF seeks to place its funds behind outcomes related to life in the community as opposed to the basic care needs to which LAs typically confine their funding, some longer established ILF awards have blurred this distinction. ILF trustees have aimed to introduce further reforms to the Fund notably to simplify assessment and charging, and the ILF is a primary funding stream (and the only joint stream) within the Right to Control Trailblazers.

The Government has made a commitment to fund awards for existing ILF users for the length of this parliament. It also wants first to receive the conclusions of the Dilnot Commission on funding and support of care in England, following which there is to be consultation on the way forward for the ILF.
The ILF believes passionately that we in the UK have achieved a high standard of independent living support for those with the greatest needs, a benchmark that must not be lost. If a new model is needed it should be fair and equitable, that can be sustained financially, and that drives forward the independent living objectives of all Government Departments and Devolved Administrations. Experience suggests that this model must:

- Enable full independent living;
- be co-produced with disabled people;
- have a clear focus upon a defined target group (especially to include people with learning difficulties);
- enable geographical mobility through ‘portability’ of care packages (particularly important for taking up education, training and employment opportunities);
- be sustainably managed and resourced;
- attract committed funds from local authorities;
- be effectively delivered with minimal overheads and duplication;
- be innovative, exemplary and incentivise best practice;
- provide ongoing and flexible support to users in a way which builds confidence in independent living;
- secure consistent quality and meet agreed standards; and
- combine national consistency with support for local innovation

The ILF is committed to continuing to support its existing users to enable them to achieve their aspirations for independent living and to work with Government and other stakeholders to secure the best possible outcomes for the future.

**Part Two**

**Views from disabled people and partner Local Authorities**

Our consultation and engagement with our users and other stakeholders (including user-led organisations and local authorities) has given us important insights into the experiences of disabled people. At 4 recent regional meetings attended by approximately 80 of our users and local authority representatives, we introduced the Joint Committee on Human Rights’ Inquiry and asked people to comment. Comments made by our users have been passed on without edit below. We have also received contributions in writing which we have sent on to the Joint Committee in full.

The following section summarises the responses from our discussions with our users and local authority representatives on the questions asked by the Joint Committee and these comments are representative of themes raised during the consultation meetings:

1. **Rights need to be assured by government and require funding**
The state should act to ensure that disabled people with complex and high support needs, who face barriers to independence, are supported to overcome these barriers. People should be made aware of their rights and their rights should be consciously considered when implementing new policies and practices. Inadequate funding to achieve independent living outcomes is the main obstacle to independence.

2. The impact of funding changes

The true impact of local authority budget cuts, changes to the Independent Living Fund, localisation and benefit changes may be too early to assess. However, local authority representatives have already described more limited options available to service users and the inability of many local authorities to meet anything more than basic (critical) care needs. They have also described how a lack of funding has prevented people from moving to live independently or from going to university. ILF users have expressed concerns about the chances of their awards keeping pace with their needs so that they can maintain their standard of living or retain their valued care support staff.

3. Participation and consultation

People agree that consultation and involvement is vital to ensuring decisions are made that empower disabled people rather than eroding their independence. However, they want consultation that is meaningful, enables them to make a real impact on decisions and allows maximum participation. Disabled people also want to be involved in co-producing Government policy rather than just being consulted on changes to it.

4. Monitoring the Convention

People felt that more should be done to make people aware of their rights and that the government should explain more clearly how their policies ensure the rights of disabled people to independent living. The ENRC, NIHRC and SHRC should work more effectively to ensure this happens and laws should be enforced with fines.

1. The Right To Independent Living

- Could the government do more to give disabled people the same rights as everyone else to live independently?
- What could they do to make this happen?
- Do you think the Government needs to change any laws or the way it does things?
- If so what needs to change?

*In order to get the ‘rights’ we need the money.*—ILF user.

Our discussions with ILF users told us that people understood that independent living was a right. They felt, however, that the Government should do more to ensure their rights were upheld.

The overriding concern of users was that systematic cuts in services and local authority budgets would ultimately erode people’s ability to live independently.
Although people generally felt that the legislation already in place was sufficient, they felt it required greater clarification and wider promotion to ensure it was enacted. People also felt that current Government plans would mean less funding, less services and less support for disabled people and that this undermined existing legislation.

Rather than changing laws, our users felt that the emphasis should be on maintaining the positive work governments have already done to improve independent living outcomes for disabled people, and on ensuring that funding remained in place to do this.

When asked how policies and practices could be improved, people made the following suggestions:

- The streamlining of services and funding streams
- The removal of bureaucracy and the amount of personal information held on disabled people
- Strengthening the law (and compliance with the law) regarding wheelchair accessibility to shops and services
- Keeping the Equality Act and re-adding the socioeconomic duty on public authorities given that disabled people are amongst the poorest in society.
- Better transport provision for disabled people, for example by incentivising taxi and coach companies to run wheelchair accessible services
- Regulating private landlords’ treatment of disabled people

Regarding the latter point, local authority representatives gave anecdotal reports of the financial exploitation of disabled people with reduced capacity, now less able to access supported living placements who were unwittingly signing contracts that tied them into weekly rental for the hire of pots, pans, mops and brushes when it would be more prudent to purchase these items outright.

“I have huge problems with transport. There are no wheelchair accessible taxis where I live […] I would like the government to look at incentives for taxi and coach companies to run a wheelchair accessible service.”—ILF user.

“They should cut down on the amount of documented personal information that is currently required by law to be kept on disabled people with regard to their daily personal needs.”—ILF user.

“Despite laws to make shops wheelchair accessible there are many shops that flout the law and local authorities do little or nothing to encourage shops to provide a simple portable ramp. Perhaps the local authorities should offer a rate reduction for making premises wheelchair accessible.”—ILF user.

2. The Impact of Funding on Independent Living

- How have people been affected by changes to benefits, cuts in funding, changes in services, the way local councils decide whether you can get a service or not?
Written Evidence submitted by the Independent Living Fund (ILF) (IL 54)

- Are these things making being independent more difficult?

As previously stated, the most commonly voiced concern of ILF users and local authority partners was that restrictions on local authority funding, the freezing of the Independent Living Fund and closure to new applications, and increased focus of localisation would make it more difficult for disabled people to live independently. However, several commented that it was too soon to properly assess the true impact.

One of the most pressing concerns for ILF users was that the current restrictions on awards for existing users devalued their assessed funding and could eventually make their present care arrangements unsustainable. Many of our users cited their fear of losing current personal assistants or agency support if no funding is available to cover wage rises or increases in agency costs. However, the ILF intends to be able to support some increase in the cost of the current package over the next financial year, due to the level of funding that has been allocated.

"Part of my care funding comes from ILF. ILF have stated they will not be increasing funding to existing users when hourly care rates are increased this year. Personally, I cannot afford to make up the shortfall out of my income which is only Guaranteed Pension Credit."—ILF user.

"ILF cap on award has led to problems as care costs have increased. I'm worried how I am going to pay for the care I need and concerned about what will happen in ILF goes."—ILF user.

These problems seem to be compounded by the budgetary restrictions affecting local authorities.

As a result ILF users are already speculating about a time when their current levels of care support cannot be maintained, and on what the personal impact to them might be.

"Interestingly enough I remember reading [that it has been decided] the ILF is 'financially unsustainable'. If that's the case how on earth are local authorities going to make up this shortfall through severe cutbacks they are experiencing? I would assume that existing recipients will be safeguarded when the fund closes? If not it will leave disabled people in a desperate and perilous condition if these changes are railroaded through."—ILF user.

"With the coming shortfall in ILF funding and no corresponding increase in my Pension Credit, I can envisage a time coming when I will not be able to receive the support I presently enjoy."—ILF user.

"The loss of this help will be catastrophic for me."—ILF user.

Local authority representatives have informed us of the effect of cutbacks in their own authorities:

- Unable to move young people into independent accommodation or support living without additional funding from ILF
- Young disabled people remaining with parents (adding increased pressure on family) or moving into residential care
- Vulnerable young people moving into private accommodation and risking exploitation by private landlords
Written Evidence submitted by the Independent Living Fund (ILF) (IL 54)

- People planning to go to university now unable to due to lack of funding for care support
- Closure of day centres and greater reliance on voluntary placements (farms, garden centres, etc.) not necessarily the most suitable for the user
- Funding only available for critical needs

There were worries that available local authority funding will necessarily be spread more widely across social care users to ensure basic care needs are met, leaving less financial assistance available for the achievement of the independent living outcomes that the ILF seeks to support.

“Without the money people will be left with ‘life and limb support’ because local authorities will not be able to meet the demand it will create.” — ILF user.

“Things have improved with Individual Budgets, but the choices are limited to being able to go out in the community and be smelly, or stay at home and be up, dressed and cleaned.” — Local authority representative.

In response to The Written Ministerial Statement, our users told us that if ILF money were transferred to local authorities as part of the move towards a localised approach it would serve only to reinforce the “postcode lottery”. They said this would reduce the portability of care support and further restrict the ability of disabled people to move freely around the country to live, work or study.

Some users were sceptical of the “big society” initiative, claiming that emphasis on voluntary services over actual funding will diminish community inclusion, and do nothing to further the personalisation agenda or the rights of disabled people.

ILF users are also concerned about other cuts and the impact these might have, particularly in relation to housing:

“It is now harder than ever for a disabled person to leave the parental home now that we have lost ‘my safe home’ enabling an Income Support mortgage, as landlords do not want their properties adapting to the degree that some disabled people require”—ILF User

3. Participation and Consultation

- How can the Government involve disabled people in planning services and deciding how to save money?
- How well are disabled people involved in planning and making decisions?

Article 4(3) of the Disability Rights Convention provides that State Parties shall “closely consult with and actively involve persons with disabilities […] through their representative organisations” in any decisions concerning disabled peoples’ issues.

From our discussions with our users it was evident that people feel this consultation and involvement is not sufficient, or simply does not happen, as far as they are aware.
“I don’t know how much representation from disabled service organisations the government presently takes note of, but such representation should be deeply involved.”—ILF user.

Local authority representatives were also cynical about the actual impact of consultation in the decision-making process, echoing the concerns of our users that often the decision is a fait accompli and the involvement of disabled people has little or no effect on the outcome.

“We are doing a consultation on increased charges at the moment. The question is: ‘how do you want the increased charge applied?’”—Local authority representative.

“We need to have a blank sheet for consultation. Actually, consultation is generally only done after decisions have been made and only small changes can be made.”—Local authority representative.

The question of how to ensure that disabled people are included in the decision process and how to encourage this seems more difficult.

Some of our users were concerned that increasingly information and the means of participation were only available online. People complained that they were not able to give their views because they had no access to a computer or were not aware of the consultation taking place.

If consultation were co-produced, disabled people and their organisations would understand the issues and provide solutions and more informed decisions would be reached.

It was suggested that greater use be made of more traditional forms of media (newspapers, TV and radio) to ensure greater awareness of public consultation, rather than relying on the internet.

Other users complained about the timing of consultations (receiving short notice to provide submissions, for example) and the way they are organised, meaning that sometimes the people most affected by changes are not included in the debate.

People with learning disabilities were identified in discussions as a group most often overlooked or “left out” of the consultation process. It was thought to be vital that the views of parents and carers were included to ensure the needs of this group were taken into account.

4. **Monitoring the Effective Implementation of the Convention**

Our users felt that equality laws and the Disability Rights Convention provisions should be enforced by fines against institutions, if necessary, to ensure Government compliance.

It was felt that the various Equality Commissions (EHRC, SHRC and NIHRC) should take a more proactive stance in challenging the Government on the achievement of its Independent Living Strategy.

Moreover, it was felt that the Equality Commissions could do more to make people aware of their rights.

**Conclusion**
We hope that the commission finds this response of interest. We would be pleased to make any further evidence and information available if requested.

April 2011
Written Evidence submitted by Shabaaz Mohammed (IL 55)

The government could certainly do more to give disabled people the same rights as everyone else, but first and foremost in my mind is the urgent need to stop the government from enacting their current plans, which would effectively strip many disabled people of their rights to independent living.

The cuts and “reforms” that are being proposed to funds and services such as the Independent Living Fund (ILF), Disability Living Allowance (DLA) and Incapacity Benefit/ESA will have a directly negative effect on mine and other disabled peoples’ lives; and the way that the associated tests and assessments that come with these changes are carried out will have a damaging impact on our sense of dignity and independence.

The general climate of targeting the vulnerable in the name of cost-cutting—and subjecting the disabled to numerous “reassessments” to judge whether or not they are cheating the system—has led to a pervasive sense of worry and panic. Any sense of independence that we currently enjoy feels temporary or under threat. For those with “hidden disabilities” such as mental illnesses this worry is amplified and in some cases may have a direct impact on the condition itself.

The government has announced that they will be reassessing all recipients of Incapacity Benefit/ESA. Because a small minority claim benefits unfairly, the majority have to go through these tests, which are widely reported to be badly designed and based on a computerized points system which takes little account of an individual’s specific needs and restrictions. The fact that these tests are being carried out by private companies rather than doctors breeds the fear that those carrying out the test are working to a quota with the goal of removing a certain number of individuals from benefits regardless of need.

Indeed, the stated goal of this policy of reassessment is to reduce the number of ESA claimants by one million—how can this number be determined before the assessments have taken place? This spells out the government’s intention to base eligibility on their agenda of cuts rather than the actual need of those who genuinely rely on benefits. It’s very hard to believe that these cuts are not ideological when they so clearly target those most vulnerable.

One of the first things to go was the mobility component of DLA for those in residential care, a decision that would effectively trap those disabled people who cannot get out and about on their own. The scrapping of the ILF fund—which I and many others absolutely rely on to pay for the personal care that enables us to live independently—without any proposed alternative, again shamefully targets only those most vulnerable in society and is an assault on the idea of independent living.

Certain disabled people—such as myself—have conditions which will not improve, and needs which will not lessen (I have congenital cerebral palsy and am in a wheelchair). To be asked—as I recently have—to prove to a stranger, to multiple criteria, why I cannot work, dress myself or conduct day-to-day activities without assistance is stressful and demoralizing. These assessors tend not to take into account the fact that independent living is not about simply your basic needs, but being granted the same opportunities to get out and do things as able-bodied people. At present I have to be assessed annually by social services to determine how much money I need to pay for my personal care, and every year they challenge whether I could get by with less care even though this would leave me unable to
do almost any activity other than sit still for several hours of the day. To reassess me in this way year-upon-year (when my needs do not really change) is unnecessary and a waste of time and money, money that could be used to save or maintain other funds such as ILF and DLA.

I am all for simplifying the system where it is too complicated, but this process of simplification seems to be a simple code for indiscriminate cuts to the benefits system. How is cutting the ILF fund and proposing no alternative going to simplify things for me? It will make me less independent. How can local councils pick up the shortfall left by the ILF if their own funds are being slashed? Why is the government trying to reduce eligibility for DLA by 20% when DLA has one of the lowest reported fraud rates of any benefit at 0.5%? These are not in fact indiscriminate cuts—they actually discriminate against disabled people.

As far as what the government could do to bring the rights of the disabled in line with everyone else, I would like to see Individual Budgets extended across the country. At present their availability varies greatly from council to council, not based on need but on the resources available to each council. IBs and the funds that enable them are crucial to my ability to live independently.

I would also like to see the government do more to raise awareness that the benefits available to the disabled are needed, and relied upon, by the vast majority of claimants to keep them out of poverty and live independent lives. At present the government, supposedly concerned about poverty levels amongst the most vulnerable, is choosing to highlight to the media any example of “benefit scrounging” or cheating the system as a case in point for why various benefits should be scrapped by a certain percentage, with no evidence that this percentage relates to the fraud rate.

One specific policy I think the government should look into is some kind of tax relief for carers. At present care work is very low paid due to the lack of funds available, and carers are often left working more hours than disabled people are able to pay them for. As such it is increasingly hard to encourage people into the profession, which is important given the ageing population and increasing need for care workers. It is a very demanding and intimate job and takes time to build a rapport with a carer that allows you to feel independent. As such it is important to be able to remunerate employees properly as having to change your staff regularly is very difficult for a disabled person, on both a practical and emotional level. I don’t believe it is right that I have not been able to offer my carers a pay rise in the last 5-6 years. All other professions see pay rising in line with inflation, yet my care package is never raised to allow for even the most modest rise in pay.

On issues such as these, disabled people find it much harder to have their voices heard by the government and the media than other special interest groups, as there is no one voice that speaks for the disabled. Comparing the protests against tuition fees to those against cuts affecting the disabled, the difference is clear. Students have the NUS to speak directly to government on these issues and mobilize support. Disability, however, is so complex and vast in scope that there is no one central voice that can get our issues and grievances into the public consciousness. As such, the disabled seem to be an easy target for cuts such as those being proposed at present. I believe that the government ought to look to forge a clear, direct line of communication with the various disability interest groups rather than simply employ a disabilities minister who cherry-picks those opinions of individuals that support their party’s policy intentions.
If the government is serious about holding public consultations on issues relating to disability then I would like to see them consult us first, before announcing policy changes. The ILF consultation is to happen, after the fact that the ILF being scrapped has been announced, and an end date for the fund already decided upon. The decision to replace DLA with PIP came alarmingly soon after the end date of the consultation, and it is hard to believe that the overwhelming public resistance to the change was taken into consideration.

I would like to see a disabled advocacy scheme put in place whereby all government consultations with the general public are first checked by a representative from a disability rights group (e.g. the Coalition for Disabled People) prior to the consultation being rolled out. The census, for example, featured questions regarding your “general health” and “how much your disability affects you” that many disabled people found hard to answer due to their wording, which didn’t make sense from the perspective of an independent person with disabilities. I have seen local council forms, used to assess my level of disability, that are so poorly designed that I had to repeat the basic physical limitations caused by my disability over eight or nine different categories which all had to be scored individually. Such forms (or computerized tests) fail to take into account the small details that make all the difference in whether a disabled person is able to live independently or not.

The right to live as independently as an able-bodied person is a basic human right, and must be protected under the UN Convention. I hope that the EHRC can put pressure on the UK government to actually listen to the very real concerns of the disabled, and put a halt to the shameless portrayal of all who rely on benefits as cheats, or scroungers, or lazy, in order that our government can pursue an ideological system of cuts on the most vulnerable in their society.
Written Evidence submitted by the RNID (IL 56)

About us
We’re RNID, the charity working to create a world where deafness or hearing loss do not limit or determine opportunity and where people value their hearing. We work to ensure that people who are deaf or hard of hearing have the same rights and opportunities to lead a full and enriching life. We strive to break down stigma and create acceptance of deafness and hearing loss. We aim to promote hearing health, prevent hearing loss and cure deafness.

Our response will focus on key issues that relate to people with hearing loss. Throughout this response we use the term 'people with hearing loss' to refer to people who are deaf, deafened and hard of hearing. RNID is happy for the details of this response to be made public.

Comments
RNID welcomes the opportunity to respond to the inquiry into the implementation of the right to independent living for disabled people. It is essential to consider this at a worrying time when cuts and other developments in Government policy are placing at risk services provided to people with hearing loss.

RNID welcomes the empowerment of disabled people by ensuring that all disabled people are enabled to have choice and control over how their support needs are met. Similarly, RNID believes that it is essential that disabled people have greater access to housing, transport, health, employment and leisure activities.

However, we are concerned that recent Government initiatives, such as the Red Tape Challenge being undertaken by the Cabinet Office have referred to the duty to meet the needs of disabled people as a ‘burden’. We believe that these do not show due regard to the Equality Act duties to advance equality and to eliminate discrimination.

We have answered specific questions where appropriate.

Should the right to independent living continue to form the basis for Government policy on disability in the UK?
It is essential that this continues to form the basis for Government policy on disability in the UK.

Do existing policy statements, including the Independent Living Strategy, represent a coherent policy towards the implementation of the obligations in Article 19 of the UN Disability Rights Convention?
RNID welcomed the Independent Living Strategy and we believe that this represents a coherent policy towards the implementation of the obligations in Article 19.

However, in practice, we have found that the policy does not filter down into local implementation. For instance, one of the aims of the Independent Living Strategy is that disabled people should have greater access to participation in family and community life.
However, we are aware that when local authorities assess the needs of people with hearing loss, they do not always recognise their needs in terms of communication support or specialist equipment. In turn, this means that they are not provided with the support to participate fully in family and community life.

Similarly, people with hearing loss are not always aware of their rights to get an assessment from social services.

In addition, appeals processes are not accessible to people with hearing loss when their needs are not being met (for instance, communication support may not be provided) and there is a dearth of services that advocate on their behalf.

**What steps, if any, should the coalition Government, the Scottish Government or other public agencies take so as to better meet the obligations in Article 19 and to secure the right to independent living for all disabled people in the UK?**

Article 19 states that disabled people should have the opportunity to choose their place of residence and are not obliged to live in a particular living arrangement.

Current rules around ordinary residence rules work against the right to independent living for disabled people. For instance, if a disabled person wished to move from a residential care home to a more independent setting, the ordinary residence rules would make this difficult if this meant that a different local authority became responsible for funding their support. The new local authority might refuse to assess or to fund their needs, something that might mean that they remain in residential care. Ultimately, this means that some disabled people are not able to choose their preferred living arrangement. It is essential that rules around ordinary residence change so that disabled people are able to exercise choice as to where they live.

The Government has committed to greater portability of social care assessment, something that we welcome. However, we would like this to go a step further and give assurances that people will be able to move between local authority areas and into more independent living arrangements without changes to their entitlement to care and support.

**Impact of funding on the right to independent living**

We believe that the following will have an impact on the right to independent living:

**Proposal to remove the mobility component of Disability Living Allowance for all people living in residential care**

The Government has stated that the mobility component of Disability Living Allowance represents a duplication of funding, assuming that all the needs of an individual in residential care are met by the local authority funded package of support. However, research undertaken by Mencap shows that this is not the case. The evidence suggests that local authorities are not meeting mobility costs and, therefore, rather than resolving an issue of ‘double funding’, this measure will simply transfer costs to already stretched local authorities or leave people without the vital support that they need. Moreover, 73% of the residential
care users surveyed told Mencap that they would lose their independence as a consequence of this proposal.  

**Changes to the Independent Living Fund**

We are concerned by plans to phase out the Independent Living Fund. The Independent Living Fund is not perfect—for instance, its eligibility criteria mean that many people are precluded from applying to it. However, it should not be phased out without clear plans for the introduction of other means to enable people with disabilities to live independently.

**Restrictions on local authority funding, social care budgets and benefits reassessments**

However, the raising of eligibility thresholds for social care by local authorities represents a risk to the implementation of independent living for disabled people. Services are being restricted to those people who have substantial or critical needs and rationing of social care services is also happening. Specialist sensory services are also closing in some local authorities; this is of concern, as some generic social workers will lack the appropriate skills and knowledge to explore fully the needs of people with hearing loss, meaning that they do not have access to the support required to enable them to live independently.

Similarly, financial targets have been set for reductions in social care expenditure of 20% or more in some local authorities in Scotland. We are concerned that this is going to result in cuts of services that are considered 'non essential' such as equipment and adaptations for people with hearing loss.

Moreover, some local authorities are focusing increasingly on personal care needs, despite guidance from the Department of Health that needs relating to social inclusion and participation should be seen as just as important as needs relating to personal care issues. In some cases, this means that needs around communication and relating to social inclusion and participation are no longer be met. In practice, this means that some people with hearing loss are not accessing the communication and other support that they need to live independently.

**Increased focus on localisation and its potential impact on care provision and, specifically, on portability of care and mobility for disabled people**

At the moment, local authorities provide different levels of social care funding, depending on the eligibility criteria adopted. However, the Government’s vision on social care states that there will be a greater portability of assessment to enable people to move between localities or to more independent settings. Our concern is that the localism agenda means that different localities will adopt different priorities in terms of the delivery of social care. However, if different localities have different priorities as well as setting different levels of eligibility, a person will have no assurance that if they move area their needs will be met. In this way, our concern is that the localism agenda will hinder greater portability of assessment. In contrast, we believe that people should be able to move between local authority areas and into more independent living arrangements without changes to their entitlement to care and support.

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Conclusion

RNID welcomes the opportunity to respond to the inquiry into the implementation of the right to independent living for disabled people. Current developments are of particular concern, namely the raising of eligibility criteria thresholds by local authorities and moves by the Government to present the duty to meet the needs of disabled people as a burden. In addition, we are concerned that policy does not currently filter down into local implementation.

28 April 2011
Consultation response

Should the right to independent living continue to form the basis for the Government policy on disability in the UK?

1) Mencap has long argued for the right of people with a learning disability to live a more independent life. Our vision is a world where people with a learning disability, including those with profound and multiple learning disabilities, are valued equally, listened to and included.

We want everyone to have the opportunity to achieve the things they want from life. It is for this reason that we campaign for people with a learning disability:

- To be equal citizens with control over their lives
- To have a childhood like any other child
- To get the support they need to live independently
- To be supported to get a job
- To lead a fulfilling life
- To get good healthcare
- To have the money to do what they want to do
- To have the opportunity to make friends
- To form relationships and enjoy family life

2) Mencap strongly believes that the right to independent living should continue to form the basis for Government policy on disability in the UK. It is in this context, however, what we would like to see a greater acknowledgment of the importance of support and advocacy, as well as access to good housing, healthcare and employment, so as to ensure that independent living as a principle goes beyond direct payments and individual budgets. People with a learning disability should be enabled to exercise choice and make decisions for themselves, and fully participate in society.

3) Mencap also believes that the right to independent living and what this means on the ground is still not widely understood by many people, both in public services and by the general public. We therefore believe that there is still a lot more to do.

Do existing policy statements, including the Independent Living Strategy, represent a coherent policy towards the implementation of the obligations in Article 19 of the UN Disability Rights Convention? Could current policy be improved? If so, how?
4) Mencap believes that the Independent Living Strategy, as well as Valuing People and Valuing People Now, all present steps in the right direction and support the goal of independent living for people with a learning disability. Particularly, we believe that the attempt in Valuing People Now to concentrate on implementation started to change people’s understanding of learning disability and has started to make some, even if slow, progress. Having people work on the programme within the Department for Health has for example helped to facilitate better joint working between different Government departments, leading to in some cases better policy decisions on the ground. An example of such an improved policy decision is the introduction of an additional bedroom allowance under LHA rules for those who have an overnight carer.

5) However, it is important to remember that policy statements such as VPN or the Independent Living Strategy do not operate in isolation and interact with other wider policies on housing, employment and social care, and that more could be done to ensure that those take account of the needs of disabled people. There are many policies that could be improved and new legislation that we believe should be laid. In the context of VPN itself, for example, we have argued in the past, that we would like Learning Disability Partnership Boards to have a statutory footing, so that they would actually be able to fully hold to account local authorities over their policies on learning disability. Furthermore, we also believe that more should be done to outlaw disability hate crime, which plights the lives of so many people with a learning disability and has a severe impact on their ability to live independently as equals in the community. We also believe that more could be done to improve some of the policies around access to work and housing.

6) Mencap is concerned, however, that rather than moving to improving policies to support independent living for people with a learning disability, we are seeing a retreat from some of the commitments made on already existing policies. While the Government has given its commitment to Valuing People Now and the values within, the recent dismantling of the Valuing People Now programme staff in the Department of Health, the reduced amount of funding to the National Forum and the National Valuing People Families Forum, and the uncertain future of Learning Disability Partnership Boards raise concerns that we may be returning to an era of policy without a vision of implementation on the ground. For policy to work and achieve the outcomes it aims for, implementation must be at its heart. A case in point is the recent Raising Our Sights report,176 which resulted from work undertaken in the context of Valuing People Now and which makes detailed recommendations as to how the lives of people with profound and multiple learning disabilities and their independence could be improved. However, the Government response to the report was light on detail and made few commitments on how to improve the situation on the ground. As a result we are seeing little being done to ensure that the independence and lives of those with profound and multiple learning disabilities are being improved.

7) We are also starting to observe in some areas a mismatch between the values and ideas laid out in the Independent Living Strategy and in Valuing People Now and policy decisions taken by other departments. An example of that is the recent reduction of Support for

Mortgage Interest, which has had the side-effect that a long-established Homes and Communities programme of home ownership for people with long-term disabilities (HOLD) is now unable to support new claimants as a result.

8) Furthermore, implementation on the ground is also still very patchy. We hear from many of our members that there is still a lack of choice of services despite the long-established idea of personalisation. As local authorities often see personalisation as a way of saving money, the chronic under-funding of services is actually making this worse. This means that people with a learning disability do often not receive the amount of care and support that they require to live an independent life.

9) Last but not least, in its last report from 2009, the Independent Living Scrutiny group highlighted the importance of Public Sector Agreements and national reporting structures in order to monitor and ultimately improve implementation of measures to improve independent living for people with a disability on the ground. Mencap is now concerned that the potential move away from centrally collected data will make monitoring of improvements for disabled people on the ground increasingly more difficult, particularly as being able to compare the achievements of different local authorities is vital to ensuring that progress is made in the future. While the new social services outcomes framework will ensure that some national data should be available in the future, it remains to be seen at this point, how transparent and useful this information will be.

How will recent policy and budgetary decisions impact on the ability of the UK to meet its obligation under Article 19 to protect the right of all persons to independent living?

a) The decision to remove the mobility component of Disability Living Allowance for people living in residential care.

10) Mencap in line with many other disability organisations was gravely concerned with the proposal to remove the mobility component of Disability Living Allowance for those living in residential care. This would undermine the aim of increasing independence, participation and employment opportunities, three important pillars of independent living, for those living in residential care. We welcome the deferral of this proposal and would urge the Government to ensure that it is protected in the review as part of the move from DLA to PIP.

11) Mencap believes that the Government has proposed the changes to the DLA mobility component based on the assumption of double funding. We know that this assumption is wrong, and that if the Government goes ahead with the proposal to remove the DLA mobility component for those living in residential care, this will have a significant and adverse impact on the everyday life of those affected. It will lead to either people being forced to remain indoors and as a result have a diminished quality of life that would not be in line with Article 19; or social services will have to make up the difference, which Mencap believes in times of great financial constraints will not be a real option for local authorities.

12) It is for the reasons above that we have and continue to call on the Government to continue pay the mobility component of DLA to those in residential care. Many disabled adults living in residential care have all their income taken to pay for their care, and are left with just £22 per week to live on. This is not intended to cover additional mobility costs, which we believe could be the result of removing the mobility component.
13) In addition, the resulting savings of £160 million are relatively small in contrast to the total of £81 billion in spending cuts the Government plans to make by 2014/15. However, the impact on 80,000 disabled people to be affected will be huge, with many unable to afford to leave their home and denied the independence most people take for granted. This will be of particularly severe consequence to people with profound and multiple learning disabilities, who are the most likely of people with a learning disability to live in a residential care setting.

“My mobility car has changed my life. When my mum and other relatives now see me they can see how happy I am. I have freedom because of my care to do what other people can do. Before I was not happy; I would sit at home watching other people in the home going in and out as they liked. I could only dream about that kind of freedom. Please don’t take my car away from me. “ Steven Colley, care home resident, Essex

b) Changes to the Independent Living Fund

14) Since the announcements were made that the Independent Living Fund (ILF) would not be available to new applicants in December 2010, and the announcement that it is expected to fully close 2015, Mencap has heard of a number of parents and people with a learning disability worried about what this means.

15) In principle Mencap does not disagree with the decision to reform ILF, as we believe many councils use the discretionary funds to plug gaps in their funding, rather than addressing the problems in the current funding system. However we are concerned about the practical implementation of closing applications and in future to end the scheme, because the current social care system is inadequately funded. We are particularly concerned about local authorities who have seen a large cut in their funding being able to pick up the tab of closing this scheme. It is vital that local authorities protect services for the most vulnerable in our society.

Erica’s story

Erica is 28 years old and has Profound and Multiple Learning Disabilities (PMLD)—severe learning disabilities; physical disabilities; epilepsy and complex health needs.

When Erica was a child—both her parents were working full-time and her parents employed and paid for child care in order to enable them to continue employment, in the same way as other parents. When Erica left school and moved into adult services, her family considered a number of options—including the possibility of Erica moving into residential care in order for her parents to continue to work and because they realised in terms of their ages they could not continue bearing the physical strain in terms of moving and handling and being awake during the night in the long term. As residential care was not their preferred option—they have put together a package of care with the local authority and health trust which enables Erica to live at home. This package includes both direct services and managing part of Erica’s support through direct payments and Independent Living Fund (ILF).

The ILF makes a significant contribution to Erica’s package in that the ILF enables Erica to have a level of independence despite her significant needs, which the other funding does not enable her to have. Erica receives funding which means that she employs personal assistants who support her during the late afternoon, early evening—whilst her parents are working. She also receives funding for ‘floating hours’ which can be used flexibly to give her greater independence. The ‘floating hours’ will pay for a personal assistant to attend a one-off
evening or weekend activity; it enables her to spend time with her sister and allows her to have more creative breaks (ie. not residential respite). It for example helps pay for a PA to support her on holidays, enabling her to have some independence and providing a break for her parents.

c) the ‘Big Society’

16) The Government's commitments on the Big Society provides a valuable opportunity for community, charitable and voluntary organisations to run and provide services on behalf and in partnership with the public sector, particularly local government. As a cross-government policy programme, opportunities that help to create a climate that empowers local people and communities is to be welcomed and could lead to many advantages and benefits to those who are committed to independent living for disabled people.

17) We await with interest the Government's forthcoming Public Service Reform White Paper—informe by the Modernising Commissioning Green Paper—and the opportunity this aims to create for a level playing field for charities, voluntary groups and social enterprises that wish to bid for public service contracts. If local citizens, communities, and independent providers have an opportunity to play a greater role in shaping services, this could lead to considerable benefits in the quality and range of services accessed by disabled people and their families and carers. However, we seek assurances processes are developed to ensure continuity of service is maintained in any public service that is provided by voluntary, community or business groups. If such processes are not in place there is a risk that disabled people could see a decline in the quality of services they can access, thereby undermining independent living.

18) If the voluntary and community sector is to provide services in the interests of its clients, it will be vital to develop strong relationships with local authority and other public sector partners that can support a balanced and equal approach to identifying the best ways forward. Effective partnership working between the public sector and the community, charity and voluntary sectors is vital if the interests of disabled people are to enhanced.

19) At a local level across their country, recent budgetary pressures are leading to many local authorities reducing their level of grants to voluntary and community groups who provide services for disabled people. Services such as advocacy, citizens advice and community groups are amongst those facing significant reductions in their grants, thereby having a disproportionate impact on some of the most vulnerable people in society, who often most reliant on accessing them. Sometimes there is a disconnect between the government's commitment to the ideals of the Big Society and the impact of reductions in grants by local authorities.

d) Restrictions on local authority funding, social care budgets and benefits reassessments.

20) Mencap has been following with great concern the extent of the cuts to local authorities, and we are still in the process of trying to understand what these cuts mean for social care budgets for people with a learning disability. Our assessment so far has shown that cuts of social For Erica the ILF is the only funding stream which can be used in a flexible way to fund more than ‘basic care’ and give Erica a level of independence as an adult. For her family it enables them to maintain responsibility for their daughter without feeling that it is a continual financial and emotional burden and enables them to lead an ‘ordinary’ life as
they approach retirement age, services have become a reality for people with a learning disability on the ground, be it in the form of higher charges, fewer hours of support or the closure of vital services, such as shortbreak homes.

21) A recent report by the Learning Disability Coalition confirmed that our concerns are justified. Out of the local authorities, which responded to the survey that underpins the report:

a. 84% rated the funding situation for learning disability services as difficult.

b. 10% percent are already making cuts to services.

c. 53% indicated that supported living services were likely to be affected by budget constraints.

d. 45% thought that services for people with mild to moderate learning disabilities would be affected.

e. 42% felt that support for people with challenging behaviour was likely to be affected.¹⁷⁷

22) We are already seeing a growing gap between the people who need care and who are not getting it. Mencap fears that this will get worse as a result of the cuts. Mencap is aware that eligibility criteria in some areas are being moved from severe to critical only. This will have severe implications on many people's ability to enjoy an independent life. Whatever national policy is in place, unless action is statutorily required, local authorities will be pushed to circumvent it to contain costs, particularly at this time of financial constraints. Cuts to frontline services, are ultimately cuts to people's independence and will make the right to an independent life hard to achieve for all disabled people.

Case Study

Andrew is 32 and has a learning disability. He has been assessed as ‘moderate’ under the eligibility criteria set by his local council and receives care and support which has enabled Andrew to live a fairly independent life.

He currently attends a day service 4 days a week, where is takes part in various activities including learning how to live a sustainable life by growing vegetables on an allotment and learning how to use computers and the internet. He also receives 8 hours a week of living support in a one-bedroom flat.

The council are looking to tighten the eligibility criteria so that they only provide care and support to those assessed as substantial or critical. This would mean that Andrew would lose his care and support.

23) Furthermore, we are also seeing a number of changes to disabled people's entitlements, including the introduction of the Work Capability Assessment (WCA) and the employment and support allowance (ESA), as well as the current reform of Disability Living Allowance

¹⁷⁷ Learning Disability Coalition (2010) 'Social Care in Crisis: from the perspective of local authorities in England
We know from the roll-out of the WCA, that a high number of claimants are failing the WCA and not being found eligible for ESA. As a result, many of these claimants will be receiving Job Seeker’s Allowance instead. Mencap is very concerned about this in relation to people with a learning disability who will miss out on the extra support available to those in the work-related activity group of ESA.

24) Mencap is concerned that this will have a negative impact particularly on people with milder learning disabilities, who may also find that they will in future not be entitled to DLA either. While we therefore would undoubtedly argue that some of the recently suggested changes, such as the idea of simplifying the benefit system as outlined in the Universal Credit model, are a step in the right direction, we are very concerned that the detail as it has emerged may lead to greater numbers of people with a learning disability losing out and having their right to a successful independent life with employment opportunities restricted.

**Case study**

S has a learning disability and is 21 years old. He left full-time education in June 2009. At this time he made an application for ESA and attended a work capability assessment. He scored ‘0’ points against all the descriptors looking at mental, cognitive and intellectual function. Having started on a programme with Mencap’s employment service, Mencap is helping S to appeal the decision.

Mencap’s employment service has been working with S to complete a work experience placement of 6 weeks. This was in a charity shop. S’s role involved him helping to serve customers and to put stock out on the shelves. He had one to one support from his job trainer to learn his role, understand his routine tasks and develop a good working relationship with other staff members. The Mencap employment service staff working with S commented on a number of descriptors that “stood out” where they claimed they felt S should have scored, but did not get any points at all, such ‘learning or comprehension in the completion of tasks’, Andrew would not be able to attend the day service, which he has done for 14 years. It is likely that he will lose his current social networks, becoming more dependent on his family. He will also be preventing from doing the activities that he enjoyed at the service, including learning how to grow vegetables and how to use a computer.

Losing the support to live in his flat will mean that he will no longer be able to live in his own home. He needs support to organise his finances and support in identifying threats to his own safety.

His parents are extremely concerned about his future as they believe that he needs the support to live an independent life and believe that there would be no other option other than to take him into the family home. This presents further problems for the parents as they are divorced and do not own their homes, his mother has a health condition which sees her in hospital for long periods of time.

‘coping with change’, and ‘coping with social situations’. Staff therefore felt that the new assessment was not appropriate for assessing people with a learning disability.

**e) Increased focus on localisation and it potential impact on care provision, and specifically, on portability of care and mobility for disabled people.**
25) The Coalition Government is rapidly moving forward an intensive devolution programme, with the idea of ‘Localism’ at its heart. The programme is accompanied by the driver to reduce the regulatory burden on local authorities and trust decision-making to local people. As a result, more financial decisions are being taken locally.

26) While Mencap believes that local authorities are in many ways best placed to deliver services on the ground, we also know that in times of financial constraints services other than statutory ones suffer greatly. A good example of this is Supporting People. Supporting People was unringfenced prior to the new Government coming into power. While nationally Supporting People money was relatively protected in the last Budget, locally, decisions taken in some areas are most likely to have a severely negative impact on the ability of people with a learning disability to live an independent life. Cornwall, for example, is cutting its Supporting People budget by 40%, even though it’s Supporting People allocation has actually been increased. In contrast to Cornwall, Hounslow or East Sussex are protecting their Supporting People budget.

27) Greater devolution also more generally brings with it the risk of an increased postcode lottery.

While there are clearly differences between the provision of social services, for example, in one area compared to another at the moment, greater local decision-making, and fewer statutory duties on local authorities, which is what the Government seems to aim for, are only likely to increase that difference, unless steps are taken to ensure that in terms of entitlement, people are treated the same in all local authorities. Mencap therefore believes that localisation must therefore be accompanied by measures that ensure that people with a learning disability do not lose out as result of this. We would therefore like to see amongst other things national eligibility criteria in social services introduced as well as more done to explore how portability of services could be improved. Localisation should not mean that disabled people can get a service in one area, but not in another; this would severely limit their choice as to where they can live and therefore their ability to live more independently like everyone else.

f) Cuts to housing benefit and Support for Mortgage Interest, changes to social housing legislation

“We seem to be being squeezed from all sides with cuts happening locally and now DLA. I’m not sure the government is seeing the bigger picture.” Respondent to Mencap’s Disability Living Allowance survey

28) Mencap also has a concern that the changes and uncertainties with regards to Housing Benefit regulations, as well as the changes to Support for Mortgage Interest and social housing more generally, could potentially have a detrimental effect on the ability of people with a learning disability finding a suitable home, which is key to an independent life.

29) Over the last few years, a number of organisations have been working on developing new models of independent supported living. The Great Tenant Project by Golden Lane Housing is one such model. Rather than relying on the traditional route into housing for people with a learning disability via a residential care home or social housing, it works closely with private landlords to develop a partnership that means that someone with a learning disability can rent a home like anyone else. The changes to the Local Housing Allowance, moving from the LHA being set at the 50th percentile to the 30th percentile, as well as the
caps on LHA, particularly in London, will make finding landlords willing to rent to people with a learning disability more difficult.

30) Another model, that was developed over the last 15 years to increase the pool of housing available for people with disabilities, particularly those with learning disabilities, was the Home Ownership for People with Long-term disabilities. The model, which was developed to provide people with long-term disabilities, particularly those with learning disabilities, with a stable home, was based on payment via the Support for Mortgage Interest (SMI) route. It has enabled around 1,000 people over the last 15 years to find a home. At the end of last year, the interest rate in SMI was reduced dramatically. As a result, the few lenders that had been willing to lend to people in this position retreated from the market, effectively shutting down this route for people with a learning disability, and putting some people already owning a home in the position of being unable to pay for their mortgage.

"Since April this year, it has become increasingly difficult to secure private rented sector accommodation for those with a learning disability. As market rents continue to rise due to stagnant mortgage lending increasing demand for rental property, these cuts to LHA have further widened the gap between LHA levels and rental values. In affluent areas such as Surrey, London and Kent, it is now virtually impossible to find property without there being some form of top-up payments from the individual or their family needed—something that the majority of families are unable to provide. With the rise in the age limit for shared-rate LHA from 25 years to 35 years, this is only going to exacerbate the problem to the point where vulnerable people wishing to live independently in the private rented sector may be forced to live away from their family, friends and other valuable members of their support network." Katie Sherjan, Development Manager, Golden Lane Housing

31) In addition to the changes the Local Housing Allowance already touched on in paragraph 23 above, Mencap is also concerned that the extension of the single room rate from 25 to 35 from April 2012 could have severe implications for particularly those with milder learning disabilities and their ability to find their own accommodation, particularly for those between the ages of 25 to 35, who currently already rent a flat of their own. They may also find it more difficult to find someone to share a flat with. While sharing is a concept that many people with a learning disability do and enjoy, particularly those with milder learning disabilities may not be known to social services and therefore lack the support to help them find other suitable individuals to share with. The suggested new Housing Benefit rules (Clause 68, Welfare Reform Bill), are also likely to cause complications particularly for disabled people who already.

32) Perhaps one of the biggest threats, or opportunities, to independent living for people with a learning disability is the forthcoming review of the ‘exempt accommodation’ rules. Currently around 170,000 disabled people rely on this system to pay for their home; 40,000 of these are people with a learning disability. While the review is welcome, as current regulations are out of date and have caused many problems locally for those needing a home as well as providers of such homes, Mencap would be concerned if the new system would lead to restricting provision even further. We will therefore watch closely what the suggestions are and make recommendations to ensure that independent accommodation for people with a learning disability becomes the norm, not the exception. Changes that would lead to restricting the availability of accommodation provided via this route, rather than help expand it, would work against the independent living agenda, and make it even more difficult particularly for those with more complex needs to access a home in the community.
33) Summarising the above, finding accommodation for someone with a learning disability to live a more independent life is still very difficult. Many parents and individuals have to fight for many years to be listened to, and to have their right to an independent life fulfilled. With housing and support going hand in hand for people with a learning disability, it is a multiagency approach that needs to be taken to make it work; and often there are delays and problems. The changes and cuts to Housing Benefit as outlined above, in combination with cuts to social services locally, provide for a bleak outlook for the right to an independent life. Constant changes in policy and funding, with further restrictions on funding on the way also make it very difficult for providers to develop housing options.

Case study

N is 26 years old and has Williams Syndrome and a severe learning disability. She currently lives with her parents in Dorset. N has been in education all throughout her life but is now coming to the end of her last year. Both the parents and N feel that now is the right time for N to get her own home.

A friend of the family, who also has a daughter with a learning disability, was able out of own savings to turn land she owned in Somerset into nine 2 and 3 bedroom houses for a supported living scheme. The houses will be sold to a Housing Association, which will then directly sell on 75% of the mortgage to the individuals buying the house as part of a shared-ownership arrangement. N and a friend of hers from school are planning to part-buy one of the 3-bedroom houses with a mortgage of £56,250 each through this arrangement.

The changes to SMI now threaten to destroy N’s possibility of a safe and stable individual living environment. N is likely to have a mortgage rate set at around 5-6%, which would put monthly repayments at between £234 and £281. The changes now mean that she will only get £176 paid through SMI. This will leave her and her friend to cover between £15 and £25 per week each out of other benefits.

What impact does funding have on the ability of the UK to secure the right to independent living protected by Article 19 of the UN Disability Rights Convention?

34) Funding is vital to making services work and Mencap in line with many other learning disability organisations have argued for a long time that adult social care in the UK is chronically underfunded.

As touched upon in paragraphs 20-24 above, the situation is likely to get worse. We clearly have welcomed the decision to put £1 billion extra into adult social care, however, this is unlikely to meet demand in light of the increased number of people with a learning disability needing services (3-5% increase by year), the increasing numbers of people with profound and multiple learning disabilities (1.8% increase per year) and the rising number of elderly people.

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35) Without adequate funding being available for social care services, support, and housing provision, pressures on finances will mean that good ideas and progressive thinking will lose out. While some savings can clearly be made via efficiency savings and while new assistive technologies may be able to replace a few hours of support for some people, supporting for example new people coming through the system costs money. Without this funding being available, it is unlikely that someone wanting to leave the family home to live more independently will be given the support to do so easily in these times of financial constraints.

Mencap is already aware of the reluctance by some councils to fund more costly independent living arrangements.

What steps, if any, should the coalition Government, the Scottish Government and other public agencies take to meet the obligations in Article 19 and to secure the right to independent living for all disabled people in the UK? If you consider changes to policies, practices or legislation in the UK to be necessary, please explain why.

36) Mencap regularly contributes to consultations on White Papers, Bills and policy changes, in which detailed recommendations on particular areas of work can be found. Outlined below, based on these more detailed recommendations elsewhere, are some of the steps that we think the Government should take to ensure that the right to independent living moves on from being a right in theory to a right in reality.

Victoria’s story

Victoria is 38 years old. She was born with Tuberous Sclerosis. Tumours can affect all the body organs, and in Victoria this means that she has physical and learning disabilities. She also has behaviour which can challenge services and people; either passive or withdrawn or self harms, screams and lashes out.

Twenty years ago her parents set Victoria up in a home of her own, together with one of her friends, as they felt that residential care provision was not the right thing for her and that she deserved a more independent life. This was one of the first schemes to give independence, choice and control to two very disabled women. Opposition was high, particularly from medical professionals.

Victoria has now lived for the past 18 years in her own tenancy in the London borough of Islington. She has 24 hour support, a circle of friends and a person centred plan and very much lives the life of her choice. However, her mother Jean has had to consistently fight to keep this in place.

Because of the cost to meet Victoria’s needs, her support package is always under scrutiny and there have been a number of attempts to reduce it, which would make her life as it is unsustainable and seriously challenge her independent life style. Islington have now, made the decision that they will never again fund individuals with complex needs to live independently because the costs are too high, restricting other people in this situation to lead an independent life.
Written Evidence submitted by MENCAP (IL 57)

Broad recommendations

i. Teachers, social workers, health professionals and parents to raise aspirations among people with a learning disability. Finding employment and leading an independent life should be what young people with a learning disability aspire to.

ii. The social model of disability to form the basis of all policies, thinking and practice around disability. This should support the mainstreaming of the right to an independent life for disabled people.

iii. A change in the Government rhetoric around people on benefits. The language currently used in the press paints a picture of scroungers rather than one of people in need.

iv. Improved cross-Government thinking within and between departments. Many policies are inter-related, yet departments and internal working groups often still work in silos.

v. The Government should ensure that within all the policies that they are taking forward the impact on people with profound and multiple learning disabilities is assessed and addressed. This would ensure that unintended consequences and indirect discrimination are minimised.

Specific recommendations

vi. A robust monitoring system of the Work Capability Assessment by impairment group, to ensure that we fully understand the implications of the changes on people with a learning disability.

vii. A full-scale review of the additional costs of disability before reforming the Disability Living Allowance. Not doing so risks getting this reform wrong.

viii. The DLA/PIP mobility component to remain for those in residential care homes. As outlined above, this provides a vital lifeline to many people in residential accommodation.

ix. Maintain the level of benefits for disabled people under the Universal Credit model. It is vital that people with a learning disability, many of whom already live on the poverty line, do not lose out on benefits as a result of the changes to the benefit system.

x. Allowances to continue to be made and further improved within the Housing Benefit system for people with a learning disability, including those with milder learning disabilities.

xi. An exempt accommodation system that works for people with a learning disability, particularly those with more specialist needs. This is vital to ensure that independent living for those with higher support needs can also be accomplished.

xii. A Support for Mortgage Interest System that ensures that the Home Ownership for People with Long-term Disabilities model can continue. This will ensure that another avenue of housing for people who often struggle to find a suitable home is continued.

xiii. Improved co-operation between social services and housing departments locally as well as better forward planning; Community Care Assessments to include housing on all occasions. This will ensure that Local Authorities are more fully aware of housing and support needs locally and can act responsibly.
xiv. Better co-operation also between the police and Local Authorities on hate crime and safeguarding. This will ensure that they will have shared responsibility and incidences don’t get lost in bureaucracy.

xv. Police to take disability hate crime as seriously as racist hate crime. Disability hate crime cases currently are often prioritised or even recorded as hate crime.

xvi. A properly funded social care system which meets the needs for all individuals who require care and support in order to live independent lives.

xvii. A nationally set eligibility criteria system to eliminate the post code lottery within the social care system

xviii. Addressing the failures of the practice of personalisation, for example ensuring there is that there is a real choice of services, and that individuals have full access to free information and support to be fully included throughout the process.

xix. Changing Places toilets to be included in legislation and policy, as it is a practical way of widening the independent life of many disabled people.

What steps should the Government take to meet its obligations under the Disability Rights Convention to involve disabled people in policy development and decision-making, including in budget decisions such as the Comprehensive Spending Review? Are the current arrangements for involvement of disabled people in policy development and decision-making working?

37) Mencap welcomes the fact that the Government is now regularly publishing consultations in easy-read, as this clearly makes a difference to people with a learning disability. However, there is still room for improvement. More must be done to ensure that easy-read formats are published at the same time as the main consultation, which often is not the case, and sufficient time allowed for people to respond. We would also urge more focused involvement and consultancy work of people with a learning disability via focus groups or similar.

38) Furthermore, we would urge the Government to engage a wider group of people with a learning disability than is currently the case to ensure that the voices of as wide as possible a group are being heard. There is a feeling among the learning disability community that consultations often only take account of the view of a few select who have access to the consultation processes and the capability to express their views, sometimes to the detriment of the silent majority, which are not being heard.

39) On a more local level, we regularly hear from our members that they feel that consultations are not well promoted and that there is often a lack of awareness of consultations taking place. Given that many decisions particularly on service provision are made at a local level, it is vital that local authorities take their responsibility towards consulting people with a learning disability seriously.

28 April 2011
1. The right to independent living

Should the right to independent living continue to form the basis for Government policy on disability in the UK?

1.1 Yes. It is vital that this focus not only remains but is strengthened. This was a clear message from both of the focus groups we ran with local disabled people. Participants were concerned that disabled people are being ‘dropped off the radar’ in the current climate. People felt in particular that the emphasis should be on participation and inclusion. Participants did not feel that they were afforded the same rights as non-disabled people and there were significant gaps between how they want to live and how they are living.

Do existing policy statements, including the Independent Living Strategy, represent a coherent policy towards the implementation of the obligations in Article 19 of the UN Disability Rights Convention? Could current policy be improved? If so, how?

1.2 Sadly, the former government’s aim—as stated in the Independent Living Strategy—“that by 2013 disabled people have more choice and control over how their needs for support and/or equipment are met” is looking increasingly less likely to be realised effectively in the current austerity climate. We would be interested to know more about how the present government intend to take this Strategy forward, following their statement in June to this effect.

1.3 A key aim of the Strategy that disabled people requiring support should have more choice and control over how this is provided is something that disabled people we spoke with feel is an essential part of independent living: “It is being given a chance of being part of the community and having the right support—a choice of support”. Not everyone was living in circumstances they wanted to, and most had never heard of the Convention on the Rights of Disabled People (UNCRPD).

1.4 The other aim which interlinks access to housing, transport, education, employment and leisure with independent living and participation in family and community life also echoes the points people raised about how independent living cannot be seen in isolation. If there are transport barriers, for example, then people will not be able to make effective use of their support at home or work. It is therefore very important that the concept of independent living as described in Article 19 is not divorced from other policy areas. Some participants were frustrated that this Article was being addressed in isolation in the Inquiry for that reason. Disabled people have long put forward the principles of independent living, originally coined by Derbyshire Coalition of Disabled People, as a series of staged steps—one leading on from another. Access to information is the starting point, but from people’s feedback, this appears to be a missing link for many: (Background at http://www.breakthrough-uk.co.uk/AboutUs/Principles_of_Independent_Living)

1.5 The statement in the Coalition’s ‘Programme for Government’ that ‘We will extend the greater roll-out of personal budgets to give people and their carers more control and purchasing power.’ is encouraging, but needs to be matched by an infrastructure that will
allow this to genuinely happen in a way that works for people. All too often, people struggle to get the support they require at times to suit them. Effective brokerage, advocacy, peer support and advice will help, but these need to be sufficiently prioritised and resourced.

1.6 It will be important to monitor the work of the Right to Control Trailblazers so that this form of cross-cutting, linked up working across funding streams can be replicated elsewhere to protect the fundamental right to independent living.

1.7 Disabled people’s views on what independent living should be reflects the emphasis of Article 19. In particular people felt that being a part of the community was very important—both their local communities and communities of disabled people (community of interest).

1.8 The Article also talks about inclusion and participation, and preventing isolation and segregation. This too was picked up on and an area that was highlighted was around the lack of support for disabled people to network to make this right a reality. There is a danger that an individualistic focus on personalisation of services can miss this crucial need for peer support and networking.

1.9 This Inquiry is about the implementation of Article 19 and this was something that people felt strongly about: “implementation is vital otherwise it’s just words”.

1.10 Concerns were raised about segregated education, and this links into recent policy statements from the Coalition government and reiterated in the March 2011 Green Paper ‘SEN and Disability’ that “we will remove the bias towards inclusion”. This is a very regressive step. As one focus group member pointed out, young disabled people often slip through the net and tend to be invisible within the Convention. This links to Article 19 because inclusive education enables disabled children to be part of their community, as well as enabling them to be informed of the choices open to them. It also relates to the statement in the UNCRPD about community services being available on an equal basis.

1.12 We were disappointed to see that disabled people were not mentioned at all in the Programme for Government in the Equalities section, only under ‘Social Care and Disability’. This seems to indicate quite an individualistic way of looking at disabled people’s position, rather than a broader focus on social justice and barrier removal.

What steps, if any, should the coalition Government, the Scottish Government or other public agencies take better to meet the obligations in Article 19 and to secure the right to independent living for all disabled people in the UK?

1.13 More support should be made available to disabled people’s organisations and user led organisations by rerouting resources away from organisations that promote or run institutional living arrangements. Also people said that “Government should support sound organisations of disabled people to provide peer support. Peer support is vital for disabled people so they can get together, share advice and let others know what is available to them to live independently. In isolation it is very difficult for disabled people to learn from the experiences of others and have a voice. People need to be linked up so they know what to expect, what their rights are and how to challenge things.”
1.14 At the moment, independent living is far from a reality for many disabled people. Lack of choice and flexibility in support provision is a major factor, but less obvious things such as disability hate crime, stigma and harassment all impact on disabled people’s experiences of living independently too. These issues were brought up by people at the focus groups, several of whom talked about experiences of bullying in the community. Projects such as Breakthrough’s disability hate crime ‘Working It Through Together’ can provide holistic, one to one and peer advocacy support for disabled people in this situation, as well as educating agencies about the prevalence and nature of disability hate crime. But projects like ours struggle for sustainable funding, and this is a big factor in the provision of advocacy services more generally.

1.15 There is also a need to build, and continue to support, the work of action led learning sites. These enable user led organisations to learn from each other, build capacity and develop strategically so that they can support independent living in their localities. They also provide scope for user led organisations to influence policy more effectively.

1.16 One person said that “there is a perception that making people live in institutions will be cheaper for the country, but this is a false economy – disabled people living independently in the community and contributing to society is much more cost effective.”

1.17 A barrier removal approach needs to be holistic. Participants felt that a change of culture is needed. Organisations contracted to public agencies to deliver independent living services must ensure that their services provide long term solutions, rather than quick fixes. For example, one person talked about their housing support service. This aims to build her independence and it provides outreach support in the community for 2 years. However, once the 2 years is up, they have informed her that she could be moved out from her tenancy and relocated anywhere in Manchester away from her community, friends and voluntary work. So, although this service works to the principles of the Convention in the short term, in the long run she is likely to have to start from scratch elsewhere without this support as she will have exhausted her entitlement.

1.18 This lack of joined up thinking is a common experience for disabled people we work with and often comes about because of negative attitudes, funding constraints and lack of partnership working. It also stems from a paternalistic service provider/user relationship. Services based on co-production where disabled people are fully involved in service planning are unlikely to hit the same obstacles, but need to be resourced properly.

1.19 Another important point that people made was about the lack of information people had about their rights: “to be independent you need to know what your rights are and disabled people should be notified of what their rights are as well.”; “disabled people do not know that they have this right to independent living because they do not have the information they need. And their support gets cut off and then they can’t access the services.”

1.20 In each group, at least one person spoke about how it had taken them several years to find out about what they were entitled to, and about what support was out there. In one focus group of 7, only one person had heard of the Equality and Human Rights Commission. A suggestion was that a widely available address book of useful contacts should be developed with organisations—not just mainstream disability groups but with little known ones as well. This should be done with the involvement of disabled people. This sort of information should also be available in venues such as hospitals and rehabilitation centres so that people
who have just acquired an impairment can get the information they need straight away. This may already be done in some areas, but people we spoke with had not experienced it.

1.21 One focus group said that the government should set up an ombudsman comprised entirely of disabled people who would liaise with and support disabled people who are experiencing barriers.

**If you consider changes to policies, practices or legislation in the UK are necessary, please explain.**

1.22 As many commentators have already identified, the following is a non-exhaustive list of policies, practice and legislation that currently do not support independent living for disabled people.

1.23 We have called for the watering down of the Public Sector Equality Duty to be reversed—the lack of involvement required in the specific duties means that disabled people will not be in a position to effectively shape the inclusive services and practices that support independent living. We also feel that there is a real danger that the weak reporting requirements could lead to public authorities ‘cherry picking’ objectives that suit them, ignoring areas which would present more of a challenge. This will inevitably further marginalise social groups who experience significant barriers to engaging with public authorities, especially bearing in mind that the objective setting process is no longer supported by action planning.

1.24 Reducing bureaucracy should not be done at the expense of measures that allow disabled people to be meaningfully involved in decision making, decisions which will affect their independence.

1.25 The proposed replacement of Disability Living Allowance with a Personal Independence Payment has received widespread criticism. One of the fundamental flaws is that assessing someone’s mobility requirements based on how easily they can get around does not take into consideration the wider context of how their mobility equipment interacts with their environment, or of how of these items are acquired and paid for. Also DLA is a vital source of income which allows disabled people to meet the additional costs of living with an impairment in a barrier filled society. Tightening eligibility would leave many below the poverty line. This was a major anxiety of people attending our focus groups, and also of disabled people who participated in a consultation event late last year about the proposed changes to DLA. The government claims that the new benefit will follow the social model of disability, but PIP would still operate on a medicalised assessment process.

1.26 Some recent policy decisions have sent out unhelpful messages about priorities, for instance the establishment of a website this month about red tape asking whether the Equality Act should be abolished. The Act itself is not being introduced as fully as was hoped for either—for example the concept of Dual Discrimination has been lost in the recent Budget.

1.27 Disabled people also had particular concerns about the harshness of the Work Capability Assessment for Employment and Support Allowance. Several people had been affected by this and said that they found the whole system very stressful and difficult. One member of the group described how she scored 13 points in an assessment for ESA (so was not eligible), but this went up to over 70 when a professional got involved and fought...
her corner—this example shows how very difficult it can be for disabled people to get things they are entitled to without external support such as advocacy or professional intervention. This must be costed in and acknowledged.

1.28 Another said: “the government do not comprehend how the changes in this test affect people.”

1.29 It is also important to look at the wider context—high levels of unemployment, lower levels of support for the large numbers of people found not eligible for ESA and all this in the face of local authority budget cuts affecting providers of supported employment services.

1.30 A contributor said: “in the past I was in supported accommodation and I paid the whole of my rent without accessing means tested benefits unlike all the other tenants who were subsidised through income support and housing benefit. However there was not enough support provided there and the place was too noisy for me. Any future housing of this sort (in fact anything other than living with my carer) will be out of the question if the Government go ahead with the proposed changes to disability benefits.

1.31 My main concern with the changes to benefits is the plan to time limit contributory Employment and Support Allowance to one year only. After one year people in receipt of the benefit are expected to be well enough to go back to work! I am fearful that I will be affected by the change when I am migrated from Incapacity Benefit because only a very small percentage of disabled people are being granted entry into the support group which is not time limited to 1 year. It is unrealistic to say the least that long term disabled people with great support needs such as my own will be able to go back to work within a year, if ever. So, it seems that I will not be able to afford supported accommodation (or indeed any other accommodation) ever again until I am eligible for housing benefit.”

1.32 More barriers around employment that people experienced are discussed in Appendix 1 on page 20.

1.33 As already discussed, the SEN Green Paper contains elements which go against the grain of inclusion, which is at the heart of independent living.

2 Impact of funding on the right to independent living

The Committee would particularly welcome evidence on these recent developments:

The decision, announced in the CSR, to remove the mobility component of Disability Living Allowance for all people living in residential care.

2.1 This has been put on hold until the re-assessment of people currently on DLA for the new PIP, but we believe it would be a massive infringement on the already limited independence of affected disabled people if implemented. Relying on already over-stretched local authorities and community services to bridge this gap is very unlikely to enable people to have the same choices as they would have via the mobility component.

"The Big Society"

2.2 We did not discuss this in depth, but people in one group did say that charities need to change their attitudes towards disabled people because their criteria do not match what
people want or require. Voluntary organisations are also seeing drastic cuts in the funding from local authorities, so lack the capacity to respond to people’s requirements in a timely way. Issues people raised about hate crime and bullying by neighbours is also relevant as this shows that many disabled people do not view their communities as benevolent, even if they desired support from this quarter. One person talked about a neighbour with learning difficulties moving into a sheltered housing scheme. He became the subject of a petition to get him moved out when people learned he would be living there.

2.3 There is widespread concern about the expectation that the ‘big society’ will cater for people’s requirements, rather than the state, and that people will see a return to the model of disability where disabled people are seen as the needy recipients of charity.

Restrictions on local authority funding, social care budgets and benefits reassessments.

2.4 People felt strongly that community services are—or will very soon—take the support away that disabled people need to be independent because of the changes with cuts and benefits. Changes to Fair Access to Care Services criteria were mentioned for example. One person said that in 3 months time people will not have the support they get now. So we are concerned that the responses to this Inquiry will not reflect the reality of disabled people’s lives in a few months time. Recent reports about a fifth of social support providers expecting to close within the year would be another example of the gravity of the situation.

2.5 People expressed the fear that disabled people could end up in a residential institution without the right support. “Fewer people are eligible to receive support” one said, “but people’s requirements remain the same.”

2.6 Participants said that local authority money needs to be prioritised on the activities and services that support disabled people’s independence. This should be their first concern as it is a human rights issue. And then look at what budget is left for other things once this has been addressed.

2.7 The point was raised that some disabled people would feel uncomfortable about making a fuss e.g. challenging services or the government on how they do things. Especially if there is a fear that those services might be cut or reduced.

Increased focus on localisation and its potential impact on care provision, and specifically, on portability of care and mobility for disabled people

2.8 Issues were raised about the restrictions on usage of the disabled persons travel pass. For example, many disabled people in Greater Manchester now have to pay half fare on buses before 9.30am, an increase on the previous flat rate of 70p for peak times.

2.9 The wider issue of portability was not discussed in the focus groups, but this will be something that may be demonstrated through the Manchester Right to Control Trailblazer area, which covers 5 separate local authority areas. Breakthrough UK has been commissioned by the Manchester Area Partnership to be the Right to Control Centre for Independent Living.
3 Participation and Consultation

**What steps should the Government take to meet its obligations under the Disability Rights Convention to involve disabled people in policy development and decision-making, including in budget decisions such as the Comprehensive Spending Review?**

3.1 Both groups felt strongly that there is insufficient involvement with disabled people from government. One group suggested having an MP come to live with a disabled person for 2 weeks to witness first hand the barriers they faced to living independently.

3.2 One person said that “only a disabled person can describe how hard a disabled person can struggle through life. Views need to come from the people, not from a book”.

3.3 The other focus group thought that more should be done to invite experienced disabled people to be questioned on policy issues: “listen and act. Disabled people need reciprocation. People who have experience and knowledge can share this with government, if MPs are willing to listen. We don’t just want talking shops. Deeds not words!”

3.4 We note the existence of Equality 2025 and the ‘Network of Networks’ but are not clear on who these groups are reaching and influencing as the evaluation is not yet available.

**Are the current arrangements for involvement of disabled people in policy development and decision-making working?**

3.5 People expressed concerns about an over-reliance of online and written media to engage and involve disabled people in decision making. There need to be more opportunities for face to face contact. As discussed, many people are not aware of the existence of key agencies such as the Equality and Human Rights Commission, so there is a big communications gap here.

3.6 Our experience with the Disability Living Allowance consultation was not great—the Welfare Reform Bill was released before the consultation deadline had arrived. This did make the whole process appear somewhat tokenistic, especially given the short timescale and the lack of publicity surrounding any face to face events the DWP might have organised (we were not aware of any).

**4 Recommendations for Action**

4.1 More support needs to be given to user led organisations which provide peer support and promote inclusion.

4.2 Advocacy needs to be available to all disabled people in the community and seen as a big priority to enable people to navigate the system and get the support they require. This must be costed in and acknowledged.

4.3 It is very important that the concept of independent living as described in Article 19 is not divorced from other policy areas such as housing, information, education and employment—they impact on each other.
4.4 It will be important to monitor the work of the Right to Control Trailblazers so that this form of cross-cutting, linked up working across funding streams can be replicated elsewhere to protect the fundamental right to independent living.

4.5 There needs to be a broader focus on social justice and barrier removal rather than just focusing on the individual.

4.6 More support should be made available to disabled people’s organisations and user led organisations by rerouting resources away from organisations that promote or run institutional living arrangements. Government should support sound organisations of disabled people to provide peer support.

4.7 There is also a need to build, and continue to support, the work of action led learning sites.

4.8 Organisations contracted to public agencies to deliver independent living services must ensure that their services provide long term solutions, rather than quick fixes.

4.9 Services based on co-production where disabled people are fully involved in service planning need to be resourced properly.

4.10 The focus group suggested that a widely available address book of useful contacts should be developed with organisations—not just mainstream disability groups but with little known ones as well. This should be done with the involvement of disabled people. This sort of information should also be available in venues such as hospitals and rehabilitation centres so that people who have just acquired an impairment can get the information they need straight away (initiatives like this may exist in some areas, but had not reached the people we spoke with).

4.11 One focus group said that the government should set up an ombudsman comprised entirely of disabled people who would liaise with and support disabled people.

4.12 Charities need to change their attitudes towards disabled people because their criteria do not match what people want or require.

4.13 Reducing bureaucracy should not be done at the expense of measures that allow disabled people to be meaningfully involved in decision making.

4.14 Local authority money needs to be prioritised on the activities and services that support disabled people’s independence.

4.15 One group suggested having an MP come to live with a disabled person for 2 weeks to witness first hand the barriers they faced to living independently. Disabled people should be invited to be questioned on policy issues.

4.16 There should not be an over-reliance of online and written media to engage and involve disabled people in decision making. There need to be more opportunities for face to face contact.

4.17 Consultations need to employ a range of engagement mechanisms and ensure that enough time is allowed to process the results before concrete policy decisions are made.
Appendix One – Views of Disabled People

Independent Living Enquiry Focus Group:

Discussion Notes: 15th April 2011 at 10:30am – 12:30pm

Welcome and Introductions

- Who set the agenda for the Inquiry questions on the UN Convention? Who has the power here? Will anything be done about the results?

- How is the Convention on the Rights of Disabled People actually being implemented? Implementation is vital otherwise it’s just words.

- Will elements of the right to independent living impact on the changes announced to the Mental Health Act and Mental Capacity Act?

United Nations Convention on the Rights of Disabled People

- People felt strongly that community services are—or will very soon—take the support away that disabled people need to be independent because of the changes with cuts and benefits. Changes to FACS criteria were mentioned for example. In 3 months time people will not have the support they get now. So we are concerned that the responses to this Inquiry will not reflect the reality of disabled people’s lives in a few months time.

- One member of the group described how she scored 13 points in an assessment for ESA, but this went up to over 70 when a professional got involved and fought her corner—this shows how very difficult it can be for disabled people to get things they are entitled to without external support such as advocacy or professional intervention. This must be costed in.

- Disabled people could end up in a residential institution without the right support.

- A big issue that disabled people find with services aiming to promote independent living is gatekeeping—people withholding vital information or controlling who you can speak to for example.

- In the future, the government may say that disabled people are happy with the changes, when the truth is they are not (how will this be reflected in the way this committee reports back?)

- Many people say that they see disabled people and think of all the red tape that has to be waded through to support them.

- Looking at the Convention, the right to education could mean segregated education, not mainstream education. It should always be inclusive education. There was an extensive discussion around this. For example, school lessons should be tailored to the disabled person’s/child’s requirements and adjustments made where appropriate so that people are not excluded. A creative approach is required to achieve this, not segregation.
• We find that young disabled people often slip through the net—even though there is also a Convention on the rights of the child, young disabled people are invisible within this.

• There was some discussion around how the Convention may be used to address the decisions made about a group member’s pension entitlement – he feels he has been treated unfairly because of his impairment.

• There was also some discussion around abuse in residential institutions and that this often extends into the home.

• Disabled people do not know that they have this right to Independent Living (under article 19 of the Convention), because they do not have the information they need. And their support gets cut off and then they can’t get access to services. It took one member of the group 5 years following acquiring his condition to find out what his rights are and network with other disabled people.

**Could the government do more to give disabled people the same rights as everyone else to live independently?**

• Local authority money needs to be prioritised on the activities and services that support disabled people’s independent living. This should be the first concern as it is a human rights issue. And then look at what budget is left for other things once this has been addressed.

**Do the government need to change any laws or the way they do things?**

• Listen and act. Disabled people need reciprocation. People who have experience and knowledge can share this with government, if MPs are willing to listen. We don’t just want talking shops. Deeds not words!

• Invite disabled people with experience to be questioned by the committee on what can be changed. And then act upon this.

• There is an issue for government on making information available. How can the EHRC, for example, get their information across to disabled people who can’t use a computer or the internet?

• Some people would feel uncomfortable about making a fuss e.g. challenging services or government on how they do things. Especially if there is a fear that these services might be cut or reduced.

• Government should support sound organisations of disabled people to provide peer support. Peer support is vital for disabled people so they can get together, share advice and let others know what is available to them to live independently. In isolation it is very difficult for disabled people to learn from the experiences of others and have a voice. People need to be linked up so they know what to expect, what their rights are and how to challenge things. Power in numbers. There needs to be more provision for disabled people to get together.
Where do you go to if some of the support structures are gone? Mention was made of the closure of the National Mental Health Development Unit for example. There are lots of similar examples.

Another important issue is the way police approach disabled people and people with mental health conditions in particular—people feel stigmatised and targeted in their own communities. People’s rights to privacy are not respected.

Neighbours can cause problems if they find out about a disabled person’s impairment. This could result in discrimination. One person talked about a learning disabled neighbour moving into a sheltered housing scheme. He became the subject of a petition to get him moved out when people learned he would be living there. These sorts of attitudinal barriers can force disabled people into institutions against their wish and go against the Convention.

The media also can portray disabled people in an unfavourable light. They can openly target you (e.g. by talking about ‘benefit scroungers’) & therefore cause discrimination against you.

Transport can impact your life and can create barriers leading to no support. They can’t see that you need the transport to get to the support you need. For example, disabled people now have to pay half fare on buses before 9.30am, an increase on the previous flat rate of 70p for peak times. One person had to leave the group because her taxi was outside—she always uses the same driver to get the support she needs so it’s important to keep him happy.

This Inquiry needs to take account of all the Rights in the UNCRPD, not just the Independent Living one, because they are interrelated.

The emphasis must be on inclusion and participation.

We are considered below the poverty level. We need to be treated right and have the same rights as everyone else.

There is a change of culture needed to see the problems we face.

We are more than what we are perceived to be.

There has to be an understanding with drivers of transport—one person talked of the abuse they experienced from a bus driver when he showed them his concessionary pass.

**Will cuts in funding or changes to benefits make being independent harder?**

- Yes. Cuts will definitely make an impact. Providers will need to change the criteria on how they do things with inevitable consequences.

- Disabled people are being ‘dropped off the radar’ because of criteria changes. Fewer people are eligible to receive support, but people’s requirements remain the same.
• Disabled people could be perceived as ‘too expensive’ to support or spend money on in the current economic climate. This is creating an underclass.

• When talking finances, there is a perception that making people live in institutions will be cheaper for the country, but this is a false economy—disabled people living independently in the community and contributing to society is much more cost effective.

• Services need to think of a disabled person’s well-being. We shouldn’t be treated differently.

• Just because you’re not healthy or ill doesn’t mean you should be sidelined.

• It is about false economies; false priorities. In terms of mental health, more should be spent on prevention and not on recovery.

• How would disabled people get the support if they do not have the support network available to them (such as advocates)? Good advocacy is really important, but it is not available to everyone.

Notes from the Independent Living Enquiry Focus Group

Innovation Centre @ Breakthrough:

6th April 2011 10:00am—12:00pm

We talked about the United Nations Convention on the Rights of Disabled People and the main rights in it. Everyone had a handout explaining these rights and we went through this.

Then we asked everyone some questions about their views on independent living. These are from a parliamentary Inquiry that Breakthrough is responding to. What people said is below under each question.

What you think independent living should be?

• We should be part of the community.

• It is being given a chance of being part of the community and having the right support—a choice of support.

• One person said that independence is about being on your own and being free from the stigma that surrounds mental health.

• It is about maintaining your own life (e.g. managing your own bills, your own housing).

• Every country (including the UK) needs to reform to make independent living happen.

Could the government do more to give disabled people the same rights as everyone else to live independently?
• Yes!

• One person talked about their housing support service. They build your independence and give outreach support in the community for 2 years. But then they take it away from you by saying you could be moved out when the 2 years is up. This could mean she is re-housed anywhere in Manchester away from her community, friends and voluntary work. So services are going against what the Convention says.

• People have to change and charities that provide support must change too.

• The government should show a better example. MPs should get involved with the local community & speak to them more.

• MPs should spend time with disabled people and find out how disabled people struggle. One person suggested that MPs should move in with a disabled person for 2 weeks to get first hand experience.

• Stop the stigma against disabled people & stop the bullying / discrimination against disabled people.

• Someone talked about problems with neighbours, people making up things about them. And then not being taken seriously when they made a complaint to the landlord.

Do the government need to change any laws or the way they do things?

• One person was concerned that people’s views will not be taken seriously. They don’t think the government will do anything about the evidence from this Inquiry.

• The government should set up an Ombudsman consisting of disabled people in the panel who would liaise with and support disabled people.

• How can a disabled person contact the Equality and Human Rights Commission (EHRC) if they do not know about them? Many people in the group had not heard of them before. (They promote human rights and equality. Tel: 0845 604 6610, website: www.equalityhumanrights.com)

• People thought a widely available address book of useful contacts should be developed with organisations—not just mainstream disability groups, but little known ones as well. This should be created with disabled people involved.

• Many people had found it hard to get information about their rights. They had had to work hard to get this information and for some people it had taken years. It should be much easier to find.

• One person suggested having this information available in hospitals and rehabilitation centres for people who have just got an impairment through accident or illness.

• Several people talked about employment as part of independent living. For example:
• Change laws in companies who employ disabled people.

• One person in the group had been given basic tasks to do at work because her employer had not been able to find a suitable way to make adjustments to her role and be flexible. They did not understand how to support someone with a condition that varies.

• Another person has found that employers would not take him on because they are not flexible about making adjustments to job tasks. He thought cost was the reason.

• When a disabled person is employed, they should have an employment mentor / support to make sure the employer does it right.

Will cuts in funding or changes to benefits make being independent harder?

• Yes it will!

• One person said that only a disabled person can describe how hard a disabled person can struggle through life. Views need to come from the people, not from a book.

• They need to make things effective, as disabled people feel they are a minority regarding government decisions and are not being listened to.

• To be independent you need to know what your rights are and disabled people should be notified of what their rights are as well.

• Government needs to change for disabled people’s well being.

• It is difficult to get Employment and Support Allowance & other benefits such as Disability Living Allowance.

• It can be difficult. One person said that the government just want everyone back at work and off benefits.

• The Work Capability Assessment makes assumptions and people do not get what they should be entitled to.

• The government do not comprehend how the changes in this test affect people. Or the difficulties of maintaining fitness for work, due to things like medication.

• People are being discriminated against at work, so they just walk out.

• Disabled employees feel different to others and have to ‘earn’ their colleagues’ respect at work.

• Employers need an understanding of mental health and have to understand that some disabled people need time off in case of ‘blips’ in support (such as medication). People were concerned that employers would decide not to employ anyone similar again.
• (recent changes to the Access to Work scheme were mentioned here – you can now get a letter confirming you can get support at work to give to an employer when you apply for jobs. Details at the link below, or speak to your Employment Officer: http://www.direct.gov.uk/en/DisabledPeople/Employmentsupport/WorkSchemesAndProgrammes/DG_4000347)

• They do need someone to oversee this to make sure discrimination doesn’t happen & that employers are fair.

At this point we talked about the Equality Act. This says that employers must not discriminate against disabled people when they apply for jobs or are in a job.

An email from a disabled person unable to attend a focus group:

“I have been diagnosed with a long term mental illness and have complex housing and support needs. I need someone to provide support 24/7. I am not eligible for means tested housing benefit or income support because I have a moderate amount of savings. As my savings do not cover the amount of support I would need long term, I do not have access to the kind of independent support that I need. Were I to use my savings up until eligible for means tested support I would still not get my needs met because even if I was deemed eligible for residential care I am unable to live with other people apart from the aforementioned family member. It is of utmost importance to me not to have to rely on means-tested benefits because my housing and support needs are complex and do not fit in with conventional state funded care which is all I would have to access without more income. I should add that I need my own self-contained living accommodation with adjacent (not live-in) support 24/7 and it is unlikely that state funded care would provide for such complex needs. So I am in a catch 22 situation. Hence my care has to be provided by an elderly family member who is my carer and with whom consequently I have to live with though this suits neither of us. I spend a lot of time in dread of the time when my carer dies.

In the past I was in supported accommodation and I paid the whole of my rent without accessing means tested benefits unlike all the other tenants who were subsidised through income support and housing benefit. However there was not enough support provided there and the place was too noisy for me. Any future housing of this sort (in fact of anything other than living with my carer) will be out of the question if the Government go ahead with the proposed changes to disability benefits.

My main concern with the changes to benefits is the plan to time limit contributory Employment and Support Allowance to one year only. After one year people in receipt of the benefit are expected to be well enough to go back to work! I am fearful that I will be affected by the change when I am migrated from Incapacity Benefit because only a very small percentage of disabled people are being granted entry into the support group which is not time limited to 1 year. It is unrealistic to say the least that long term disabled people with great support needs such as my own will be able to go back to work within a year, if ever. So, it seems that I will not be able to afford supported accommodation (or indeed any other accommodation) ever again until I am eligible for housing benefit.

Another problem is that often the local authority do not recognise that people need (or will get) as much support as they do because they are short of money. Thus it appears that disabled persons with support needs who are very poor get SOME of their support needs
met. And the very rich (who can therefore afford to pay their costs out of their capital) get their housing and support needs met adequately.

The solution to the problem is that support should not be means tested and that the state pay enough to satisfy the need.”

Appendix Two: Supplementary Evidence to Independent Living Inquiry Submission

Prepared for Breakthrough UK, in collaboration with Vision Sense and the ULO Network NE, by Susie Balderston.

1) Introduction.

This response evidence thematically addresses the principles of Independent Living highlighted by respondents in the consultation held by Breakthrough UK. It also asks the Inquiry to acknowledge the diversity of disabled people and discrimination against them, which is intersectionally compounded by discrimination on the grounds of disabled people’s age, ethnicity, sexual orientation, cultural background, religion or belief, gender, accommodation status and recourse to public funds. Firstly, this appendix discusses the context of disabled people’s struggle for justice, recognition and human rights.

2) Context of the Inquiry.

This submission recognises that Article 19 of the Convention does not exist in isolation; recognition of concepts of dignity, diversity and protection from cruel or inhumane treatment underpin the rights of disabled people to live independently and be included in the community. In addition, attention is drawn to the principles of human rights being minimum standards (which we hold that a democracy like the UK should exceed), not aspirations. Social and civic justice, along with basic legal redress if human rights are denied (Zizek, 2005) are necessary to achieve choice (Rabiee and Glendinning, 2010) and independent living for disabled people.

3) Disabled people require access to information and peer support, to assist them in making choices about how their support is provided, by whom and when.

Advocacy, advice and information, provided by other disabled people (in User-Led Organisations based on a Centre for Independent Living Model (PMSU, 1995) is a cornerstone, without which independent living cannot become a reality. Therefore, this should be a state-funded priority for health and social care (ideally by public health, GP Commissioners and Local Authorities working together) in all local authority areas which have social services responsibility. In 2010, when the Putting People First milestone for provision was monitored, many local authority areas in the NE had groups of disabled people providing these services, but who were not securely, or state funded, despite this cost being small (Davey et al, 2009) compared to Town Hall in-house teams which assess and gate-keep resources. In addition, the community contact, employment benefits of these activities may prevent stepping up to more acute, expensive medical and social care services in the future for many disabled people.
The provision of this peer and case advocacy is the minimum necessary for personalised services to become a reality. Several disabled people and social workers now report that existing (often for-profit) agency providers are coaching disabled clients to ask for their service to remain in place; without independent advocacy from their peers (who know about the choices available and can support disabled people accessibly to make informed choices) the system is open to manipulation of this sort, impeding choice and leading to market distortion.

There are significant differences in the geographical provision and uptake of Deprivation of Liberty assessments and protection (DH, 2010 quarterly figures), which points to unequal human rights protection arbitrarily by area.

4) Accessible Housing.

Disabled people often have to wait disproportionate lengths of time, compared to other people, for accessible housing and face significant barriers in accessing the systems (http://www.housingoptions.org.uk/general_information/gi_resources_docs/choice_based_le ttings_report.pdf). This may mean they languish in hospital longer than is necessary or desirable. Eventual access to some independent living is not the same as timely and appropriate access. Some disabled people have to choose between their choice to work and essential adaptations they cannot then afford, because of means-testing which is often unfairly applied, or the lack of advocacy to access their own equipment. 2% of the housing stock have to be created as lifetime homes, yet in the North East, the population of disabled people is between 24% and 30% in some areas, resulting in need outstripping supply.

5) Young people’s human rights.

For many young disabled people, the lack of provision of safe, inclusive, mainstream education where they can learn with their brothers and sisters or others in their community, still prevents them fundamentally from having choice over where they live, who provides their support to learn and having a family life. The failure of the Government to ratify the whole Convention (including Article 24 (2a.)) without reservation means that the UK still falls short of these basic rights. This affects the aspirations and performance, ability to take part in community life and transition to their own home, mental health outcomes (Honey et al, 2011), further or higher education access in a timely way or at all, safety from abuse, freedom from stigma (Cooney, 2006) and life chances of young people, not only during their school years, but sometimes for their whole lives. Many disabled people are allowed only to learn basic ‘living’ skills, rather than being afforded education in literacy after pseudo-medical judgements about their capacity by professionals with no pedagogical skills themselves. Some commentators have noted that, for disabled people in institutions, in terms of denying their diversity, this treatment may be akin to the early racist constructions of African and Indian men and women being unable to learn or express themselves (Kliweer et al (2006)). This unethical segregation (Alderson and Goodey, 1998) can lead to abuse thriving and damage the life chances of disabled children and young people, disproportionately compared to non-disabled children’s chances and choices.

For some young people with disabled parents, siblings or family members, the lack of provision of adequate support can mean that they sometimes under-take inappropriate support roles, which disrupts the human right to a family life. The existence of ‘young carers’ projects should not be necessary, if adequate support is provided. (Morris, 1992).
6) Postcode lottery differences.

Most disabled people’s rights and access to independent living vary because of the geographical area in which they live, or from where they originate, not only nationally, but with significant variations between county and city areas. There is currently no national right to advocacy or information, which is crucial for disabled people to make informed choices about where they live, their activities, access to employment and education and crucially, when, how and by whom their support is provided.

Currently, many local authorities with social services responsibility, still contract providers for ‘beds’ in institutions or have block respite provision in certain areas, giving little or no choice and control to where people are placed. The persistence of ‘out of area’ placements (Emerson & Robertson, 2008), prevents many disabled people having access to a family or community life and may leave them institutionalised and isolated, without even adequate, annual assessment by independent advocates or social workers who know them (Balderston and Joyce, 2008, unpublished).

7) Recommendations to the Select Committee.

That the UK ratifies the UN Convention without reservations.

That inclusive education be the presumed right of all disabled children and young people, to prevent segregation and ensure they can continue to live as part of their family and community (including their peer group), so that Article 19 (b) can be fulfilled for all age groups.

That disabled people have the right to choose who provides their support. The current prevalent system of Housing and Institutional Living providers being contracted by health and social care Commissioners to deliver support and accommodation together denies disabled people the chance to move, choose who baths them, what time that happens, what they eat and can lead to isolation and abuse. Many disabled people living in institutions or supported living are denied adequate support at weekends or out of work hours. Several report fear of complaining about the inadequate support in case they lose their housing. Many disabled people do not have the choice of the gender or age of the person providing personal care and support, which denies their dignity and may risk their safety. Some disabled people with complex support packages rarely, if ever, have the chance to interact with other people away from the control or presence of the provider’s employees, compounding isolation and making disclosure of abuse almost impossible in many circumstances.

That the Committee ascertain the spending use of the Social Care Reform Grant by local authorities; in the North East, disabled people’s organisations and disabled beneficiaries received less than 5% of this spend and many historic services were not de-commissioned or retendered as a result of the process.

That the Access to Work scheme is extended to volunteering, so that disabled people can serve their community as citizens, reducing isolation, segregation and improving citizenship for disabled and Deaf people (19c).

That requirements for levels of accessible housing and transport are set to match local need (through the JSNA) not just on arbitrary national guidelines of 2% and 6%.
That the Inquiry makes recommendations to upgrade the Mental Capacity Act provisions to reflect the required international Human Rights standard and that it makes recommendations to reduce the different levels of Deprivation of Liberty and Advocate provision in different areas of England.

References


People First (Scotland) is an organisation of people with learning difficulties. Our members prefer the terms ‘learning difficulty’ and ‘learning difficulties’. We believe that they are less stigmatising and more accurate. In this document when we use these words we are talking about people that Scottish law and guidance calls people with a ‘learning disability’ or ‘learning disabilities’.

The Right to Independent Living

Could the government do more to give disabled people the same rights as everyone else to live independently?

Yes, the government could do more to give disabled people the right to live independently.

At the moment we don’t have the same rights as other people to choose where we live or who we want to live with, to get the support we need to learn, or to be fully included in community services and the wider community because general services are not accepting of people with learning difficulties and there is a lot of prejudice against people with learning difficulties in the wider community.

We have rights by law but these are not always fulfilled.

What could they do to make this happen?

We should have the same opportunities as everyone else to have our own tenancy and live with who we choose, whether this is partners, families, friends or on our own if we want to. We shouldn’t have to live in group homes if we don’t want to. We shouldn’t be made to live with people we haven’t chosen or who we don’t get on with. More houses should be built that are suitable for people with disabilities and people with learning difficulties. People who have 24-hour support needs, or close to it, are not getting the chance to make choices about where they live and who they live with. The support needs of a person should not dictate whether a person has choice; that is discrimination.

Living in a shared house means a lack of privacy. This can be very stressful, and further discriminates against people.

Advocacy organisations are really important because they support people to take control of their lives and to have choices.

It is important that the government and people who provide services listen to us. We are the experts in what is best for us. Sometimes people listen to parents and carers more than they listen to us.

Do you think the government needs to change any laws or the way it does things?

Yes. There are lots of things that need to change.
If so, what needs to change?

Lots of people with learning difficulties don’t know what their rights are. The law should give us more power and a good way of understanding and reporting if we don’t get our rights.

We don’t like the way people with learning difficulties are defined. The Mental Health (Care and Treatment) (Scotland) Act 2003 defines people with learning difficulties, people with mental health problems and people with personality disorders as having a ‘mental disorder’. People can get better from mental health problems. People with learning difficulties are able to learn, but will always have a learning difficulty. We should not be grouped together in the same way under the law.

We should be able to make choices about intimate and sexual relationships like anyone else. People with learning difficulties have often not been educated about sexual relationships, or we have been told we should not have sexual relationships. Section 17 of the Sexual Offences (Scotland) Act 2009 states that people that have a ‘mental disorder’ may not be able to consent to sexual relationships. This law is needed to protect some people from abuse, but can also be used in the wrong way, and can prevent people from making their own informed choices about sexual relationships. Our parents and carers can make assumptions that we are not able to consent to or understand sexual relationships. This can be even more restrictive than the law.

We should be able to get a job. For a long time there has been little or no expectation for us to find paid employment. People should have more money for going to work, not less. The current benefits system is a barrier to earning money for work. Too many people with learning difficulties do voluntary work placements instead of paid work.

Good quality employment services are really important to support people with learning difficulties to be able to work. The support to find and maintain paid work is being reduced, as is the budget to fund adaptations to the workplace. Supporting people to work is better in the short term and the long term. If saving money dictates who has the chance to come off benefits and go to work this is discriminatory.

We are still much more likely to be bullied, harassed or abused than other citizens. Disabled people are now included in hate crime legislation but we don’t think this makes much difference in practice. Social attitudes toward people with learning difficulties are still very negative, and this needs to change.

At the very root of the way people’s attitudes develop is our exclusion from mainstream education when we are of school age. We strongly disagree with the Government’s reserved position on education and think that it actively discriminates against us and denies us the opportunity to engage with the wider community, to learn social skills, sometimes to get qualifications and to find work. The argument about “parental choice” is not a genuine reason and parents tell us that they are afraid to send their disabled children to mainstream schools.

It is important to raise awareness of human rights. We should be part of this awareness raising.

Lack of money
Written Evidence submitted by People First Scotland (IL 59)

**The government needs to save money. The Joint Committee would like to hear how people have been affected by:**

**Changes to benefits**

We are worried that changes to benefits will affect our quality of life.

We are worried about work capability assessments. If we don’t understand the assessment, it can be very worrying. We need more information about this.

We have been affected by receiving our benefits less frequently. This makes it harder to live independently because we need more support to manage our money. More time spent managing money means less support time to do things we want to and learn new skills.

We think that it is better to keep money for housing and money for everyday living separate. This would make it easier to earn money from paid work.

**Changes in services**

We need more information about changes in our services.

We don’t always get the support we need to learn. Some people have never learnt basic skills like cooking because it is quicker for support workers to do things for us when time is limited. Sometimes we cannot learn because we are limited by inflexible health and safety procedures, or because we are not getting good support.

How much support people get is very inflexible. Sometimes we need more support and sometimes less, depending on what is happening in our lives. Having bad news could mean that extra time is needed to address the emotional impact of that news but the time to complete the tasks the support time is usually allocated for also needs to be protected. As support usually need to leave right on time to get to someone else this is not possible.

Sometimes we attend day centres because we think there is nothing else we can do. We think day centres separate people from the rest of the community. Services to help people find and maintain work and engage as citizens in our communities are really important.

When services have been put out to competitive tender, people felt that where consultation happened it didn’t always make a difference. When a consultation or Equality Impact Assessment happens there must be enough time to listen to the responses and act on them before changes are made.

There are sometimes good reasons for services being put out to tender. However, when a service is meeting people’s needs and is only put out to tender on the basis of cost this upheaval can affect the support we receive. Also if you pay less for a service, you are likely to get less for it.

**The way local councils decide whether you get a service or not**

Local councils are beginning to apply eligibility criteria for services, but these are based on the assumed physical needs of older people. We don’t think these are suitable for people with learning difficulties.
Sometimes we need more support to learn new skills and to be able to make choices, not just to fulfil our basic needs. When people have low needs, the support they receive tends to be with practical everyday tasks like keeping the house clean and going to appointments. Assessment for services should be flexible and individual, not based on criteria for everyone. People should be able to get more support if they need it without having to wait for a crisis to happen.

We also think there is too much emphasis on the provision of services; we should get the support we need to be able to gain confidence and learn new skills with the ultimate goal being leading inclusive lives in the wider community.

The Joint Committee would like to know if you think these things are making being independent more or less difficult.

The thought of cuts to funding and services is making being independent more difficult. People are worried about not having services and not having enough money in the future.

Being included and developing as citizens in the community with the same ability to make choices as everyone else requires this support.

Getting involved and saying what you think

The UN convention about rights for disabled people says governments must involve people in decisions that affect them.

How can the government involve disabled people in planning and deciding how to save money?

We appreciate that in government the voices of people with learning difficulties are better represented than in the past.

We think that it is really important for people with learning difficulties to be included in making decisions. It is important for us to understand the information so that we are not involved in a ‘token’ way. It is important for our views to be listened to.

We shouldn’t have to suffer because the government needs to save money. It is our right to get the support we need to live independently.

How well are disabled people involved in planning and making decisions?

We should have the opportunity to participate in our own organisations. When we are expressing our views we should be supported by people who are independent of the government and the services we use. Ideally they should be accountable to us and our organisation.

It is common for us to be invited to meetings and to be consulted about changes. However, we are not always listened to. Sometimes we are concerned that our responses are not listened to and acted upon. Sometimes we feel that decisions have been made before we are consulted.

We get asked about strategy and policies for the whole country, but sometimes we are not involved locally. It would be good to help make decisions about the services we use locally.
If we get easyread information that is sent out in advance, we will be able to understand meetings much better. It is important we have enough time to digest what is being asked of us.

**Sticking to the UN Convention**

In summer 2011 the government has to say how well it is sticking to the UN Convention about rights for disabled people.

How can the government make sure it includes ideas from disabled people in its reports?

Make sure the government listens to us, not just our parents and carers. We are the most important people because we are the experts in what works for us.

Sometimes getting accessible information in advance and providing people with the support to access and respond to that information comes as an afterthought in many consultations. It should form the basis of these events.

Advocacy organisations need support and money to help people get their voices heard.
Executive Summary

1. AKW Medicare Ltd is the market leading provider of Bathroom, Showering, Kitchen and Daily Living products for people with mobility difficulties.

2. Our home adaptations and products are vital in enabling individuals to stay in their own homes and live independently for longer.

3. The Comprehensive Spending Review announced that the Disabled Facilities Grant (DFG)—the main grant administered by local authorities for home adaptations for elderly and disabled people—would not be cut but critically removed its ring-fencing. We are concerned that, in practice, the removal of the ring fence means that the DFG is being eroded by other competing demands upon local authorities’ financial resources.

4. In late 2010, we submitted Freedom of Information (FOI) requests to 434 local authorities which revealed 14,451 fewer home adaptations in 2010 compared to 2009 representing a 22% reduction overall in the number of adaptations taking place.

5. We believe, however, that cuts in funding for home adaptations is a false economy, costing the NHS and local authorities vastly more in care services than the cost of home adaptations.

FOI data reveals decline in home adaptations

14. FOI requests were sent by AKW Medicare Ltd to 434 Local Authorities late in 2010.

15. They were asked the following:

- Number of home adaptations carried out in their own housing stock in 2009
- Number of home adaptations carried out in their own housing stock in 2010
- Number of home adaptations carried out through DFGs in 2009
- Number of home adaptations carried out through DFGs in 2010

16. 221 (51%) responded to the questions as asked:

- There was a 26% reduction in the number of home adaptations carried out in the housing stock owned by these respondents (10,607 fewer adaptations)
- There was a 15% reduction in the number of home adaptations carried out under DFG's by these respondents (3,844 fewer adaptations)
17. 139 (32%) Local Authorities based their responses on adaptations carried out during the fiscal years 09/10 and 10/11. As the fiscal year had not been completed this data has not been included in the analysis.

18. 74 (17%) Local Authorities did not respond or were unable to provide the requested data and were excluded from the analysis.

Consequences

19. With an ageing population, we are concerned that thousands of people who are mobility impaired but want to live in their own homes have to go into care or rely on the support of others because they are unable to have a home adaptation.

20. While the Chancellor said he was protecting the DFG in the Comprehensive Spending Review, we believe this has been undermined by the removal of its ring-fence which has led, in practice, to fewer home adaptations. This decline in the number of home adaptations is clearly illustrated in our FOI data.

21. This has created a false economy since those who are being denied home adaptations are no longer able to live independently, costing the NHS and local authorities vastly more in care services.

22. A Saga survey commissioned from Laing & Buisson and published in September 2009 found that the average annual cost of care homes across the UK is £36,348 per person.

23. A research report undertaken on behalf of The Office for Disability Issues in 2007 entitled Better outcomes, lower costs found that an hour’s home care per day costs £5,000 a year and adaptations that remove or reduce the need for daily visits pay for themselves in a time-span ranging from a few months to three years and then produce annual savings. In the cases reviewed, annual savings varied from £1,200 to £29,000 a year.

24. Better outcomes, lower costs also found that the average cost to the state of a fractured hip is £28,664 which is 4.7 times the average cost of a major housing adaptation at £6,000.

25. In addition to cost savings, supporting elderly and disabled people in their own home enhances their quality of life and reduces burdens on carers.

Disabled Facilities Grant:

26. We believe that the Government needs to make funding for housing adaptations a priority which will deliver overall cost savings with fewer people going into care or using NHS services.

27. The Government should therefore reverse its decision to remove the ring-fencing of the DFG and ensure that local authorities do not make cuts to the funding of home adaptations when our FOI data has revealed a significant decline in home adaptations in 2010 compared to 2009.
Written Evidence submitted by the Welsh Assembly Government (IL 61)

Introduction

1. The evidence set out below highlights the work being undertaken by Welsh Ministers’ at the Welsh Assembly Government to provide the right to disabled people to live independently in Wales. The development of policy that facilitates independent living for disabled people is a matter of great importance to the Welsh Assembly Government.

Setting the legal context

1.1 In the United Kingdom, devolved government was created following simple majority referendums in Wales and Scotland in September 1997 and in Northern Ireland in May 1998. Following the Government of Wales Act 1998 (which was subsequently succeeded by the Government of Wales Act 2006), the National Assembly for Wales was established with 60 members, with 40 members elected via First Past The Post and 20 Members elected via by the Additional Member System of proportional representation.

1.2 In 1999, the National Assembly for Wales began to exercise their powers. The UK Parliament remains sovereign and retains the right to legislate on all matters, devolved or non-devolved (such as defence, national security and foreign affairs), but, by convention, it does not do so in relation to devolved matters without first seeking the consent of the relevant devolved legislatures and/or devolved administrations.

1.3 The Government of Wales Act 2006 created a legal separation between the National Assembly for Wales as a legislature and the Welsh Assembly Government as an executive. The National Assembly for Wales has the power to pass Assembly Measures relating to specific Matters (or defined policy areas) in certain devolved Fields (as listed in Schedule 5 to the Government of Wales Act 2006). Once Schedule 5 has been amended through the insertion of a “Matter”, the Assembly has the ability to pass a Measure(s) in relation to that Matter which can do anything which an Act of Parliament can do (subject to certain restrictions). The Assembly’s legislative competence is not as wide as that of the Scottish Parliament (for example in relation to Wales, the UK Government retains responsibility for the police and the legal system).

1.4 Under the Government of Wales Act 2006, executive-type functions exercised by the Assembly established under the 1998 Act transferred to the Welsh Ministers. As a result, another change introduced by the Government of Wales Act 2006 was that the Welsh Ministers and not the Assembly make subordinate legislation.

1.5 The First Minister of Wales is the head of the devolved executive in Wales i.e. the Welsh Assembly Government. The First Minister is nominated by the Assembly and appointed by Her Majesty the Queen and is responsible for appointing portfolio Ministers and their appointments are also approved by Her Majesty.

1.6 The Assembly and the Welsh Assembly Government are funded by the annual block grant from HM Treasury. At present, the Assembly has no power legislate about general taxation—e.g. income tax, corporation tax.
Government of Wales Act 2006

1.7 The Government of Wales Act 2006 places a legal duty on the Welsh Ministers to make appropriate arrangements with a view to securing that their functions are exercised with due regard to the principle that there should be equality for all people.

Section 77 Equality of opportunity

1.8 (1) The Welsh Ministers must make appropriate arrangements with a view to securing that their functions are exercised with due regard to the principle that there should be equality of opportunity for all people.

(2) After each financial year the Welsh Ministers must publish a report containing—

(a) a statement of the arrangements made in pursuance of subsection (1) which had effect during that financial year, and

(b) an assessment of how effective those arrangements were in promoting equality of opportunity, and must lay a copy of the report before the Assembly.

Section 81 Human Rights

1.9 (1) The Welsh Ministers have no power—

(a) to make, confirm or approve any subordinate legislation, or

(b) to do any other act, so far as the subordinate legislation or act is incompatible with any of the Convention rights. “Convention rights” is defined in GOWA 2006 and means the rights incorporated under the Human Rights Act 1998.’

Section 82 International obligations etc.

1.10. (1) If the Secretary of State considers that any action proposed to be taken by the Welsh Ministers would be incompatible with any international obligation, the Secretary of State may by order direct that the proposed action is not to be taken.

(2) If the Secretary of State considers that an action capable of being taken by the Welsh Ministers is required for the purposes of giving effect to any international obligation, the Secretary of State may by order direct the Welsh Ministers to take the action.

One Wales: A progressive agenda for the government of Wales

1.11. One Wales is a four year agreement made in 2007 between the Labour and Plaid Cymru Groups in the National Assembly for Wales. The agreement offers a progressive agenda for improving the quality of life of people in all of Wales’s communities, from all walks of life, and especially the most vulnerable and disadvantaged. The agreement contains eight high level statements with a number of commitments.

High level statements—

1. a strong and confident nation
2. a healthy future
3. a prosperous society
4. living communities
5. learning for life
6. a fair and just society
7. a sustainable environment
8. a rich and diverse culture

1.12. The Welsh Assembly Government set out its commitments for equality in their ‘One Wales Commitment’. It has:

- a vision of a fair and just Wales in which all citizens are empowered to determine their own lives and to shape the communities in which they live;

- an ambition of a Wales where everyone is enabled to achieve their full human potential and everyone can live free from poverty, discrimination, fear or abuse.

- a commitment to be unswerving in its adherence to the principles of inclusion, pluralism and fairness, ensuring that all sections of the Welsh population are engaged as citizens; and

- a firm commitment to supporting and including those who are marginalised from society and to offer appropriate and effective treatment and support to engage with the wider community and to ensure that the wider community is fully inclusive.

** Equality Act 2010 **

1.13 In Wales, both the regulations and the order for the equality duties were passed by the National Assembly for Wales during March 2011. The focus of the specific public sector equality duties is to enable better performance of the general duty by the delivery of positive outcomes through evidenced based equality objectives. The objectives can only be developed with the engagement of the people affected by the objectives, and after relevant information has been collected and analysed.

1.14 These duties will come into force on 6 April 2011 and each authority’s equality objectives will be publicised by 2 April 2012.

** Inclusive Policy Making **

1.15. The Welsh Assembly Government’s method for equality impact assessment is known as Inclusive Policy Making (IPM). It provides policy makers with an opportunity to consider the many different ways that a policy or practice can affect people on the grounds of age, disability, gender (including transgender), race, religion and belief (or non belief) and sexual
orientation. Inclusive Policy Making also aims to reflect the principles that underpin our approach to human rights principles of fairness, respect, equality and dignity.

1.16. IPM has been integrated into the Welsh Assembly Government’s policy gateway, which is a mechanism for ensuring that policies from our agenda for government set out in ‘One Wales’ are joined up and engage with the right people. The trigger for IPM is the Welsh Assembly Government’s policy gateway process, or when a final consultation or draft document is ready for consideration.

**Single Equality Scheme**

1.17. The Welsh Assembly Government is legally required to publish equality schemes for gender, race and disability. The decision was taken by the Welsh Ministers to go beyond this and publish a single scheme that also included religion and belief/non-belief, age, transgender and sexual orientation, helping to recognise and to tackle the possibility of multiple discrimination.

1.18. A framework for principles and priorities for the Scheme was published for consultation in March 2008 and concluded in June 2008. A variety of methods were used to engage with groups to further inform development of the scheme and best practice gathered from the consultation process has been published on the Assembly Government website.

1.19. The Welsh Assembly Government officially launched its Single Equality Scheme on 31 March 2009. The Scheme aspires to go beyond the fulfilment of legal requirements to eradicate unlawful discrimination with regard to gender; race and disability. The scheme also includes religion and belief and non belief; age, sexual orientation and transgender issues. It is reviewed at regular intervals and progressed over three years (2009–2012).

**Evidence**

2. In Wales, as part of the Welsh Assembly Government’s One Wales agenda, work is progressing to achieve a nation with access for all, where travelling between communities and accessing services, jobs and facilities in different parts of Wales is both easy and sustainable, and which will support the growth of our economy. Independent living features in many of our policies and strategies across the Welsh Assembly Government, and we are keen to explore work that brings this together so that we can build on that.

2.1 In Wales, Independent Living was subject to a campaign and debate at plenary. Disability Wales’ Independent Living NOW! Campaign was launched on 28 April 2010 and ran until March 2011. Following the launch a series of regional Independent Living NOW! Campaign briefings were held in North, Central and South West Wales in partnership with local disabled people’s organisations.

2.2 The campaign provided an opportunity for all disabled people in Wales to make their voices heard ahead of the 2011 Welsh Assembly elections. The campaign had six main strategic aims:

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180 Disability Wales is the Welsh national association of disability organisations.
- to raise awareness and understanding of what Independent Living means for disabled people in Wales;

- to call for a National Strategy for Independent Living;

- to develop a Manifesto for Independent Living throughout the campaign to influence policy makers;

- to collect disabled people’s stories to establish an evidence base for Independent Living in Wales both good and bad;

- to develop a stronger coalition of disabled people’s organisations and disability activists; and

- to develop stronger links to the wider Independent Living movement.

2.3 On 12 May 2010 a debate regarding the Campaign was held as part of plenary session. In addition, Disability Wales lodged a petition with the National Assembly for Wales, which was open to signatures until December 2010. The petition called for a National Strategy for Independent Living to be produced. The Minister for Social Justice and Local Government who is responsible for equality in Wales, and the Deputy Minister for Social Services have met and discussed the issues and agreed that Independent living features in many of the policies and strategies across the Welsh Assembly Government, and it was considered that a further strategy was not the best way to progress this work. The work is to be considered to be taken forward as part of ongoing work to implement the Equality Act 2010. The Equality Act 2010 provides a cross-cutting legislative framework to protect the rights of individuals and advance equality of opportunity for all; to update, simplify and strengthen the previous legislation and to deliver a simple, modern and accessible framework of discrimination law which protects individuals from unfair treatment and promotes a fair and more equal society.

2.4 Wales is the first government in the UK to introduce specific regulations to support the wider duty imposed by the Equality Act. The regulations will bring about real changes in terms of people’s life chances and life experiences.

2.5 Whilst the Welsh Assembly Government supports the Independent Living Strategy in principle, we believe that considering this work within the new legislative framework will ensure that positive outcomes are effectively delivered and delivered across all Welsh Assembly Government portfolios. It is also the case that the means to deliver independent living are not solely the responsibility of the Welsh Assembly Government. The UK Government has, for example, responsibility for areas such as welfare and benefits that are key to facilitating independent living. Similarly, the Independent Living Fund assists individuals in leading independent lives and the decisions taken by the UK Government on the future of this fund will have a profound impact on this agenda.

2.6 The Deputy Minister for Social Services has expressed concern about the proposed changes to Disability Living Allowance (DLA) and the closure of the Independent Living Fund to new applicants. She has discussed these issues with Maria Miller MP, Minister for Disabled People and submitted a formal response to the consultation on DLA reform. There is a
potential significant impact on Welsh claimants of these benefits. In Wales, as of May 2010 (the most recent date from which figures are available from the Department for Work and Pensions website), there are 126,100 DLA claimants of working age compared to 1,476,930 working age claimants in England. The population of Wales is 5% of that of the UK as a whole compared to England at 84%. So, proportionally, the changes to the DLA rules will have a greater adverse impact on the Welsh population in terms of the additional demands placed on Social Services: as fewer people are likely to be receiving DLA as a result of the new rules and it is therefore likely that there will be more people requiring Social Services assistance or enhancements to the services which they already receive.

3. Health and Social Services

Social Services in Wales: A Framework for Action

3.1 In relation to Social Services and Social Care, the recently published Paper on Social Services in Wales: A Framework for Action, commits the Welsh Assembly Government to an approach that focuses on stronger citizen control. The Welsh Assembly Government will work with stakeholders to develop a model of self-directed support that is consistent with our principles for social care. The Paper also builds on the theme of independent living contained in the Welsh Assembly Government’s Social Services Strategy for Wales: Fulfilled Lives, Supportive Communities. The Welsh Assembly Government’s vision is to ensure that "we modernise social services in order to provide more accessible, personalised care for people. We want to ensure that people are supported earlier and helped to retain their independence for longer. Whatever their difficulty or impairment, people should be supported to have control over the life they wish to live."

Direct Payments

3.2 Direct Payments is one means of facilitating independence. More than 2,000 people a year in Wales are now benefitting from a Direct Payments arrangement across Wales and we have placed a duty on local authorities to offer a Direct Payments arrangement to all people who may be eligible to receive one. In Wales we have not adopted the personalisation or individual budget approach that is presently being rolled out in England, but we remain fully committed to ensuring that assessment and care management approaches support person-centred care and contribute to our aim of helping people achieve control over their life. The Direct Payments Regulations in Wales have now also been extended arrangements to cover people who lack capacity.

Social Care Charges (Wales) Measure

3.3 In Wales, more than 66,000 older and disabled people receive community based social services - such as homecare, day care and other non-residential services - each year. Approximately 14,000 people, who rely on these services to be able to live independently at home, are charged for them. Currently, there is a wide variation in the charging undertaken and in the level of charges set by local authorities in Wales.

3.4 People in Wales who receive homecare and other non-residential social services will pay a maximum charge of £50 a week for these services from 11 April 2011.

3.5 In 2009, the Deputy Minister introduced groundbreaking legislation – the Social Care Charges (Wales) Measure 2010—to end the postcode lottery and introduce fairness and
greater consistency in charging by local authorities for social care provided in the community. The maximum charge is part of a wider £10.1m per annum ‘First Steps Improvement Package’, being introduced in Wales on 11 April 2011. In addition, this package will:

- prohibit local authorities from charging for the provision of transport to day centres;
- make the existing statutory elements of the Fairer Charging Guidance mandatory. These provide financial safeguards for those on low incomes; and
- require authorities to introduce a consistent procedure for reviewing charges within a specific timeframe.

**Community equipment services**

3.6 As part of the objective of integrating community equipment services between local government and the NHS; the Welsh Assembly Government has invested £12.5 million to improve the infrastructure to support community equipment services. This involves investment in storage, refurbishment and decontamination facilities as well as IT systems to facilitate the tracking, servicing, recall, decontamination, refurbishment and recycling of equipment. This will help community equipment services cope with the rising demand for services in the future.

**Development of telecare services**

3.7 The Welsh Assembly Government has invested £8.9 million in the development of telecare services to promote the independence of service users. This will provide support to 10,000 households throughout Wales. Telecare provides censors in the home to detect when an individual has, for example, fallen or when someone with dementia has wandered off. The censors are monitored at a central location and appropriate help can be summoned immediately. This will help vulnerable people to manage risk and allow them to live their lives knowing that if they get into difficulties help can be summoned.

**Artificial Limb and Appliance Service**

3.8 The Artificial Limb and Appliance Service offers a consistent and equitable service to people in Wales who have a permanent or long-term impairment. It is provided by a unique collaboration between three NHS Trusts and is commissioned via Health Commission Wales (HCW). The three ALAS centres (ALAC’s) are situated in Cardiff, Swansea and Wrexham, working together to provide an All-Wales service.

3.9 The Welsh Artificial Limb and Appliance Service is committed to providing an excellent rehabilitation service to people with an impairment, with their objective being to maximise ability and minimise disability.

**Sensory Loss Steering and Reference Group**

3.10 In September 2009, the Welsh Assembly Government established a Sensory Loss Steering and Reference Group to identify the issues experienced by people with a range of sensory loss, when accessing healthcare services in Wales. The Steering Group comprises of
a range of sensory loss voluntary sector organisations, Welsh Assembly Government officials, and members from Wales’ health organisations. The Reference Group is made of members of the sensory loss community in Wales, and is chaired by the Community Health Council.

3.11 Six key areas of work have been identified for progression:

- Healthcare Standards, to be known as Doing Well, Doing Better, Supporting Guidance and resource support
- Inclusive inspection & review approaches
- Accessible communication
- Workforce Training
- Complaints
- Monitoring of progress & Accreditation

*Equality Impact Assessment Toolkit*

3.12 To assist NHS organisations in Wales, the NHS Centre for Equality and Human Rights has revised its Equality Impact Assessment Toolkit to support health organisations in making good, evidence-based decisions that promote public and patient involvement, support service improvement and takes people’s diverse needs into account at the beginning of planning and policy development. The revised Toolkit also incorporates questions to test the potential impact of proposed policy changes on individuals’ human rights and will help prepare organisations for the likelihood of a renewed focus on human rights and the ‘FREDA’ (Fairness, Respect, Equality, Diversity, Awareness) principles in policy development and service delivery.

*All Wales Dignity at Work Policy*

3.13 The NHS All Wales Dignity at Work Policy has been produced which aims to promote positive behaviours inside the workplace and enable all staff to work together effectively and to treat each other with respect and dignity. The principles of the policy are grounded in the promotion of fair and equal treatment. It offers protection and redress to disabled staff in relation to discrimination and harassment. The policy implementation will be supported by an action plan to ensure that robust data is available when the policy is reviewed in 2012.

4. Housing


*Housing Strategy for Wales ‘Improving Lives and Communities: Homes in Wales*

4.2 The Strategy describes the overall approach to meeting housing need. It sets out the challenges, priorities and action that will be taken. It recognises the housing needs of disabled people and enabling them to have a range of choices focusing on living
independently for as long as possible in their own homes and, where necessary, providing quality care and support.

4.3 Improving people’s lives and social, economic and environmental well-being is at the heart of the approach. The strategy has three main priorities:

- Providing more housing of the right type and offering more choice
- Improving homes and communities, including the energy efficiency of new and existing homes.
- Improving housing-related services and support, particularly for vulnerable people and people from minority groups.

**One Wales commitments to housing**

4.4 Housing issues also feature very strongly in the One Wales Coalition Government agenda, with 16 specific commitments including:

- An additional 6,500 affordable homes over 4 years.
- Increased resources for social housing.
- Extra funding for the Supporting People programme.
- Obtain legislative power to restrict right to buy in areas of housing pressure; and
- The development of a Homelessness Plan

4.5 This challenging agenda, the impact of the economic recession and the significant change in the landscape of social housing in Wales, with the major programme of stock transfer by local authorities, combine to provide a dynamic and demanding backdrop to housing policy.

**Housing services for disabled people in Wales**

4.6 Service delivery to meet the needs of disabled people is undertaken by housing associations, local authorities and the third sector in collaboration with the Assembly Government, who sets the policies and funds the programmes to make this happen. These policies and programmes include:

- **Supporting People (SP)**—a core policy and funding framework for delivering housing related support to vulnerable people in society by enabling vulnerable people to live independently and to maintain a tenancy. An independent review of the Housing-related Support Programme, led by Professor Sir Mansel Aylward CB, Chair of Public Health Wales, was published on 22 November 2010. The review was undertaken to ensure that those in need were getting the best possible services. The review is very positive about the Programme and its impacts on the lives of individuals and the savings it offers to public spending.

- **Increasing the supply of affordable housing** for those in need, includes supporting schemes for older people including those needing extra care and people who need support with independent living. New affordable homes built by housing
associations are required to meet ‘Lifetime Homes’ standards, so that people do not necessarily need to move if their circumstances change. The increasing emphasis on sustainability and making homes more energy efficient can also have a significant benefit for disabled people, making it easier to keep their homes warm and cheaper to run. The ‘One Wales’ agreement committed the Assembly Government to providing an additional 6500 affordable homes by 2011 and this has been achieved.

- **The Strategy for Older People in Wales (2008–13)** has improving well being and independence as key objectives to ensure that older people—especially those with disabilities—have access to the help they need to remain in their own homes including timely access to heating, adaptations, repairs, ‘telecare’ as well as other assistive technologies and supported housing programmes.

- **The National Service Framework** sets out the framework for home maintenance and adaptations services and provides funding and guidance on delivering services in Wales so that independence can be achieved or maintained.

**4.7** There are several main funding mechanisms to support this work:

- **Social Housing Grant** (SHG): In 2010/2011, the Welsh Assembly Government has allocated £93.9 million in SHG to Housing Associations in Wales to provide affordable housing.

- **Supporting People Revenue Grant** (SPRG): £63m per annum in 2010/11 to provide accommodation based support for a range of vulnerable people by allowing users to obtain and maintain independent accommodation or developing or maintaining the necessary skills & confidence to live independently.

- **Supporting People Grant** (SPG): £76m per annum in 2010/11 funded via local authorities. This grant is intended to provide support services for longer term or permanent accommodation for tenants such as the elderly or those tenants receiving assistance via the community care route. SPG activities are largely concentrated in mental health, learning disability, physical disability and older persons housing schemes.

**4.8** Keeping people in their own homes is facilitated through:

- **Physical Adaptation Grants**—just over £7.8 million has been spent by the Welsh Assembly Government in 2010-2011 to provide assistance to over 1,400 tenants for adaptation works such as the installation of stair lifts and hand rails. These are designed to enable tenants with a disability or with disabled children, to remain and live as independently as possible in their own homes.

- **Disabled Facilities Grants** (DFGs) for local authority tenants or home owners. These are mandatory and means tested. In 2008-09 £34.4m was spent on DFGs in Wales.

- **Care and Repair services**—Agencies offer help to older home owners so that they can stay longer in their own homes in safety, comfort and security. In particular, they give help and practical advice to older homeowners to enable them to undertake important adaptations, repairs and other improvements to their homes.
Agencies also manage building work, take the strain on form filling and advise on suitable contractors. There are 22 agencies operating in Wales with Care and Repair Cymru as the national intermediary body. In 2010–11, £4.9m was provided by the Assembly Government to support Care and Repair services

- **Rapid Response Adaptations Programme**—Care and Repair also administers this programme for the Welsh Assembly Government which provides non means-tested minor repairs and adaptations to older homeowners (up to £350) which assist in deferring transfers into residential care and enabling speedier hospital discharges. £2.094m was provided for the Rapid Response Adaptations Programme in 2010–11.

- **Social Housing Management Grants** (SHMG): £2.2m in 2011–12 aimed at improving the quality of housing management in Wales through piloting innovative housing management policies and schemes; developing good/best management practice; helping implementation of new practices and supporting research. People with disabilities benefit from these grants such as the recent work carried out by Disability Wales in “Delivering Accessible Housing Registers” in Wales.

4.9 Although the Welsh Assembly Government does not undertake the day to day delivery of services and programmes to assist people with disabilities is has put in place controls and mechanisms to guide those who do. This includes:

- A new Regulatory Framework for housing associations in Wales.
- Requiring all Social Landlords to publish a Statement of Policy and Procedure for dealing with Anti Social Behaviour
- Guidance for local authorities and housing associations on the allocation of social housing [currently under review]
- Funding the development and implementation of a Toolkit for “Tackling Anti Social Behaviour and Hate Crime” in Housing. The Toolkit covers all seven strands of equality including disability.

5. Employment

5.1 As the government of Wales, the Welsh Assembly Government strives to be an exemplar employer. Recruitment and selection procedures operate the ‘two ticks’ system whereby disabled applicants will receive an interview if they meet the minimum criteria for the post.

5.2 The Welsh Assembly Government offers reasonable adjustments to candidates at all stages of an application process, from initial application through to interview and have published guidance on providing reasonable adjustments which all interview panel members must follow. Diversity data on recruitment exercises is produce annually and is included in the Employer Equality Annual Report.

**Access to Work and Employer Engagement**

5.3 The Welsh Assembly Government has developed a number of strategies to support people into employment. As part of this, the Welsh Assembly Government has
acknowledged that employer engagement is a crucial element of the overall picture, not least when responding to the needs of disabled people. In recognition of the need for better employer engagement, the Welsh Assembly Government is developing a single employer offer with a number of key partners in Wales which is designed to develop a more integrated package of support for employers in order to encourage recruitment and employment retention measures.

Remploy

5.4 Remploy currently delivers essential services for disabled people and a number of Welsh communities rely on Remploy factories as they are a major employer within their area. Remploy employs 591 people and operates nine Enterprise Business factory sites across Wales. Its Employment Services business has found jobs for 16,000 people this year to date, including more than 1,750 jobs for disabled and disadvantaged people in Wales.

Remploy are also delivering the “Wellbeing through Work” ESF project, which will support more than 17,000 people in West Wales and the Valleys who are at risk of losing their jobs due to ill health. The programme provides quick access to a range of support services for people with a career-threatening social or health problem, as well as those on temporary or long-term sickness absence from work.

5.5 Wales is one of the strongest performing areas for Remploy Employment Services in the UK, with the network of 9 branches and offices achieving growth in job outcomes of around 20% this year. They have also delivered a number of specialist programmes for hard to help groups, including the Improving Access to Psychological Therapies (IAPT) pilot with Cardiff GPs. In several locations across Wales, such as in Porth, Employment Services staff are working closely with the local factory to collaborate on training and work experience opportunities for disabled people.

Right to Control

5.6 Right to Control does not currently operate within Wales and, unlike in England, there is no personalised budget in Wales. Therefore disabled people in Wales will not attain help in this way to get supported employment. Direct Payment in Wales only relates to social care provision and does not support someone into work or at work.

Social Enterprises

5.7 The Welsh Assembly Government provides funding to three social enterprise support organisations - the Wales Co-operative Centre, Development Trusts Association Wales and Social Firms Wales. These organisations provide support to numerous social enterprises and/or work in an advocacy role to promote social enterprise development. This includes stimulating good quality jobs for disadvantaged groups which could include people with learning, physical or sensory disability, and people with mental health problems.

Outreach activities

5.8 Recruitment is supported through a range of outreach activities aimed to promote the Welsh Assembly Government as an employer of choice to under-represented groups. In 2008 the Assembly ran a recruitment exercise for Team Support grade whereby workshops were arranged to explain the recruitment process and roles that were available. They were
attended by Remploy, Scope Cymru, Careers Wales, several disability employment advisers and Tydfil training. There is evidence that this outreach activity had a beneficial effect on changing perceptions about the Welsh Assembly Government as an employer both within the under represented communities and amongst managers within the organisation. A review of the recruitment exercise in 2008 to establishing a pool of Team Support staff demonstrated that overall candidates declaring themselves as disabled made up 4% of applicants.

5.9 During 2009-2010 the Welsh Assembly Government continued to develop relationships with disability organisations. For example, in summer 2009, the Assembly hosted an event for Remploy where current Welsh Assembly Government staff with a disability spoke about their experiences of working for the organisation.

Work Placement Opportunities

5.10 The Welsh Assembly Government supports a wide range of work placement opportunities to support underrepresented groups to gain experience of work and an opportunity of obtaining employment with the Welsh Assembly Government. An example of a placement targeted at disabled people that the Assembly Government supported in previous years was Scope’s ‘Leadership Recruitment Programme’. The recruitment scheme was open to any disabled person able to work (or who has the potential to work) at graduate level.

Workstep Initiative

5.11 The Welsh Assembly Government is currently working with Scope Cymru to support their Work Preparation Program and to support the Workstep initiative. A recent evaluation of the placement schemes by an independent company praised the Welsh Assembly Government on its level of commitment to providing people on placements with high quality experiences and effective support so that they could get the most out of their time in the organisation.

Public Appointments

5.12 In January 2008, the Welsh Assembly Government’s Public Appointments Unit undertook a targeted awareness campaign using role models to raise awareness of public appointments among currently under represented groups including disabled people. Following on a tailored training course was provided to help people with the public appointment application process.

5.13 Any new public appointment opportunities are brought to the attention of a range of groups representing disabled people including Disability Wales, RNIB Cymru, RNID Cymru and Young Disabled People’ Network.

Want2Work

5.14 The Welsh Assembly Government supports activities to help disabled people gain employment. Want2Work is a joint Welsh Assembly Government and Jobcentre Plus Wales initiative, supported with European funding, specifically designed to support economically inactive people closer to or back into work.
Written Evidence submitted by the Welsh Assembly Government (IL 61)

5.15 **Want2Work** tests a range of measures including financial incentives to prepare for work; and in-work support from a health professional working with Jobcentre Plus services to help those people who are already claiming benefit, but who would like to move into work, to progress voluntarily into sustained employment.

5.16 The initiative focuses on helping to raise employment and economic activity levels in areas of greatest need in Wales. Operating in wards in local authority areas across Wales, it plugs gaps in other employment provision and creates additional labour market support in the most disadvantaged communities. The key objective of the project is around community engagement with those people who traditionally don’t volunteer to participate in the standard employment programmes, and extending support to those people who are ineligible to participate in traditional programmes because they are non-benefit recipients.

5.17 The original **Want2Work** programme (2005–2008) surpassed original expectations in helping over 2,300 people into employment.

**Want2Work II**

5.18 **Want2Work II** was launched in July 2008, with funding from the European Social Fund, matched by funding from the Department for Work and Pensions and the Welsh Assembly Government, which resources the project up to 2014. It is expected that, the project will support around 14,000 people with preparation and training for making the transition into employment.

5.19 **Want2Work II** has engaged with over 5,000 participants since its inauguration in July 2008–April 2010. Of these participants, around 1,500 are in receipt of Incapacity Benefit, and 1,280 receive Income Support Benefit. Over 1,200 people have subsequently entered full-time employment, and an additional 117 people have entered part-time employment.

**Genesis Cymru Wales 2**

5.20 The Genesis Cymru Wales 2 project aims to increase labour market participation by identifying and providing support to individuals who are furthest away from the labour market. This is achieved by providing a package of easy to access client centred support including personal development and soft skills, enabling the project to engage with individuals who may otherwise be excluded from training and economic activity opportunities. The main focus of the project is to support female lone parents who are economically inactive, but it also assists a number of other disadvantaged groups who may or may not also fit into this category.

5.21 The total project cost (ESF and match-funding) over the life of Genesis Cymru Wales 2 is £68.55million.

**Promoting Business Start Ups**

5.22 The Welsh Assembly Government is actively promoting business start ups in Wales. The main policy driver is contained in One Wales Commitment ‘A Prosperous Society—Stimulating enterprise and business growth’ and ‘A Fair and Just Society’ in promoting equality.
5.23 The policy intent is to actively promote and encourage entrepreneurship amongst all sections of the community. A key feature of the policy is to deliver an inclusive service to all individuals who participate in business start up services, meaning that contracted providers are required to provide business start up advice to all sections of the community. This approach meets the requirement of One Wales for a citizen centred service.

5.24 The Assembly Government aims to improve the recruitment and retention of disabled people by SMEs in Wales. The tools in place to support the business start up policy intent are:

- A Diversity Champion service that supports the capacity building of providers. This focuses on the policies and procedures providers have to identify and achieve to meet the needs of disabled people (and other under represented groups). Support to providers also includes raising the awareness of issues affecting disabled people and how best to provide tailored support to disabled people.

- Specific funding has been made available, currently £450k, through The Inclusion Challenge Fund. This fund provides additional financial support to help overcome the barriers disabled people (and other under represented groups) face in participating in business start up activities and setting up in business.

- To support the policy, specific targeted marketing is aimed at disabled people through representative organisations, the media and websites. All materials and web entries are tested against Accessibility criteria.

- To promote entrepreneurship amongst young people, including disabled young people, a network of established entrepreneurs 'Dynamo Role Models' has been established.

**Tools to support Established Business policy Small and Medium Enterprises (SMEs)**

5.25 In Wales, each Relationship Manager who contacts a business is required to discuss the company’s equality and diversity polices. Those businesses with out of date or limited polices are offered the free services of a specialist adviser. Where the services are taken up, a follow up evaluation is conducted to establish the changes made in recruitment and retention policies; a specific section relates to the employment of disabled people.

5.26 The Assembly Government provides an average of two and a half days of free specialist advice in equality and diversity to established businesses. During the past year, 219 SMEs have received specialist advice. The aim of this policy is to encourage businesses to recruit and retain people from all sections of the community, including disabled people. The provision forms part of the Business Growth service which is part funded by European Regional Development Fund. The aim is to engage half of all businesses who receive Business Growth support in reviewing their Equality and Diversity policies and practices.

5.27 The Welsh Assembly Government is just over two years into this new policy. All providers have been measured against Assembly Government criteria for providing this service and against their performance in relation to demography. Progress is being made with all providers showing improvements in service delivery.
5.28 Currently the percentage of people who indicate they are disabled as a proportion of all business starts supported by the Welsh Assembly Government are, by Regions in Wales: North 5.1%; Mid Wales 10%; South East 5.1%; South West 6.2%.

5.29 Future measurement of performance is being improved against 17 criteria and presented in a visual ‘Dashboard’ format. Providers will also be supported to acquire a recognised ‘kite mark’ for the delivery of their services; this could be Committed to Equality, Investors in Diversity or Positive about Employing Disabled People.

5.30 As part of this process, providers who act on behalf of the Assembly Government hold regular focus group meetings with disabled people and representative organisations. The purpose of these groups is to explore the current service and seek views on improvements. Customer satisfaction surveys are also conducted to gather the views of all customers.

5.31 In Wales we continue to address the rates of employment and unemployment of disabled persons.

- The rate of disabled people in employment increased by 5.9 percentage points from 36.9 per cent in 2001 to 42.8 per cent in 2008.
- The gap between disabled people in employment and all people in employment narrowed from 32.3 per cent in 2001 to 27.9 per cent in 2008, a total of 4.4 percentage points.
- In 2008, the gap between disabled people in employment and all people in employment was 27.9 per cent compared to a figure of 7.7 per cent for the gap between non-disabled people in employment and all people in employment.

6. Transport

6.1 In order to achieve its One Wales commitment the Welsh Assembly Government has produced a transport strategy ‘One Wales: Connecting the nation’. The strategy sets out how the Assembly intend to achieve positive social, economic and environmental outcomes over the next 25 years. One objective is the removal of barriers which prevent disabled people accessing the transport network.

Staff training

6.2 The Welsh Assembly Government convened training for staff working within specific departments to ensure the rights of disabled people to travel independently and conveniently were being considered in transport planning, policy and implementation, to ensure the needs of disabled people are being considered in the design, building and management of properties and to ensure access issues were considered in the planning and delivery.

National Stations Improvement Programme

6.2 The National Stations Improvement Programme (Plus) a piece of work which looks at the upgrading of Wales’ railway stations. The focus of this work is the removal of barriers faced by people from protected groups. Central to the concept of independent living is that of the ability to travel independently (personal mobility). By inviting disabled people to be involved in the design and planning of the station improvements in Wales, the Welsh
Assembly Government have been able to greatly increase accessibility and improve perceived and actual safety in rail based travel.

**Public Transport Users’ Committee**

6.3 The Welsh Assembly Government has recently established a Public Transport Users’ Committee (PTUC) to advise the Minister on strategic issues relating to public transport services in Wales. This includes for instance issues relating to accessibility, information and barriers to public transport services. The PTUC will provide a perspective based on the experiences and needs of people who use public transport as part of their everyday lives. We know through research that disabled people are more likely to use all forms of public transport than the general population.

**Easier Access Programme**

6.4 The Easier Access Programme is an innovative solution designed by Network Rail which will deliver easier access for wheelchair users and pushchairs to board trains at low footfall stations across rural Wales. The aim of the project is to provide easier access installations (“humps”) at 20 sites, representing 10% of the stations in Wales. Humps as part of the pilot project was installed at Aberdyfi on the Cambrian Coast on 3 December 2009. It was supported by 100% of respondents at an informal local community consultation conducted by the Welsh Assembly Government in partnership with the community rail partnership. The second station in Wales to have easier access installations (“humps”) is the Valley Railway station in Anglesey. The programme will continue to be rolled out covering rural railway stations across Anglesey, the Conwy Valley Line, Cambrian Coast Line and Heart of Wales Line.

**Arriva Trains Wales**

6.5 Arriva Trains Wales have commissioned Shaw Trust to carry out accessibility testing of their website which will be undertaken during 2010/11. Arriva Trains Wales want to ensure that this website is as inclusive as possible and presents no barriers to anyone using it regardless of ability. The website will go through stringent accessibility testing by experienced users of adaptive technology for access for people who have:

- No Vision
- Low Vision
- Colour Blindness
- Dyslexia
- Hearing Impairments
- Mobility Impairments
- Learning Difficulties

**Concessionary fare scheme**
6.6 In Wales there are two concessionary fare schemes on local bus services currently in operation. The Welsh Assembly Government’s free bus travel scheme is both successful and popular. More than 620,000 free bus passes have been issued throughout Wales, and the scheme continues to go from strength to strength. Disabled people resident in Wales of all ages, are eligible for the scheme. The scheme also allows free travel on local bus services in Wales by companions to disabled persons.

- The concessionary bus pass can be used at any time of day
- The concessionary fare bus travel scheme is operated by Local Authorities across Wales.

**Blue Badge Scheme**

6.7 The Scheme assists individuals with particular types of impairments. It allows Blue Badge holders to park close to their destinations so that they can access facilities and services. Currently work being undertaken to modernise the scheme to ensure it’s relevance to the 21st century. One of the early priorities is to extend the blue badge scheme to children under 3 with specific medical conditions, people with severe disabilities in both arms and automatic entitlement for severely injured armed forces personnel. These proposals have been subject to consultation and widely supported. We expect these regulations to come into force in summer 2011.

**Bus adaptations**

6.8 Bus companies in Wales are continuing to improve disabled access and the percentage of low-floor buses, ahead of government targets for all buses in the UK to be wheelchair accessible and fitted with ramps by 2017. Bus companies in Wales give priority to wheelchair users on their services.

**7. Education**

**Transition Key Workers**

7.1 The Welsh Assembly Government has been developing the role of transition key workers in Wales for young people with a disability, and have funded pilot projects through Care Coordination Network UK to improve transition key working services, which was one of the key recommendations of the National Assembly for Wales’ Education, Lifelong Learning Committee and the Equal Opportunities Committee. The work of the pilot projects has been showcased and includes guidelines, DVDs, transition protocols and the development of key working support services.

**Unlocking the Potential of Special Schools**

7.2 In 2006 the Welsh Assembly Government made £5.1 million available to all local authorities in Wales over three years to establish pilot projects under the *Unlocking the*
**Potential of Special Schools initiative.** As part of the wider strategy to raise standards for disadvantaged groups, the aim of the complementary pilots was to promote inclusion and develop the role of special schools by identifying and disseminating good practice and developing practical links with mainstream schools. This was done to promote the contribution made by special schools to an increasingly inclusive education system and help to ensure that, wherever possible, pupils' needs are met appropriately within their local mainstream school, with access to high quality specialist provision where required. All authorities participated in the programme with a total of 43 projects piloted.

7.3 The Welsh Assembly Government commissioned Estyn—the schools inspectorate in Wales, to conduct an evaluation of the pilot projects. A final report was published in March 2009. It concluded that the pilot projects had been very successful and indicated that there were many examples of good practice and benefits resulting from the funding. The Welsh Assembly Government agreed to provide additional funding of £4m to extend the Unlocking the Potential Grant for a further two academic years from September 2009.

**Education (Wales) Measure 2009**

7.4 The Welsh Assembly Government’s Education (Wales) Measure 2009—The right of a child to make a SEN appeal and/or a disability discrimination claim in relation to education to the Special Educational Needs Tribunal For Wales builds on the United Nations Convention on the Rights of the Child and the Welsh Assembly Government’s Seven Core Aims. The Measure places neither age nor competency barriers on children so that they will have parity of rights with adults. In that respect, the proposed Measure will extend rights unparalleled in the UK and further afield.

7.5 The Measure extends children’s entitlement by providing them with a parity of rights as their parents currently possess to make special educational needs (SEN) appeals and claims of disability discrimination to the Special Educational Needs Tribunal for Wales. The Measure amends the law that gives parents the right to make appeals and claims to the Tribunal, as set out in Part 4 of the Education Act 1996 and part 4 of the Disability Discrimination Act 1995.

7.6 The Education Wales Measure 2009 was passed by the National Assembly on 3 November 2009 and approved by Her Majesty in Council 9 December 2009.

**My Life, My Way**

7.7 ‘My Life, My Way’ leaflet is aimed at 14 to 25-year-olds and aims to guide young people through the options available such as college, training and employment. The leaflet highlights the professional support available to help young people whilst empowering individuals to make a plan that is based on what they want to do. The leaflet was written by young people with support from Learning Disabilities Wales, who received funding from the Welsh Assembly Government.

**Disabled Students Allowance**

7.8 The Welsh Assembly Government provides funding in the form of Disabled Students’ Allowances (DSAs). It can be awarded to students who can show that they have a disability, mental health condition or specific learning difficulty which affects their ability to study. The DSAs help pay for extra costs students may have to pay when studying their course, as a
direct result of a disability, mental health condition (such as depression or anxiety) or specific learning difficulty (such as dyslexia or dyspraxia). The allowances can help with the cost of a non-medical helper, items of specialist equipment, travel and other course-related costs.

7.9 DSAs can be awarded to students studying:

- full-time and part-time undergraduate courses (degree or HND-level courses) including Open University and other distance-learning courses; and
- certain full-time and part-time postgraduate courses (courses for which the entry requirement is at least a first degree or equivalent) including Open University and other distance-learning courses;

**Further Education Provision**

7.10 The Welsh Assembly Government has in place a supplementary funding grant which contributes to the costs incurred by colleges of securing the additional learning support necessary to enable them to make their mainstream provision accessible to learners with learning difficulties and/or disabilities. Further education institutions offer a range of support arising from an assessment of a learner’s individual need. This support may be human support in the form of learning support assistants or specialist tutors or technical support like specialist IT hardware or software.

7.11 Exceptional funding may be allocated to Further Education providers on a case-by-case basis to enable learners with profound and complex learning difficulties and/or disabilities, who would otherwise be funded to attend specialist residential establishments, to access provision locally.

7.12 Whilst most learners can attend their local college with support, a small number have needs that can only be met in a specialist residential college setting. Many of the places that the Welsh Assembly Government secures in specialist residential Further Education establishments are jointly funded with local health boards and local authorities.

**Transforming Education and Training**

7.13 The policy and framework for *Transforming Education and Training Provision in Wales*, published in 2008, challenged all providers of post-compulsory education and training in Wales to set aside traditional, narrow, institutional arrangements and to plan provision collectively; direct more of the funding available to teaching and learning and learner support; and transform the network of providers so that more options at 14-19 and higher education can be provided.

7.14 In November 2009, *Transformation, Y Siwrnai* was published. The document reported on the progress made on post-16 transformational change one year on from the launch of the Transformation Policy and Framework. The progress report also highlighted the intention to extend the Transformation Policy to cover all phases of education and training, setting out a system-wide, all-age approach to the agenda. This reflects a desire for a joined up approach to transformation that links pre and post-16 delivery. To maintain the momentum of change and support stakeholders in delivery, the publication also focuses key priorities for each sector up to 2011.
7.15 Local Authorities and Further Education Colleges in Wales responded positively to the transformation of education and training provision challenge by developing a range of different types of proposals based on local needs and local circumstances. The proposals are being developed into more detailed plans for implementation, and this is expected to lead to different patterns of provision for post-16 delivery across Wales.

7.16 All proposals were developed in line with legislative requirements on access to learning for those with disabilities, to ensure that the needs of disabled people are fully considered and improvements to access, where appropriate, secured.

Advocacy

7.17 The Welsh Assembly Government is currently out to consultation on Statutory Guidance that will take forward children and young people's advocacy in Wales. This guidance focuses on 5 main areas:

1. Open-access advocacy
2. Integrated specialist advocacy services
3. Quality of advocacy services
4. Involvement of children and young people
5. Evaluation of advocacy services

7.18 Section 2 is about the improved coordination and coherence of advocacy services for vulnerable children and young people. Currently a number of different services that work with vulnerable children and young people commission advocacy services to be available to certain groups of eligible children or young people. They usually have their own points of contact and referral routes. This can lead to confusion as to where to go to access advocacy and can deter children and young people. It can also confuse people who are trying to help vulnerable children and young people. This new guidance works to identify the various groups of eligible children and young people and pull together and integrating the arrangements for commissioning advocacy services for them via the Children and Young People's Partnerships. This will make it easier for vulnerable children, young people, and those referring them, to know where to go when they need advocacy, and easier to monitor for consistency of quality and effectiveness.

7.19 The Guidance lists vulnerable groups of children and young people who have a statutory entitlement to an advocacy service under current legislation. This includes children and young people with a disability as they would be considered 'children in need'. It also includes children and young people with Special Educational Needs who, under the Education (Wales) Measure 2009, now have the right of to have access to an advocate to appeal to the SEN tribunal against certain decisions made by Welsh Local Authorities (LAs) about either the assessment of, or provision made to meet their Special Educational Needs. There will be a two year pilot scheme within two local authorities from September 2011; this right will be rolled out across Wales following the completion of the pilot scheme in 2013.
8. Participation in cultural life, sport and leisure

 Rights of Way

8.1 The Welsh Assembly Government have worked with our partners to make improvements to the ‘Rights of Way’ network to better meet the needs of disadvantaged groups, in particular disabled people. The Welsh Government and the Countryside Council for Wales (CCW) are making good progress with the Coastal Access Improvement Programme (CAIP) and improving public access to the Welsh coast. Over 85 kilometres of Coast Path was created or improved in 2009/10, including new and improved disabled access sections. This is in addition to the 50 kilometres completed in 2008/09. The Welsh Assembly Government and CCW have made good progress to date to ensure that funding provided to local authorities for the implementation of their Rights of Way Improvement Plans is used to improve access to the countryside for disadvantaged groups. In 2008/9 37 actions were taken to improve access for these groups across Wales - these include 16 actions specifically aimed at disabled users and 11 multi-user benefits.

 The People’s Collection

8.2 The People’s Collection is a One Wales commitment to develop an on-line resource on the history of Wales, the Welsh Assembly Government are in partnership with Cardiff and Vale Coalition of Disabled People and Disability Arts Cymru, working to provide content related to disabled people’s history. A series of workshops funded by CyMAL have taken place to involve disabled people in content development for People’s Collection Wales.

 Paralympics

8.3 The Welsh Assembly Government recognises and celebrates the success and achievements of individuals and teams to help promote participation among population groups where levels of engagement are identified through surveys, as relatively low or where an increase can be achieved. For example: by celebrating the success of our Paralympic athletes to promote participation by disabled people. A major public homecoming event was held at the Senedd in Cardiff to welcome the Welsh Paralympians home from Beijing—a major event that mirrored the welcome for Olympic athletes.

8.4 Pre Games Training Camps provide the opportunity to raise the profile of the Games in Wales and the profile of Wales in the World through sustainable sporting, cultural and economic relationships with those countries that come to Wales. To date, multi-sport Paralympics teams from Australia, New Zealand and South Africa have decided to carry out their immediate pre Games training in Wales involving c.500 athletes and support staff.

8.5 A Welsh Assembly Government led strategic 2012 legacy steering group is underpinned by a pre Games training taskforce, incorporating all key stakeholders in Wales. Organisations represented on the Taskforce include the Federation of Disability Sport Wales, Welsh Local Government Association, Higher and Further Education, South Wales Police and sports science/medicine practitioners to provide the reassurance that visiting teams will be able to prepare in a safe and secure environment enabling them to perform at an optimum level at the Games.

8.6 The Welsh Assembly Government is in the process of assisting the three National Paralympic Committees in building their 2012 camp infrastructure, including finding
appropriate accessible accommodation, sports facilities and transport. All three Paralympic teams are committed to engaging as much as possible with schools and local community groups in order to promote healthy and active lifestyles and the values of sport through the Paralympic movement.

**Opportunities for play**

8.7 In October 2008 the Welsh Assembly Government announced an additional £250,000 in the draft budget settlement for 2009-2010 to help local authorities provide play opportunities for disabled children. This funding was been approved again for 2010–2011 for the same purpose of extending pre-school play opportunities for disabled children. Potential projects should align with the Play Sufficiency Assessments carried out by the Play Infrastructure Projects for the Child's Play Big Lottery Fund and Local Authorities’ own sufficiency assessments.

**Free swimming lessons**

8.8 In Wales, to encourage accessibility to leisure facilities we have developed a number of schemes such as free swimming sessions.

- In 2007–08 and 2008–09 disability sessions for people aged 16 and under accounted for 2.6 per cent of structured swims for that age group.
- In 2007–08 disability sessions for people aged 60 and over accounted for 3.6 per cent of structured swims for that age group.
- In 2008–09 disability session for people aged 60 and over accounted for 3.1 per cent of structured swims for that age group, a fall of 0.5 per cent from the previous year.

**Children and Young Peoples Partnerships**

8.9 Children and Young People’s Partnership is a Welsh Assembly Government initiative that provides a context for planning and delivering services for children and young people from 0–19 years, together with care leavers up to 21 (or above if in continuing education or training) and those receiving youth support services (within the meaning of Section 123 of the Learning and Skills Act 2000) up to the age of 25.

8.10 The Partnership works to seven core aims which are that all children and young people should be given every chance. Working with public authorities and the voluntary sector in Wales a specific grant of £1.5 million to promote and improve short break services for disabled children, young people and their families in Wales has been introduced.

**Disabled Children Matter Wales Campaign**

8.11 In Wales disabled children are able to express their views directly with Ministers in Wales. In January 2008 the Welsh Assembly Government set up the ‘Rights into Action for Disabled Children in Wales Task Group which comprises of Disabled Children Matter Wales (DCMW) Campaign members and senior officials to provide advice which will not only help to achieve the objectives of the DCMW Campaign, but also address issues which have arisen as a result of other policies and reports.
8.12 The Deputy Minister for Children has agreed to meet with the RIA group at regular intervals to review progress and share concerns. The RIA group are currently contributing to 5 Assembly policy areas, those being:

- Short breaks
- Wheelchair review
- Child poverty
- National Service Framework
- Play

**Management of owed buildings**

8.13 A Guidance Note is being developed in the respect of the management of Welsh Assembly owned buildings. It is intended that this resource will assist in removing barriers experienced by people from protected groups. This will particularly improve the experience of disabled people in accessing and using buildings.


9.1 The Welsh Assembly Government has a responsibility to implement and commit to the UN Convention on the Rights of Persons with Disabilities as agreed when the UK Government signed and ratified the Convention and Optional Protocol.

9.2 The UK Government is currently developing its first UK report, which is to be submitted to the UN Monitoring Committee during July 2011. The Office for Disability Issues is the lead focal point in terms of reporting; however each devolved administration has a lead focal point to ensure continued liaison and proportionality within the report, to ensure that it is truly reflective of the UK position.

9.3 In order to seek disabled people’s view on the welsh contribution to the UK report, the Welsh Assembly Government requested case studies from several disability organisations, held discussion at its Disability Equality Advisory Group and had provided information and the draft welsh text on its website for disabled people to comment on.

9.4 The Welsh Assembly Government has also been working with the Equality and Human Rights Commission to look at how the Convention is to be continued to be implemented following the publication of the UK report and the Monitoring Committee Concluding Observations.

**10. Conclusion**

10.1 There is a lot of work being done across the Welsh Assembly Government to support disabled people to live independently in Wales, as explained above. However, as highlighted by the Independent Living Campaign held by Disability Wales, we know that there is a lot more that we could be doing to enhance the services already provided and to promote more collaborative work. We will be looking at how we can address the issues that have
been brought to our attention and work with disability organisations to further promote disabled peoples right to independent living.

**Key documents and links**


Tackling Hate Crime  
http://www.wwha.net/OurServices/ManagingTenancies/AntiSocialBehaviour/AntiSocialBehaviourUnit/

The Code of Guidance for Local Authorities on Allocation of Accommodation and Homelessness  

One Wales: Connecting the Nation – Transport Strategy  
http://wales.gov.uk/topics/transport/publications/transportstrategy/?lang=en

Education (Wales) Measure 2009  


Transforming Education and Training Provision in Wales  

United Nations Convention on the Rights of Persons with Disabilities  
http://wales.gov.uk/topics/equality/unccs/rpd/?lang=en
Written Evidence submitted by the Equality and Human Rights Commission (IL 62)

Summary

1. The Equality and Human Rights Commission (the Commission) welcomes the opportunity to provide evidence to the Joint Committee on Human Rights (JCHR). Our submission is provided in the context of our statutory duties to promote human rights. 181

2. The Commission considers the JCHR’s inquiry provides an important opportunity to examine the progress made on the right to independent living for disabled people, as guaranteed by Article 19 of the UN Convention on the Rights of Persons with Disabilities (UNCRPD). 182

3. As part of the UK's 'independent mechanism' as required by Article 33 of the UNCRPD, the Commission is required to protect, promote and monitor the implementation of the government's obligations arising out of UNCRPD including Article 19. An outline of the Commission’s work on the UNCRPD and in particular Article 19 is included in annex 1.

4. In our submission, the Commission assesses the degree to which Article 19 has been implemented in England and Wales, and the potential impact of recent legislative reforms on the enjoyment of this right in future.

5. Based on the available evidence, the Commission considers that progress is still required in terms of implementing Article 19 rights. These issues are explored in greater detail further below.

Independent living and the UN Convention on the Rights of Persons with Disabilities

The Commission’s position

6. Alongside its counterparts in Scotland and Northern Ireland, the Commission is part of the UK’s 'independent mechanism', that is required to protect, promote and monitor implementation of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) 183

7. As part of this role, the Commission believes that the implementation of Article 19 demands attention to the following:

181 Section 3 and 9 of the Equality Act 2006.


183 Article 33 of the UNCRP details the domestic architecture which states party to the Convention must develop with respect to implementation. These include focal points within government, a coordinating mechanism, an independent framework to promote, protect and monitor implementation including ‘one or more independent mechanisms’ (generally held to mean Paris Principles compliant national human rights institutions) and the active involvement of disabled people’s organisations.
the mechanisms by which disabled people are empowered to exert choices about their own lives (and those which protect such choices) and in particular their living arrangements; and

• the development and availability of options sufficient to make such choices meaningful, and which enable disabled people to enjoy 'choices equal to others'.

Background information

8. Independent living, in its broadest sense, refers to the rights of disabled people to enjoy the same level of choice, control and freedom in their daily lives as everybody else. This idea is reflected in the underpinning principles of UNCPRD:

"Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons [...] and full and effective participation and inclusion in society" 184

9. The UNCPRD reaffirms disabled people's civil, political, economic, social and cultural rights and sets out the steps which states party to the Convention must take to transform societies in order to make these rights a reality. It forms part of the UK’s international legal obligations, meaning that the government must ensure that its domestic legislation complies with the UNCPRD and demonstrate that it is taking concrete, targeted and deliverable steps to implement the Convention articles

10. The UNCPRD has also been 'concluded' (ratified) by the European Union (EU), requiring compliance by all EU institutions and by member states in relation to areas of EU competence. Implementation of the UNCRPD is addressed by the EU Disability Strategy 2010-2020 launched in November 2010. 185

11. Article 19 of the UNCRPD sets out the specific steps states party to the Convention must take to protect, promote and fulfil disabled people’s right to live independently and be included in the community. 186 It builds upon Article 12 of the UNCRPD which requires states party to the Convention to ensure that:

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185 The EU Disability Strategy seeks to break down the barriers that prevent disabled people from participating in society on an equal basis: http://ec.europa.eu/social/main.jsp?langId=en&catId=89&newsId=933&furtherNews=yes

186 Article 19—Living independently and being included in the community

States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

a. Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
“disabled people enjoy legal capacity on an equal basis with others in all areas of life.”  

12. Where Article 12 aims to restore disabled people's power to assume control over their own lives, Article 19 is concerned with providing disabled people with equality of opportunity to make choices about how and where to live their lives.

13. Article 19 places this right in the particular context of choice over living arrangements, reflecting the aims of the UNCRPD's drafters. That is, to eliminate living arrangements which segregate and isolate disabled people from the wider community. Article 19 therefore focuses on the development of living options and all associated support services or mechanisms which cumulatively accord disabled people equal opportunities to be included and to participate as fully as they wish in the community.

Implementation of Article 19 in England and Wales—the law

14. Disabled people in England and Wales do not enjoy an explicit and positive legal right to choose a place of residence, where and with whom they live, or to not be obliged to live in a particular living arrangement.


16. With respect to the HRA, Article 8 of the European Convention on Human Rights (ECHR) has provided some protection regarding disabled people's right to self-determination and to participation in community life.  

17. However, the Commission considers the courts have generally been reluctant to engage with matters involving the allocation of resources as illustrated by the case of R (on the application of McDonald) v Royal Borough of Kensington and Chelsea [2010] EWCA Civ 1109).

b. Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

c. Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.


188 See A, B, X and Y v East Sussex County Council [2003] EWHC 167 (Admin) and Botta v Italy (1998) 26 EHRR 241

189 This was an application for judicial review against her local authority by Elaine McDonald who had been disabled by a stroke in 1999. She had been awarded a care package that included night-time care, allowing her to receive assistance in using the toilet during the night, but the local authority decided to withdraw night-time care on the basis that the claimant—who is not incontinent—could use incontinence pads instead. The Court of Appeal held that the local authority had acted reasonably, given that its responsibility for acting in the interests of all clients whose welfare it supported with limited resources. The court also found that, although
Equality Act 2010

18. The Commission would suggest the Equality Act 2010 is instrumental to the implementation of UNCPRD. This Act includes general provisions on non-discrimination, including a duty on providers of goods, facilities and services—including community services—to make reasonable adjustments and from April 2012 provisions concerning the prohibition of age discrimination in health and social care.190

19. The Act also includes the duty on public bodies to have due regard to eliminating discrimination and promoting equality of opportunity for disabled people - the public sector equality duty.191

20. Of particular relevance to Article 19 is section 149(3) (c) of the Equality Act 2010, which clarifies that in meeting the public sector equality duty requirements, public authorities must have due regard in particular to the need to:

“encourage persons who share a relevant protected characteristic to participate in public life or in any other activity in which participation by such persons is disproportionately low.”192

21. Further, section 149(4) of the Equality Act 2010 makes clear the duty of public authorities to have due regard to 'the steps involved in meeting the needs of disabled persons that are different from the needs of persons who are not disabled include, in particular, steps to take account of disabled persons' disabilities'.

22. Thus, the provision of 'community support services' to help facilitate such participation, and the making of reasonable adjustments to 'community services and facilities for the general population' are inherent both to Article 19 and s149 of the Equality Act 2010.

23. Clause 153 of the Equality Act 2010 provides the Secretary of State with powers to impose 'specific duties' on public authorities for the purpose of 'enabling the better performance by the authority of the duty imposed by s149' (the new public sector equality duty). The new duty came into force on 5 April 2011 and at the time of writing the Westminster government has yet to lay regulations setting out such specific duties for England before Parliament. In Wales Specific Duties were introduced on April 6th as the power to create them is now devolved to the Welsh Ministers.

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190 Chapter 2, Equality Act 2010

191 Clause 149—Public Sector Equality Duty, Equality Act 2010

192 The duty replaces the previous Disability Equality Duty, which included a similar provision. 'Public life' was held to refer to any part of life which was not private and hence corresponds strongly with the meaning of Article 19 in relation to 'full inclusion and participation in the community'.
24. The Commission supports efforts to reduce the bureaucracy faced by public authorities in meeting their duties, and to ensure that their efforts and increasingly stretched resources are focused upon achieving transformative outcomes rather than internal processes.

25. However, we believe the regulations must offer organisations clarity regarding the steps required to meet the duty, for example, in relation to demonstrating 'due regard'. Otherwise, the Commission considers that there is a significant risk that public bodies could simply replace bureaucratic procedures with costly legal protection to guard against every possible source of challenge, thus undermining government's aims.

26. Prior to the Equality Act 2010, the Disability Equality Duty (DED) under the Disability Discrimination Act 1995 (amended in 2005) was of particular relevance in relation to decisions concerning changes to eligibility criteria for social services and other support services related to independent living, such as the provision of benefits advice. 193

27. Hence, the Commission considers the OED has proved itself to be of considerable importance towards protecting, promoting and fulfilling disabled people’s rights under Article 19 of UNCRPD and wishes to ensure that the new PSED and the associated specific duties continue to have this positive effect.

**Welfare Reform Act 2009**

28. The Commission participated in the development of the 'right to control' which was included in the Welfare Reform Act 2009. 194 The Act provides the Secretary of State with powers to lay regulations which would enable disabled people to receive an individual budget. This would be under a range of statutory provision.

29. The right to control is presently being piloted in seven test areas. The Commission hopes that the pilots provide the government with the confidence to implement the right to control in full which we consider an instrumental mechanism for the progressive implementation of Article 19.

**Social care reform**

30. At present, disabled people have no right to transfer their package of care and support from one local authority to another (so called ‘portability’) which also circumscribes the enjoyment of Article 19 to choose 'where and with whom' to live.

31. The Commission supported an amendment to the Personal Care at Home Act 2010, tabled by Baroness Jane Campbell, to introduce such an entitlement, and welcomes the government’s commitment in its vision for social care to achieve greater portability of assessments.

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194 Part 2—Disabled people: right to control provision of services, Welfare Reform Act 2009
32. In Wales, new proposals for adult social care could herald the introduction of a national eligibility threshold and portability of care packages, thus ending the so-called postcode lottery and facilitating much easier movement by disabled people between local authorities in Wales.\textsuperscript{195}

33. As part of the wider agenda of reform of adult social care, the Law Commission will shortly publish proposals for the reform of community care law, which will in turn contribute to a forthcoming white paper on social care.

34. The Commission agrees that community care law needs to be rationalised and updated. However, we would advise that an appropriate balance is struck between national minimum outcomes founded on fundamental rights and local discretion.

35. Outside the sphere of local authority funded support, the Commission considers that the Disability Living Allowance (DLA) has played a transformative role in empowering disabled people. In particular, the DLA has enabled disabled people both to assume control over their own lives and overcome some of the financial barriers to participation on family, community and economic life arising from the extra costs of disability.

36. The Commission welcomes the continued commitment by the government that the Personal independence Payment (PIP) which will replace the DLA, will remain a non-means-tested benefit focused on helping disabled people meet the extra costs arising from their impairment or health condition. However, the Commission hopes the government’s detailed proposals for eligibility do not inadvertently preclude or discourage any groups of disabled people from accessing this important benefit.

### Implementation of Article 19 in England and Wales—policy and programmes

#### The Commission’s position

37. The Commission considers that the strategy of the UK government devolved administrations, and local authorities on independent living (and the UNCRPD more generally) should be considered from the perspective of Article 4, relating to general obligations under the UNCRPD. This states:

“With regard to economic, social and cultural rights, each State Party undertakes to take measures to the maximum of its available resources and, where needed, within the framework of international cooperation, with a view to achieving progressively the full realization of these rights without prejudice to those obligations contained in the present Convention that are immediately applicable according to international law”\textsuperscript{196}

38. To this end, the Commission welcomed and strongly supported the government’s Independent Living Strategy 2009 (ILS), which forms part of the government’s ‘Roadmap’ to

\textsuperscript{195} See Independent Commission on Social Services in Wales report

equality for disabled people by 2025. The strategy provided a coherent vision, with aims and objectives and a cross-government programme of action, albeit over a long time-frame.

39. However, the Commission is unclear of the ILS's current status in the light of the change in government following the 2010 General Election and the impact of policy reforms and spending decisions including in relation to local government and social security.

40. Therefore, it is unclear whether or not there is an up to date and viable plan to implement Article 19 of the UNCRPD, as required by the government's international human rights treaty obligations.

41. We therefore consider the JCHR's inquiry provides an important opportunity to clarify the continued relevance of the 2009 ILS.

42. The Commission believes significant progress has been made over the past decade according to disabled people's greater choice and control. However, we consider the following issues continue to demand particular attention:

- **Disabled people's perception of the choice and control they are able to exercise over their own lives.** This has remained static since the Office for Disability Issues began recording it in 2008 (23% of disabled people in England believe they do not frequently have choice and control over their lives).

- **Uneven take-up of direct payments across different disabled groups and across local authorities.** In particular, people in England with mental health conditions have a very low take-up of direct payments or personal budgets (5.1% of adults aged 18-64 with mental health conditions received community-based services in the year to 31 March 2010, compared with 20.2% of comparable adults with physical impairments).

- **Disabled people's access to community facilities and services available to the general public.** The Life Opportunities Survey (2010) commissioned by the government's Office for Disability Issues found that when all public services are considered together, 36% of adults with impairments in Great Britain experienced difficulties accessing public services, compared with 22% of adults without impairments. In addition, adults with impairments were almost twice as likely as adults without impairments to have only two or less close contacts (defined as

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197 The Independent Living Strategy was published in March 2008, sets out actions aimed at improving the choice and control disabled people have over the services they need to live their daily lives.


someone who could be counted on if they had a problem); adults with impairments were more likely to say that difficulties with transport, financial reasons and caring responsibilities stopped them from having contact with the people they felt close to.201

Impact of policy reform and spending decisions on disabled people

The Commission's position

43. The Commission is unable at present to assess the impact of spending decisions on the enjoyment of Article 19 (many of which are only now being implemented).

44. Nevertheless, the Commission would seek clarification from the government on the potential cumulative impact of different spending decisions and policy reforms on disability equality and the right to independent living, for example:

- Widespread tightening of local authority social services eligibility criteria.
- Reform of Disability Living Allowance
- The decision to close the Independent Living Fund
- Reform of Local Housing Allowance
- Closure or threat of closure of centres for independent living,
- Proposals for reform of legal aid
- The closure of advice centres

45. The Commission considers that the question of proportionality in relation to spending decisions is not simply one of comparative expenditure on different groups or public services. The critical question is that of the impact on the individuals or groups concerned: the impact on what people are able to be or do as a consequence of spending decisions. This includes basic rights to self-determination, as well as participation in and contribution to family, community and economic life.

46. Article 19 provides an internationally recognised framework for assessing the impact of spending decisions on disabled peoples rights to live independently and be included in the community.

Monitoring the impact of spending decisions on human rights and equality

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http://odi.dwp.gov.uk/docs/res/los/social-contact.pdf
47. The UN Committee on economic, social and cultural rights states that any deliberately retrogressive measure requires the most careful consideration. The Committee has not specified exactly what constitutes a ‘retrogressive measure’ but General Comment 4 provides some guidance:

“A general decline of living and housing conditions, directly attributable to policy and legislative decisions by States Parties, and in the absence of accompanying compensatory measures, would be inconsistent with the present Convention.”

48. Thus, a deliberate retrogressive measure means any measure which implies a step back in the level of protection accorded to economic, social and cultural rights in the Covenant on Economic, Social and Cultural Rights as a consequence of an intentional decision by the State.

49. The Commission considers that such retrogressive measures must be evaluated in the context of the ‘maximum resources’ available to the State. Implicit in this duty is a process requirement to show that adequate consideration has been given to all the possible resources to satisfy economic, social and cultural rights, even if the effort to give full realisation to the rights is not immediately possible.

50. If expenditure designed to realise economic, social and cultural rights is dropping in comparison with GDP or other government expenditure, this may indicate that there are available resources, but that particular rights have not been prioritised. If, on the other hand, expenditure on economic, social and cultural rights is dropping in direct proportion to general reduction in GDP or other government expenditure, then this may indicate only a retraction of the state’s maximum resources.

51. Hence, the question of proportionality both in terms of comparative expenditure and comparative impact is again engaged in determining whether the cumulative impact of spending cuts represents a regression in relation to compliance with Article 19.

52. A significant number of key spending decisions affecting the enjoyment of the rights set out in Article 19 are distributed across a wide range of actors at the national and local level.

53. In a recent example, the government proposed to withdraw eligibility for the upper rate mobility component of Disability Living Allowance from disabled people living in residential care on grounds that such funding (for costs of transport and mobility) duplicated funding which should be available from local authorities. This proposal was widely challenged on the grounds that local authority discretion meant that no such guarantee of funding could be made. This concern was amplified by context of the localism agenda, devolution in such decisions in Scotland and Wales, and local authority spending cuts.

54. The government has said that it will now review this proposal. The Commission considers the cumulative—even if unintended—effects of DLA reform and cuts in local authority expenditure risk seriously eroding the enjoyment of Article 19 of Convention.

202 Committee on economic, social and cultural rights ‘General Comment No.3 The Nature of States Parties Obligations’ UN Doc. E/1991/23 annex 3 at 86 (1990) paragraph 9
55. Although central government can de-centralise the implementation of its international human rights treaty obligations, it cannot delegate its own accountability to ensure that such implementation takes place.

56. Hence, when the UN Expert Committee on the UNCRPD comes to examine the UK’s performance in implementing the UNCRPD it will appraise the success of the UK, as a state subject to the Convention, as a whole.

57. A failure to be able to demonstrate having accounted for the likely cumulative impact of policy and spending decisions may leave the government exposed to serious criticism regarding its compliance with its duties to realise the implementation of UNCRPD.

58. Related to this point, the Commission is presently conducting an assessment of the extent to which, and the manner in which, HM Treasury met the (pre-existing) public sector equality duties covering gender, race and disability in carrying out its functions in relation to the 2010 Spending Review. This includes having regard to any relevant prior fiscal events and analysis, including the government’s emergency Budget, where appropriate.

59. In the context of the assessment of HM Treasury, the Commission will consider whether and to what extent it is within HM Treasury’s functions to assess the cumulative impact of government policies, and if so, whether it has had due regard to the public sector equality duties in that function.

60. The Commission also anticipates that the Office for Disability Issues, acting in its capacity as both the focal point and co-ordinating mechanism for UNCRPD in the UK and the lead department in relation to disability equality and the Independent Living Strategy, should be providing policy oversight and assessing the potential impact of spending decisions and reforms and adjusting its implementation plans accordingly.

61. The Commission will continue to monitor the impact of national and local spending decisions on disabled people and to promote and enforce the public sector equality duty, having regard to implementation of Convention when doing so.

Annex 1.

What the Commission is doing to promote, protect and monitor implementation of disabled people’s right to live independently and be included in the community

The Commission and its predecessor body the Disability Rights Commission have played an active role in protecting and promoting disabled people’s right to independent living and the UN Convention on the Rights of Persons with Disabilities more generally.

An outline of the Commission’s work is provided below.

Partnership and capacity building

- The Commission hosts and works closely with the Independent living in Scotland project, which aims to develop and build the capacity of disabled people’s organisations in Scotland

The Commission is working closely with regulators including the Care Quality Commission to build human rights and equality performance measurement into the inspection and assessment of social care and health provision.


Inquiries, research and policy development

- The Commission is presently conducting a formal inquiry looking into the protection and promotion of older disabled people’s human rights in the context of care and support delivered at home.
- The Commission is also conducting an Inquiry into disability related harassment, including an appraisal of the efficacy of safeguarding policy and practice in protecting and promoting human rights.
- In 2010 we published research into the availability of independent advocacy to different groups of disabled people.
- The Commission actively participated in the development of the 'Right to Control' included in the Welfare Reform Act 2009.
- In 2009, we published the influential report 'From safety net to springboard—a new approach to care and support based on equality and human rights'.

Legal intervention and enforcement

- The Commission supported the case brought by Elaine McDonald v Royal Borough of Kensington and Chelsea referred to in the submission paper and pending judgement by the Supreme Court.
- The Commission supported Sharon Coleman’s successful case at the European Court of Justice paving the way for carers and others who share their lives with disabled people to bring cases of discrimination ‘by association’ with a disabled person.

Monitoring implementation of the Convention
The Commission works collaboratively with the four other UK bodies nominated to form the 'independent mechanism', meeting twice yearly, sharing information and intelligence. The bodies have all made assessments of the situation in each jurisdiction regarding UNCRPD implementation and will shortly provide feedback to the UK Government regarding its draft 'State Report' to the UN Expert Committee.

In late 2010, the Commission worked with Members of Parliament to table parliamentary questions regarding implementation of UNCRPD across government. To view this information visit the Commission's website at the following link: http://www.equalityhumanrights.com/human-rights/internationalframework/un-convention-on-the-rights-of-persons-withdisabilities/monitoring-the-implementation-of-the-convention/

**International work**

- The Commission chairs the European Group of National Human Rights Institutions' working group on the UNCRPD which coordinates engagement with European and EU institutions such as the Fundamental Rights Agency and European Commission and potential Amicus Curiae at the European Court of Human Rights.

- In its role as Chair of the group, the Commission has prepared and delivered two statements to the Human Rights Council and one to the Conference of States Parties regarding implementation of UNCRPD in Europe and globally.
Responses to specific questions

1. Should the right to independent living continue to form the basis for Government policy on disability in the UK?

Yes, we believe that the right to independent living is fundamental to disabled people and should form the basis of government policy. It is the central plank upon which most other disability-related policy should be built, and of course is underpinned by Article 19 of the UNCRPD.

One in five people in the UK live with disability or health-conditions. Disabled people are parents, employees, managers, MPs, home owners, transport users, students and members of every other conceivable interest group. However their ability to participate in society and to realise their full potential is often limited by the environment and by lack of support. The right to independent living is a vital measure to ensure that disabled people enjoy the same basic human rights and life chances as their non-disabled peers. Not meeting these needs and rights has significant and unnecessary adverse consequences for our society and the economy.

The realisation of independent living should be measured to assess government performance, focusing on equality of outcomes rather than just opportunities. Measures should include how many disabled people have been lifted out of poverty, are not isolated in their homes, are supported to take out Direct Payments, participate fully in education and employment, lead full economic lives, are represented in public life, etc.

This would exceed the Office for Disability Issues (ODI)’s notion of, simply, “having the same level of choice, control and freedom”. Choice is a means to an end but not an end in itself. Choice is only meaningful if supported by information, action and resources, and if there is genuine choice. This includes, but is not limited to, choice between types of support that are accessible and based on clear entitlements to health, social care and welfare provisions.

2. Do existing policy statements, including the Independent Living Strategy, represent a coherent policy towards the implementation of the obligations in Article 19 of the UN Disability Rights Convention? Could current policy be improved? If so, how?

We do not consider that existing policy statements are an adequate coherent policy towards implementing Article 19. We observe with continued concern that the Government has not yet clarified if and how it will take forward the Independent Living Strategy (ILS).

Furthermore, while we welcome some of the ambitions of national policy, many of these commitments don’t filter through to disabled people’s everyday experiences of independent living. The ILS should give disabled people and government a tangible and focused framework that helps to realise independent living progressively. Given that the UNCRPD does on its own not create a domestically enforceable right, central government needs to ensure that there is a robust policy framework in place for local and national authorities to have due
regard to human rights and equality in their policy making and delivery, and that they do not take steps that reverse progressive realisation of disabled people’s independent living.

We are concerned that the latest government reviews of the statutory duties on local councils (Department for Communities and Local Government) and the ‘Redtape Challenge’ (Cabinet Office) do not adequately put their questions in context. They should consider ‘how do we as a society want to live?’ and on the minimum entitlements we as a society require in respect of support for disabled people. We need safeguards to ensure that equality and human rights of disabled people are not played off against needs that are thought to be more relevant to wider society. We are concerned that there appears to be a narrative that various protections against discrimination and duties to support disabled people cause unnecessary ‘burdens’, the abolition of which would not be detrimental to anyone. The evidence appears to be to the contrary, when even before there was a need for austerity measures, disabled people and carers experienced a lack of rights and access to basic support (eg social care from councils).

Many people who respond to these consultations may not understand the necessary detail, but will be happy to buy into the idea that these proposed changes are merely of a bureaucratic nature. It will not be until they themselves are affected directly or expected as carers to provide support that they understand the original requirements.

With regards to the public sector equality duty in the Equality Act 2010, it would be helpful to develop how this can be used as a driver for realising independent living. The ILS could help to set out steps or examples on how it could achieve this.

Current policy places great emphasis on the active choices of the disabled individual by ‘putting purchasing power into people’s hands’. This positive change of direction from previous notions of ‘dependency’ will help to empower disabled people and instigate whole systems change from a capacity-driven model to one that is led by (actual) demand and thus much more cost-effective. This is welcomed, although we do observe other impediments within the wider system to achieving this.

There is a lot of waste in the current system (eg for equipment which does not fit requirements and/or is not re-used or for repeat and overlapping assessments). We believe this could be reduced if disabled people “own” more of the decisions that affect them. Achieving this would be more likely if (paid) peer support was put in place for disabled people to take on such roles in the provisioning of their health and social care.

The Government has very helpfully stressed the link between involvement and health outcomes, and the Health and Social Care Bill places a duty on the NHS Commissioning Board to promote choice. However, many people struggle to navigate by themselves through complex health and social care pathways. Others may not at all be able to take on such a role. The lack of corresponding commissioning support to promote and facilitate choice at an individual level cannot be mitigated by greater involvement at a strategic level, eg in Joint Strategic Needs Assessments. This is the chance for the individual to be involved

203 Coalition Manifesto, May 2010

204 White Paper Equity and excellence: Liberating the NHS, July 2010
directly and maximise independent living for themselves, their peers and the wider community.

3. What steps, if any, should the Coalition Government, the Scottish Government or other public agencies take better to meet the obligations in Article 19 and to secure the right to independent living for all disabled people in the UK?

We need coordinated and consolidated action—including timelines and delivery mechanisms—to address and bridge the various gaps between policy and the reality of lived experience. This should be delivered through a (revised) Independent Living Strategy, which should take into consideration the following points.

It is particularly important that a holistic approach is taken to decision-making which affects disabled people, especially when one decision may impact upon another. For example, an individual may face the abolition of council-funded taxi cards which, if coupled with reduced or cut disability benefits and housing allowance, will greatly reduce their ability to achieve independent living. Yet, there is no consideration of the cumulative impact across such various funding streams which are sometimes ‘passported’, that is the individual needs to qualify for one stream in order to be considered for another.

The Government should do more to foster good relations across society, including promoting positive attitudes towards disabled people. Many of the barriers to achieving independent living, faced by disabled people, are exacerbated by others' attitudes towards them.

Local authorities should support disabled people better to develop their own solutions and more effectively utilise public money. For example, disabled people could be empowered through schemes and measures that support people to pool their personal budgets. Such initiatives may lead to user-led mutuals, contributing to further social and economic capital. There will be a variety of creative solutions that will enable disabled people to get better outcomes from existing resources, particularly if existing commissioning processes (which favour larger providers) are dismantled in parallel.

New social care legislation (proposed by the Law Commission) and the Dilnot Review on long-term funding of social care should reflect the evident increase in unmet need as well as shared benefits from pooling risks. Unmet social care need will impact on the public’s purse in the form of premature increased need for referrals to health services.205

The wider public should be informed and encouraged to think about how their own needs would be served in the future without an overbearing impact on their families and friends (who in an ageing society may not be as available as in previous decades). Local accountability—eg for referendums on priority spending by councils—needs to be

205 as evidenced by the ODI and Audit Commission http://odi.dwp.gov.uk/docs/res/il/better-outcomes-report.pdf
predicated on statutory duties with minimum guarantees for disabled people. Otherwise there will be too much pressure from a majority, lacking an understanding of the issues, not to support disabled people adequately. To facilitate this, ring-fenced budgets are helpful rather than counter-productive in ensuring that authorities spend dedicated money to secure independent living. Otherwise there does not appear to be any imperative or driver for them to deliver national policy, in particular in times of austerity measures.

Furthermore, disabled people need to be empowered to act for themselves, strengthening the benefits of involvement and reducing the need for others to speak on their behalf. Direct involvement with paid peer support should increasingly replace input from others, wherever appropriate - disabled people are usually the best experts in what they need.

4. What impact do funding, policy and budgetary decisions have on the ability of the UK to meet its obligation under Article 19 to protect the right of all persons to independent living?

— the impact of (restricted) funding on the right to independent living (eg emergency budget; Comprehensive Spending Review; 2011 budget)

— the decision to remove the mobility component of Disability Living Allowance for all people living in residential care

— changes to the Independent Living Fund

— the “Big Society”

— restrictions on local authority funding, social care budgets and benefits reassessments

— increased focus on localisation and its potential impact on care provision, and specifically, on portability of care and mobility for disabled people

5. How will recent policy and budgetary decisions impact on the ability of the UK to meet its obligation under Article 19 to protect the right of all persons to

Disabled people and society as a whole need to have certainty on statutory duties as minimum guarantees. This applies in particular if the Audit Commission will be abolished, public service agreements scrapped (despite evidence of targets having increased the proportion of socially excluded adults in settled accommodation, and employment, education or training) and CQC inspections stripped back.

We don’t think that the ‘Big Society’ can flourish in an adversarial local context with disabled people not adequately supported to have their voice heard. A recent High Court decision (Judge Walkers—judgement not yet available) has helpfully clarified that a council (Birmingham) cannot expect disabled people to identify the necessary spending priorities so that their support at substantial level could be maintained.

Innovation and creativity will emerge locally if proper incentives are set out, for example:
A. There must be clear minimum statutory duties guaranteed to disabled people with a commitment to universal support wherever possible. This will reduce unnecessary tensions and help foster good relations.

B. Local ULOs and smaller providers should be trained in setting out their ‘social return on investment’, and cost-benefit analyses need to be commissioned to help ULOs to compare their costs and benefits against council management and any other qualified willing provider.

C. Service agreements, ‘payment by result’ and preferred provider lists need to be revamped to create a more level playing field between ULOs and ‘in-house’ or large third or private sector providers. This should include provisions for light touch regulations and strong incentives for sub-contracting to micro providers.

We are particularly concerned about the impact of the following measures on individuals:

A. Reduced formula grants affecting Adult Social Care, including through raised eligibility thresholds for support and increased charging (up to full cost recovery without cap as in Westminster) place disabled people at the mercy of volunteers (provided that they are available in sufficient numbers). Some people report having to stop social care support while their needs deteriorate. This will increase and accelerate the demand for health services that are currently free at the point of need.

B. We are concerned that legal redress against public authorities will be even harder to achieve with the proposed restrictions to Legal Aid. Many disabled people do not have the resources or capacity to fight such cases without this support. This is not just a theoretical concern. The High Court has just ruled against Birmingham that tightening eligibility to critical needs only has been unlawful for ignoring provisions in the Disability Discrimination Act. The expected ‘saving’ by that council was £17.5m. Wirral has just confirmed a whistleblower’s concern of several people with learning disabilities having been charged £244,000 in contravention of the council’s own charging policy. We are becoming increasingly aware that other authorities are introducing measures which should be contested in court, yet the increasing difficult to access resources to do this challenges fundamental rights of access to justice.

C. Austerity measures are already driving behaviours within local authorities that are contrary to independent living. For example, in the London Borough of Tower Hamlets they have unilaterally removed the self-directed assessment and resource allocation processes which underpin the personalisation agenda. The council suggests it is too expensive to maintain this approach. In fact, the local ULO believes this is simply because of poor implementation. This action has been taken without consultation. The same local authority is

206 See NCIL consultation response ‘Supporting a Stronger Civil Society’
http://www.ncil.org.uk/categoryid1.html

207 ‘Charging into poverty’ by Coalition on Charging http://www.disabilityalliance.org/chargingintopoverty.pdf

208 Snapshot survey by Coalition on Charging, April 2011 http://www.disabilityalliance.org/cochomecare.htm

209 www.communitycare.co.uk/Articles/2011/04/18/116701/whistleblower-forced-to-quit-is-offered-jobback.htm
also reassessing people and including the availability of unpaid support to reduce the assessment of presenting needs, in order to reduce support packages. Independent living is taking a back seat to cost factors, reducing those disabled people to relying on the charity of others.

D. While we welcome that the Disability Living Allowance (DLA) has been kept as a universal benefit, the cut of 20% is arbitrary, which places many months of uncertainty even on people with greater needs. The assessment for the new ‘Personal Independence Payment’ (PIP) has so far been excluded from consultation and also from parliamentary scrutiny (as has the ‘review’ of DLA for care home residents), and it has not been answered how disability-related expenditure will be covered for those people who will be denied PIP.

E. Equally, the closure of the Independent Living Fund to new applicants is forcing those eligible to request support from cash-strapped and unprepared councils. We have had evidence on our helpline that councils have been unable to make up the shortfall. We have significant concerns that the same will apply to existing users of the ILF, upon its closure, and the resources will not be used by local authorities to support independent living.

F. People can still not move from one council area to another—for instance to be closer to supportive networks of family and friends or to access education or take up jobs—without taking fundamental risks to how their needs are being cared for after their move (at stake are both assessment and corresponding support package).

G. Subject to an appeal at the Supreme Court against Kensington & Chelsea, Ms MacDonald is required to wear urine pads over night purely to save costs for a carer despite her not being incontinent which in our view violates Ms MacDonald’s dignity. The judgment is now being used by many local authorities to justify cuts to care packages without proper reassessments.210

6. What steps should the Government take to meet its obligations under the Disability Rights Convention to involve disabled people in policy development and decision-making, including in budget decisions such as the Comprehensive Spending Review?

7. Are the current arrangements for involvement of disabled people in policy development and decision-making working?

The Government does reach out to the wider public but not necessarily particularly effectively with those who are affected most by reforms, as noted in response to question 2. This seems inadequate. The DLA reform has generated considerable anxiety amongst disabled people and the DWP consultation received over 5,500 responses. However it is unclear if and how this large level of involvement—including the direct input from disabled people and their representative organisations—has affected government plans; the DWP consultation response makes no mention of any changes (however small) to government plans in this area. Furthermore, the speed of proposed changes and reforms and the cuts to the ODI make it difficult to ensure appropriate level of input from disabled people (who are

210 http://www.communitycare.co.uk/Articles/2011/04/05/116623/controversial-court-judgement-used-to-justify-care-cuts.htm
often not paid for this). The ODI or Equality 2025 should be better utilized as vehicles for intra-government representation for crucial decisions—and especially issues affecting only disabled people (eg time-limiting ESA).

Involvement and greater choice and control of disabled people are paramount to counteract the detrimental impact of reforms, eg reduced quality and continuity of care arising from the abolition of targets in health and social care. The more involved an individual is in their care and support and in practical tasks such as budget-setting, the greater the positive impact on health outcomes as reported by the Department of Health. Aside from personal health gains, individual involvement then also reduces the burden on the taxpayer by delaying referrals to NHS Continuing Care. The Right to Control and envisaged right to a personal (health) budget correspond with positive examples of continuous and meaningful involvement.

For the time being, these compelling issues do not appear to have been recognised or implemented, not least due to the absence of incentives for long-term investment across health and social care. On the contrary, Hammersmith and Fulham carried out a consultation—only when forced to—according to the letter of the law rather than the spirit of the law. We had hoped that the specific duties under the Equality Act will reinforce the benefits of involvement. The level of involvement achieved under the previous duty was insufficient to deliver independent living. We are unconvinced that the Equality Act duties will replicate or enhance the level of involvement achieved and risk undermining the obligations of the Convention.

8. What steps should Government take to ensure that disabled people’s views are taken into account when drafting their reports to the UN under the UNCRPD?

9. As part of the national monitoring mechanism, what steps should the EHRC, NIHRC and SHRC take to ensure that the Convention is implemented effectively?

The Government needs to involve disabled people to determine meaningful outcomes and appropriate indicators of the UK’s performance in securing the right to independent living. It is important that we do not exclusively rely on the UN reporting procedure as it can take years for the UN Disability Committee to consider the UK Government and shadow reports. In order to keep the momentum going, the Government should commit to an independent living strategy, backed-up by a range of domestic reports which would strengthen the UK’s credibility towards the UN. To this end, findings at local levels should be linked back to changes at the national policy level and vice versa.

Any such input needs to be funded and research commissioned, for instance on the tensions between choice and control and cutting back on the welfare state. Research designs need to be robust. Finally, these reports need to identify action points and disabled people must be given a fair chance to keep momentum towards these action points.

About the Disability Rights Partnership

211 White Paper Equity and excellence: Liberating the NHS, July 2010
Our organisations are led by disabled people. Between us we represent over 500 local and national organisations.

The National Centre for Independent Living (NCIL): is a national support, advice and consultancy organisation that aims to enable disabled people to be equal citizens with choice, control, rights and full economic, social and cultural lives. See: www.ncil.org.uk

Disability Alliance: is a UK charity and aims to break the link between poverty and disability. We have over 250 members and 36 years of benefits and welfare experience. See: www.disabilityalliance.org

Radar: The Royal Association for Disability Rights (Radar) is a pan-disability organisation led by people with lived experience of disability or health conditions. Radar’s vision is a just and equal society whose strength is human difference. Radar’s mission is to enable individuals, networks and policy-makers to do things differently—and better. See: www.radar.org.uk
My name is Kate and I am writing on behalf of the members of North Somerset People First. North Somerset People First is a self-advocacy organisation for people with learning disabilities. The members of this organisation have said they would like to respond to the Independent Living Inquiry.

The following answers to the questions are from the member’s personal experiences.

The Right to live independently

The group feel that the government could do more to give disabled people the same rights as everyone else. The group feel there are not enough properties available for people with a disability to rent. The council do not appear to have enough council properties for people with a disability to move into and most privately rented accommodation; landlords do not accept housing benefit. This has left some of the members in a difficult position as they are either still living with parents or are living in communal care with shared facilities. Members who live with their parents are worried what will happen to them when their parents are too ill or old to support them.

Many of these members live with parents who are in the later life part of their life. The members feel that when the time comes they will be put into a care home.

The members think the law could be changed to allow the tenant’s rent to be paid directly to the landlords rather than the monies being paid to the tenant and for the tenant to pay the landlord. Some of our members understand this is giving them more independence but some have problems with budgeting and feel this gives them extra anxieties.

Lack of Money

Changes to benefits

Some of the members have been affected by changes in benefits. One person told of a change in housing benefit he received which has affected him, as the amount he now lives on is a lot less, he is finding this hard as he depends heavily on public transport and the cost of this has also risen. He has said he is unable to go out as much and socialise with his friends due to the changes in the money he receives.

Cuts in Funding

I have support from a provider for my care needs and I had someone independent to do my Person Centred Plan, since all of the cuts there is no funding from the independent person to do my person centred plan this has now stopped. The providers for my care are suppose to be doing my Person Centred Plan but they say they don’t know how to do one. I am worried now that all of my dreams and goals for my life, I will not be able to do. I want to go out and get a job but I won’t be able to have any support or help to plan my path for this.

My friend and I share a flat and we have support for a few hours everyday. The support we used to have recently have been made redundant due to the cuts. We have now been allocated a new provider my flat mate and I are not very happy with the provider as the
support they offer us is at times when we don’t need it, but when we do need support we
don’t have it. We were not given any choice over the provider we were allocated and could
not interview the support staff who support us now. I have asked the provider why we
couldn’t interview the support staff we would have, there reply was, we have no time to do
this.

Changes in Services

I work in a library, I like working in there and I am good at my job. The council are closing
the library and this will mean I will have no job. It is nice to have my independence and earn
my own money without having to rely on Mum and Dad. I am upset about this.

I use a wheel chair and over the last few months I have been unable to access any disabled
toilets, as they are locked or out of order. I cannot weight bare on my legs so using a
‘normal’ toilet is virtually impossible for me. I try not to go out for long periods of time just
in case I need to use a toilet.

The way local councils decide whether you can get a service or not.

I live at home with my mum and brother. I would like to have my own flat and live
independently. My person centred planning facilitator arranged for a reviewing officer to
come to my review. She said she would put a referral in for an assessment from a social
worker. I had this assessment but I didn’t fit the criteria for a service

I now have to stay living with my mum and brother because I can’t live on my own without
support. I can’t talk to my Person centred planning facilitator anymore, as she has no funding
for her to continue to help me with my life plans.

How can the government involve disabled people in planning services and
deciding how to save money?

The members would like to have a group of people set up with representatives from each
local authority. The people that represent the area would gather views and opinions through
the use of consultations.

How well are disabled people involved in planning and making decisions?

All of the members said they have not been involved in any planning or decision-making. All
of the members agreed they have just been told about changes and decisions and not asked
for their opinions.

If you would like any more information or any clarification on any of the member’s
experiences please do not hesitate to contact me.
Summary of main points

1. The Government’s changes to SMI and the ILF are having a profound effect on the ability of disabled people to live independently in the community.

2. The Government needs to re-assess the effect of the planned reduction to Housing Benefit on the long-term disabled.

3. The Government’s directed cuts to local authority spending are causing hardship to the disabled population.

Introduction about disabled daughter and myself

1. I am the mother and Deputy (under the Court of Protection) to my daughter who is disabled. She has severe learning disabilities and is long term disabled. She is living in a private rented flat in the community with 24-hour support but is unable to achieve what she wants because of current Government policy.

Factual Information

1. Support for Mortgage Interest rate (SMI) has been reduced by 40% to 3.63%. Whereas this may be considered ‘reasonable’ to someone having a standard mortgage it is not possible for someone with a disability to obtain a mortgage under a shared ownership scheme for less than 6-7%. Indeed, the main lender (KRBS, part of The One Savings Bank plc) has decided that it can no longer support the scheme. The shortfall that would have to be met by a disabled person is excessive (£50 upwards per week) and therefore cannot be accepted by the agencies involved, as the risk of defaulting is too high for this vulnerable group in society.

2. The Government’s HOLD scheme (Home Ownership for People with Long-Term Disabilities) has also been affected by the problem with SMI and is therefore unavailable to new applicants. At present there is no way for the long term disabled to achieve independent living with a choice and safe, secure shared ownership.

3. My daughter wishes to live with 2 friends whom she met when at college. All 3 young ladies want to live out of county. We had secured approval from 3 different local authorities to achieve this and identified a Housing Association able to offer multiple shared ownership, which would give them security of tenure. A suitable property had been identified and proposed building works signed off. However, with the change to SMI it has become impossible to complete, as it is not possible to obtain a mortgage. Two of the young ladies are living in their chosen town (out of county) but the third is living temporarily at home as it is not possible to make the adaptations she requires to private rented accommodation. Because of this, even if the HOLD scheme were available, the Housing Association authorised to run the scheme in their area stipulates that all 3 must be resident in the county in which they wish to live and would therefore not accept their application.
4. The type of mortgage that would be applied for under shared ownership with a Housing Association would be for a small percentage of the total value of the property and an interest only mortgage. Current Government Guidelines to the Financial Services are that an interest only mortgage should be viewed as a 100% mortgage. Thus causing the high interest rates to the product.

5. Housing Benefit does not meet the rent costs (private rented) and the local authority therefore has to top-up the amount as part of their direct payments. If the young ladies were able to achieve multiple shared ownership, the Housing Benefit they would qualify for would meet their rent costs to the Housing Association, thus saving money for the local authority.

6. Recent changes to Housing Benefit allow for an individual to claim for 2 bedrooms when they require a non-resident carer to use the 2nd bedroom, as they require overnight support. This is a welcome change, but still does not meet the rent costs involved.

7. The Independent Living Fund (ILF) has been stopped. My daughter applied for ILF ahead of this change and therefore receives it. However, this is not guaranteed for more than a year. Local authorities make their offer of support and direct payments dependant on receipt of ILF as a top-up to care costs.

8. Local authorities carry out an Assessment of Need to obtain an indicative budget for an individual. There is no transfer of this assessment between authorities. In the case of my daughter, her needs have not changed, neither has where she lives, but she has still been required to undergo re-assessment because one authority wishes to transfer her to the other. The indicative budgets are worked out to be very similar.

9. My understanding of the situation and the law is that the assessment should not be used to impose a fixed cap or maximum amount of support. My daughter's current package has been increased based on her detailed support needs. Without prejudice, my understanding is that the new local authority wishes to use the indicative budget as the maximum amount they will provide.

10. The new authority also has a policy that a disabled individual should not live alone unless they present with major behavioural issues. This does not give a disabled person freedom of choice.

11. If a disabled person is assessed as not having critical or substantial needs then under the present cut backs some local authorities are offering nothing towards the social care of those with moderate needs.

Recommendations

1. The Government should make an exception for disabled people to receive SMI at a higher rate. The current rate has prevented pre-existing plans from happening.

2. The Government should change Financial Services guidelines so that the long term disabled can apply for an interest only mortgage for part of a property under shared ownership and not have the mortgage treated as a 100% mortgage.
3. Housing Benefit for the long term disabled should be reviewed, especially as the Comprehensive Spending Review will cut amounts paid in 9 months’ time.

4. ILF should be re-instated, especially as local authorities are reliant on the grant topping up their payments to individuals.

5. There should be more autonomy between local authorities and the same interpretation of rules for disabled people.

6. If disabled people are to be able to live independently with the same rights as others they should not be reliant on local authorities agreeing ‘out of county’ provision to achieve living where they want in the country.

7. Cuts imposed by local authorities are restricting the choices of disabled people (who are dependent on benefits), particularly with regard to housing and funding for support/care to live independently.

8. That the Government does give disabled people the right to independent living, giving the same level of choice, control and freedom in their daily lives as any other person.

9. The Government should be aware that the implications of some cost saving measures actually cause higher costs to individuals and their direct payments from local authorities.

19 April 2011
Summary

1. The right to independent living continue to form the basis for Government policy on disability in the UK, but a definition of independent living should include accessible information, peer support, accessible housing, access to aids and equipment, access to personal assistance, accessible transport, accessible housing, and access to education and employment.^{212}

2. The right to independent living does not exist in isolation from the other Articles of the UN Convention on the Rights of People with Disabilities (UNCRPD). This document will refer to other rights outlined in the UNCRPD but considers them to be aspects of the right to independent living and being included in the community in Article 19.

3. This is expressed in the Equality and Human Rights Commission guide to the Convention, which says that: “steps that a government can take to enable independent living and full participation in the community are wide ranging and are also detailed in other rights listed in the Convention. For example the right to be free from violence (placing a responsibility on police to deal with abuse in your local area) and the right to participate in leisure.”

4. Independent living means: “all disabled people having the same choice, control and freedom as any citizen—at home, at work and as members of the community. This does not necessarily mean disabled people ‘doing everything for themselves’, but it does mean that any practical assistance people need should be based on their own choices and aspirations.”^{213}

5. This means that Article 19 can only be upheld if, for example, Article 9 on accessibility and Article 27 on work an employment, are also upheld along with the other Articles. Parker and Clements (2008) say that: “While Article 19 makes express provision for ‘living independently and being included in the community’ these are also core themes of the Disability Rights Convention. For example, the general principles set out in Article 3 include ‘the freedom to make one’s own choices’, and ‘full and effective participation of persons’. The purpose of Article 9, which requires States to take action to make a range of areas accessible to disabled people (such as the physical environment, public" services and information), is to enable disabled people ‘to live independently and participate fully in all aspects of life’. Similarly, Article 26, which deals with rehabilitation services, seeks to enable

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disabled people ‘to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life.’

6. The Government’s Independent Living Strategy should be updated to reflect this fact, making explicit the link between a disabled person’s right to independent living and their other rights, working together with devolved legislatures where necessary to implement the strategy.

7. Parker and Clements (2008) say that “It is strongly arguable that a European consensus already exists concerning the qualified right of disabled people to live independently,” prior to the writing of the UNCRPD in the form of the European Convention on Human Rights and especially Articles 5, 8, and 14, and consequently the Human Rights Act 1998.

Impact of funding on the right to independent living

Welfare reform and the Welfare Reform Bill 2011

8. The last Government decided to scrap Incapacity Benefit and to replace it with a tougher, medically-assessed Employment and Support Allowance (ESA). This was provided for in the Welfare Reform Act 2007. The Welfare Reform Act 2009 provided more detail on the transition period between IB and ESA, and estimated that 1 million of the (then) 2.71 million IB caseload would be judged fit-for-work and moved onto Jobseekers’ Allowance rather than ESA, thus moving them back into the labour market.

9. Claimants are eligible for ESA if they are determined to have a limited capability for work. The decision is made by requiring claimants to undertake the Work Capability Assessment (WCA). The test involves awarding points on a piece of software when a person is deemed incapable of particular tasks. Those determined to have a limited capability for work must have an overall score in excess of 15 points.

10. The WCA is a blunt instrument, which does not properly take account of a number of symptoms and conditions. It has been roundly criticised, with a high rate of appeal and a success rate at appeal of 70% for those with representation, and the validity of its conclusions are in doubt.

11. The process may find claimants fit for work and disallow the claim, find them to have limited capability for work and place them in the Work-Related Activity Group of ESA where payment of benefits is conditional on work preparation, or find them to have limited capability for work-related activity in which case they are placed in the Support Group without conditionality.

12. Article 27 and Article 28 of the UNCRPD say that disabled people should be protected from compulsory labour and have a right to help from the State with their extra living costs.

13. The Government proposes time-limiting to 12 months of contribution-related ESA, paid only to those with sufficient NI contributions. After 12 months, only income-related ESA will

be available, so that claimants will be means-tested.\textsuperscript{215} Those with a working partner or with other income or capital—up to 300,000 people—will lose entitlement to the benefit completely.\textsuperscript{216}

14. This is a disincentive to cohabitation, partnership and marriage. Time-limiting will thus work counter to Article 23 of the UNCRPD, which guarantees the right to ‘Respect for the home and the family’. Specifically, “Governments must ensure there is no discrimination against disabled people in laws about [...] marriage.”\textsuperscript{217}

15. This will cause significant hardship to families reliant upon ESA and may well lead to further unemployment and higher overall benefit claims as families find the only way they can provide care to the disabled member is for the carer to drop out of employment altogether.

16. This means that time-limiting ESA also works counter to Article 28 of the UNCRDP, which guarantees the right to an adequate standard of living.

17. Local Housing Allowance is to be linked to the Consumer Price Index, which does not take into account housing costs, will further limit disabled people’s access to suitable housing. The Impact Assessment\textsuperscript{218} notes an “illustrative average notional loss” to claimants of £5.50 per week. Accessible housing is expensive and difficult to find in the social housing sector, so that this change will simply compound the difficulty for disabled people of finding suitable housing.

18. The changes to Housing Benefit do not operate in accordance with Article 28 of the UNCRPD.

19. Sweeping changes were announced to DLA in the Emergency Budget\textsuperscript{219} and Comprehensive Spending Review, which intend to reduce overall eligibility by 20% or 620,000 claimants.

20. This cut is at 40-times the estimated rate\textsuperscript{220} of fraud in DLA of 0.5%, which is the lowest in the benefits system. Disability and social campaigners\textsuperscript{221}, and academic experts,\textsuperscript{222}

\begin{flushleft}
\textsuperscript{215} Library Standard Note, Time-limiting contributory Employment and Support Allowance (SN/SP/5853)
\textsuperscript{216} DWP, 2011, Time limit Contributory Employment and Support Allowance to one year for those in the Work-Related Activity Group
\textsuperscript{218} DWP, 2011, Housing Benefit: CPI Uprating of Local Housing Allowance
\textsuperscript{219} HM Treasury, Budget 2010, HC61 2010-11
\textsuperscript{220} Department for Work and Pensions, Fraud and Error in the Benefit System: October 2008 to September 2009
\textsuperscript{221} Disability Living Allowance reform (SN/SP/5869)
\textsuperscript{222} 2011, Letter: Welfare reform bill will punish disabled people and the poor, The Guardian, 9th March
\end{flushleft}
Written Evidence submitted by the Broken of Britain (IL 67)

as well as other organisations223 including the Social Security Advisory Committee224 have voiced concerns that the case for reform of DLA is not clear, and that there is very little supporting evidence.

21. The loss of DLA to 620 thousand claimants and probable decreases to others will affect those people’s right to independent living and to be included in the community, as well as contravening Articles 9, 20, 21, 24, 26, 27, 28, 29, and 30 of the UNCRPD.

22. The consultation225 paper states that reform of Disability Living Allowance is needed for the reasons that: “The benefit caseload and expenditure is increasing at a rate never envisaged”; “The benefit can act as a barrier to work”. Neither of these reasons is convincing, as explained below.

23. The fact that expenditure is increasing at a rate ‘never envisaged’ does not prove that the system is broken, as claimed in the consultation. 71% of caseload growth in the past 8 years can be explained226 by population growth and demographic change, whilst an explosion in quarterly on-flows can be ruled out for the rest of the increase.

24. Article 27 of the UNCRDP, guaranteeing the right to an adequate standard of living and social protection, does not cease to apply when there is an increase in the number of people with disabilities.

25. “The characteristics of DLA recipients put them at a disadvantage in the labour market even greater than those within the general IB claimant population.” This quote is sourced from a report which also maintains that: “DLA recipients may be more likely to return to work if they feel that they will receive adequate support regarding their health condition.”227

26. The proposition that DLA is a disincentive to work is both false and disingenuous. People who receive DLA do, as the reform consultation paper suggests, often have lower work expectations. This is because regardless of desire or ambition, many conditions and impairments make work impossible. Disabled people are often unable to compete equally in the labour market, even if there is work for them.228

27. The Government is failing to enforce the disabled person’s right to work and employment as stated in Article 27 of the UNCRPD. Removing DLA from people in employment will only serve to make work more difficult.

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223 The Broken of Britain, Demolition of the case for reform, 09 January 2011


225 Department for Work and Pensions, Public consultation – Disability Living Allowance reform, Cm 7984, December 2010

226 Left Foot Forward, The ‘inexplicable’ rise in Disability Living Allowance explained, 14 February 2011


28. There are only 8 variations proposed in the payment of PIP as opposed to the existing 11 in DLA. This is a 27% reduction in the ability to personalize PIP to the needs of each claimant.

29. The consultation paper on reform tells us that: “We need a benefit that helps contribute to the extra costs of living independently, in a way that is right for each individual.” A 27% reduction in the ability to shape payment according to individual need conflicts with this aim and with Article 19 of the UNCRPD.

30. Clause 78 should be amended to clarify that the use of mobility aids will not be considered when considering ability to carry out mobility activities. This is because the extra cost of disability will continue to exist, through the financial cost of aid or adaptation.

31. This reform means that it is questionable whether the Government is doing enough to ensure the right to personal mobility in Article 20 of the UNCRPD.

32. The proposal to remove the mobility component for those in residential care homes has been the most visible issue of DLA reform, with strong arguments against.229

33. Removing the mobility component will mean that care home resident will be trapped in the institution, even if the institution makes its own group mobility arrangements.

34. This clearly contravenes the right to personal mobility under Article 20 of the UNCRPD, as disabled people will not be able to travel when they want at a price they can afford, and will not have access to affordable mobility aids and technologies of their choice.

35. There are also questions to be asked over whether this reform conforms with the Government’s duty to uphold the right to liberty under Article 14. More broadly, this move interferes with a host of other right such as that to education, family life and being included in the community.

Abolition of the Independent Living Fund


37. The decision was announced without consultation or an equality impact assessment.

38. The review into ILF in 2007 signalled the incorporation of ILF into the Individual Budgets programme.230 It did not, however, provide the basis upon which to abolish ILF without a consideration of the impact on individuals who currently depend on their ILF to meet their social care needs.

39. ILF was open to disabled person who were in met the eligibility criteria for community care services and the higher rate of DLA in all countries of the United Kingdom.

229 Disability Alliance, Don’t limit mobility, January 2011

40. Changes in the process of delivering of social care in England through increasing use of Individual Budgets is not a policy development that pertains to all the countries of the United Kingdom.

41. It is not yet clear as to how the ILF will be re-allocated, although the funding has been guaranteed\(^{231}\) for the duration of this parliament. The situation beyond 2014/15 is unclear.

42. Should ILF monies be subsumed within the wider social care funding to English local authorities it will not ensure the current level of support and continuity of care for current ILF recipients.

43. This raises the problem of the localisation of disability services, as each local authority may use this increased funding in different ways. For example, even if increases in social care funding are not redirected to other areas, individuals may see their care packages cut to provide smaller packages to a wider range of people. This could vary widely depending on the locality.

44. Should ILF monies be subsumed within wider social care funding in England it will be reflected by an increase in the block grant to each of the devolved legislatures. There is no way of knowing whether Wales, Scotland and Northern Ireland will use this increased block grant for social care funding.

45. Service users who currently draw down ILF based on their local authority social care funding are now unsure of the extent to which their current care packages will be retained and thereby the likelihood of continuing to live independently.

46. Changes to the social care eligibility thresholds may render some recipients of ILF ineligible for continuing social care.

47. A recipient of ILF was deemed to have needs that made him/ her eligible for Higher Rate DLA, eligible for community care services that were to costed at a minimum of £200 and with requirements for additional community care services.

48. The variation in the use of ILF across the countries of the UK and its social services authorities are a reflection of the extent to which local authorities used the ILF to meet eligible community care needs.

49. The abolition of ILF at a time of stringent local authority cuts places the care of many of these recipients in jeopardy.

50. Loss of a care package funded jointly by a local authority and the ILF because of changes to eligibility criteria may have the unintended consequence of undermining a disabled persons quantity and quality of care and thereby propelling a disabled person into institutionalized care.

51. If the convention rights outlined in Article 19 below are to be upheld, it would require a commitment on the part of state parties to ensure that the abolition of the ILF and the

\(^{231}\) Written Ministerial Statement, 13 December, 2010, Independent Living Fund, DWP
impeding changes to social care provision arising out of budgetary constraints, do not lead to a contravening of these rights and those set out in Article 4 and Article 8 of the ECHR.

**Cuts to Council Provision**

52. Funding cuts to local government are already impacting on the provision of social care to people with disabilities. The number of councils in England cutting back on free adult social care has increased by 13% this year, according to the Association of Directors of Adult Social Services (Adass).

53. The ongoing legal action against Kensington & Chelsea, and the recent action against Birmingham are other examples of council attempting to restrict eligibility to services and the nature and extent of provision.

54. The knock-on effects of cuts will affect services in the devolved nations.

55. A majority of councils in England and Wales are now restricting social care to those who fall within the “critical” and “substantial” needs bands, as set out in the Fair Access to Care Services (FACS) policy guidance.\(^{232,233}\)

56. The policy guidance considers needs in relation to a risk to independence and distinguishes between assessed needs and eligible needs.

57. The cuts imposed by the CSR strongly reflect the Coalition Government’s intention to contract the welfare state.

58. Within a residual model of welfare\(^{234,235}\), the critical needs are likely to be reduced to a focus on harm, protection and personal care with needs to maintain involvement in work, education, leisure, family roles and responsibilities and social relationships being considered as non-eligible needs.\(^{ibid}\)

59. Disabled people who fall outside the eligibility criteria of their local authority may be left without direct community care services to promote their independent living. It is also possible that new DLA eligibility aimed at reducing the number of claimants may leave such individuals without funding to buy even minimal care.

60. A consequence will be an even greater reliance on informal carers as they are required to make up the deficit in social care provision.

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\(^{233}\) Unified and Fair System for Assessing and Managing Care (Wales) 2002


\(^{ibid}\)

62. These consequences some of which may be unintended will lead to Coalition Government and the devolved administrations failing to ensure that disabled people have the same rights to choice and control as non-disabled people with regards to Article 19 of the UNCRPD and are likely to contravene the rights enshrined in the ECHR as in Articles 4 and 8.

63. The rights of carers to non-discrimination as enshrined in the Equality Act 2010, will require public authorities to consider the impact on unpaid carers of changes to, for example, eligibility criteria.

64. In addition to the removal of the high rate mobility component of DLA from care home residents there are also cuts to various council-funded community transport schemes.

65. These cuts mean that disabled people will pay far more for transport in future, contravening the rights guaranteed by Article 9 and Article 20 of the UNCRPD.

29 April 2011
People First Isle of Wight is an organisation that brings together adults with a learning disability on a regular basis to share problems, issues, etc., and to discuss things associated with living in the community as an adult with a learning disability. We recently discussed your questionnaire, and the following are the points that came out of the discussion. We hope you find them useful.

**Cuts in funding and their impact**

Many of our members have been significantly impacted by the cuts made by the local authority to the funding of their care. There have been two major areas of change. One is to reduce the amount of money being made available to care homes, and the other is to change the criteria for evaluating peoples needs by removing “substantial”, and providing only support for people categorised as “critical”. There have been a significant number of other cuts, such as the closure of daycare centres, whilst implementing personal budgets for people, and expecting them to find their own services.

A number of people, particularly those living in residential care, have now lost services outside of the residence. With the reduction in money provided to these places, the companies running them have done their best to provide “daycare” in the homes, but this has meant that for many people many days are spent without leaving the place in which they live. Because of the restricted funds, staff limitations means there are not people to take them out. As a result, people who are not mobile do not have the choice of going out, which they had before. Because of the cuts in support money, they do not have sufficient funds to be able to pay for independent transport, e.g. taxis, and even where subsidised transport is provided they cannot afford this. This has meant that, whether they live in residential care or in the community, they have been much more restricted in their ability to be involved in community activities.

**Personal budgets**

The move to personal budgets has been beneficial in the first place for many people. However, now that the local authority is significantly cutting the money available to fund the scheme, people are finding they are unable to be able to afford to buy support to meet their needs (which are not classified as “critical”), or to pay transport costs.

Another significant loss for people on the Isle of Wight has been that the local authority has withdrawn funding for advocacy, saying that people need to pay for this from their personal budgets, but the reality is they do not have enough money in personal budgets to be able to pay for advocacy. This has had a particularly negative impact on people who live in care homes, where often the advocacy is needed to challenge the care home’s provision, and this facility is not available to these people. They are excluded from having personal budgets. They are therefore left in a position where the right to be heard is negatively affected.

One of the other affects of moving to a personal budget is that there is no longer a rigorous process for checking the quality of services being delivered. Whereas before the local authority had a specific contract with providers which laid out in detail what they must provide, personal budgets are managed by parents or carers who do not have the time or
expertise to be able to focus on the actual quality of the service delivered to someone. The result of this is that people delivering the care at the point of the provision can choose to do what they want rather than what the client needs or wants. The result of this as an example, is that a support worker takes a person out shopping and has a cup of coffee during a period of three hours, whilst completely ignoring the need for cleaning their kitchen, doing the ironing, washing up, etc. This is just a general illustration but it is the kind of thing that is happening. The quality of carers is very variable, and without a process of checking, poorer service delivery can go on unnoticed for a long time. The carers get the client to sign a form to say they have delivered to a good standard, but the client does not have the capacity to be able to judge whether this is the case, or to express their real views.

People living in the community

For people living in their own accommodation in the community, the cuts in funding from local authority has meant that they can no longer afford to have people to support them with even the basic things like cleaning, cooking, shopping for clothes, general home maintenance, etc. This has meant that where people previously had a small degree of support which kept them above an acceptable threshold for personal hygiene, etc., that has now gone and they are sliding into situations where their homes are becoming dirty, unhygienic, not functioning, and as a consequence of this they are beginning to despair and become depressed. This is likely in the long run to move them into “critical”, and the cost of restoring their situation is likely to be significantly more than it would have cost to have maintained their small degree of support.

Transport

Cuts made by the local authority to fund transport has meant that many bus services have been reduced or removed. This has had a serious impact on many individuals and their ability to move about in the community. It has also forced people who are at risk when travelling on their own to have to walk significant distances at all times of the day and night, which has made them much more vulnerable.

Being able to influence policy and planning

The situation of people with a learning disability has never been strong in this area, but until recently on the Isle of Wight there was a Partnership Board which provided a focal point for issues to be raised. The local authority funded this. The local authority also funded the support of advocates to enable people with a learning disability to attend these and other meetings to be involved in the process in a meaningful way. All of this funding has now been removed, and the local authority is saying this should be taken over by the voluntary sector. However, the voluntary sector is not equipped either with the expertise or the financial support to be able to do this adequately. The consequences of this are that people with a learning disability in the community now have even less impact on decisions than before. There is nothing provided for in personal budgets to allow for this kind of activity, and it would not be regarded as “critical”. In our view, the ability for people with learning disability to be involved in planning and influence decision-making has diminished significantly, and we see no prospect of an improvement in the near future.
My partner and I currently live with 24 hour care each in a bungalow in Bracklesham Bay, we are both in electric wheelchairs and at the moment enjoy life to the full. My partner has Tetraplegia and has male care, I have Arthrogryposis and have female care. We need 24 hour care each so we can live independent lives as we are a couple but do completely different things throughout the day.

We recently had a meeting with our Social workers who wanted to first make all our carers redundant and make us have 3 month at a time live in care from an agency so we, not only would have to stop having our carers that we interview and choose ourselves but also have people we can’t choose at all in a very small bungalow, which would feel very uncomfortable, it would also mean we would have to re-home our dogs who mean a lot to us, and get me out meeting people.

When we refused this they decided we could cut the hours of our carers, to not only totally impede our independence but also to the detriment of our health. My partner has male care, he has an open wound on his bottom but cutting his care budget will make him have to wear pads as he can’t hold on for long when he needs the bathroom, so his wound would keep getting infected. He is also borderline diabetic, and asthmatic and needs sugar or his pump which means he can’t be left alone.

I also need assistance with the bathroom, and require female care. To cut my night care my social worker suggested I wear a pad, but I’m not incontinent and never have been, I just need help in getting on the toilet.

Our Social workers also told us going out was not a priority, but couldn’t answer when I asked if it was a priority for them to go out.

We enjoy a wide variety of social activities, like gym, dog agility, cinema, concerts, painting for the Mouth and Foot Painters Association, and the odd holiday which might all have to stop if our care budget is cut, leaving us stuck in a damp house watching television in our 30s, that’s not a life that I could manage. Please can you help us.

28 April 2011
Written Evidence submitted by C Lloyd (IL 70)

Introduction

I hope this counts as an adequate submission to the JCHR. Despite having above-average intelligence, the cognitive impairment from my ME/CFS often renders me unable to write coherently, so I have to resort to bulletins of information rather than flowing sentences and paragraphs.

Benefit reforms

I am terrified of the benefit reforms, and I fail to see how they could be legal with regards to the UN Convention. Too many people are erroneously being refused benefits, and this is leading to higher dependency on others (both practical and financial), reduced quality of life and even basic human dignity, and increased stress/depression leading to worsening of illness—which ironically, keeps people on benefits for longer than they may need to be. My concerns about the benefits reforms are below:

- One’s own GP’s/consultant’s opinion that one is not fit for work should not be discarded in favour of a generalist health professional who sees one for about half an hour, and yet this frequently happens. The argument that one’s GP may not be impartial can also be applied to ATOS assessors who are effectively employed by a government who wants to cut down the number of people on benefits.

- The LIMA software used by ATOS is not fit for purpose, as it often comes up with misleading results.

- A person can fail to score enough points simply because they weren’t asked about the right descriptors. An obvious example is claimants with mental health problems being asked questions on their physical abilities and not enough questions from the mental health descriptor list, but there are many other examples.

- Some questions appear to be designed to ‘catch out’ claimants / some ATOS staff make assumptions to the claimant’s detriment. For example, on being asked what sorts of TV programmes a claimant may watch, ATOS examiners have been found to assume that that means the claimant can sit in a chair for 30 minutes - which loses the claimant points. I tend to watch TV lying down, because I can’t sit for very long. It’s become so normalised for me, I wouldn’t even think to volunteer the information if I was merely asked about programmes I watched. More info on assumptions and duty of care here: http://www.bmj.com/content/342/bmj.d599.full.html?ijkey=1MHG4NxT0ujX4Lq&keytype=ref

- There are inconsistencies in the ESA50 form with the actual regulations, which could also trip claimants up. People are asked how far they can walk before they have to stop, when the correct legal test is ‘before you stop or feel severe discomfort’. This can lead to claimants erroneously giving a higher ‘walking distance’ figure, giving them fewer points than they’re really entitled to.
• Although examiners are supposed to take into account fluctuating conditions and whether a person can perform a task ‘reliably and repeatedly’, they often do not. Thus, people with chronic pain/fatigue conditions etc can be found fit for work because they were able to perform single examples of the tasks required of them on the day they were examined. That such activity could not be repeated, or would render them inactive for days afterwards is often not considered.

• ATOS and the DWP appear to be allowed access to appeal tribunal records before the appeals occur, and to ask for some appeals to be struck out before they’re even heard—all without the appellant’s knowledge. This is similar to employers being granted access to employment tribunal records—which I imagine would cause uproar. I cannot understand how this is allowed, as surely it is preferential treatment of one party, and making a mockery of the impartiality of a Tribunal. Please see: http://www.disabilityalliance.org/harrington.htm under ‘The appeals process’, in particular the quote ‘Learning from a recent exercise whereby a joint team of Atos healthcare professionals, Decision Makers and Tribunals Service personnel reviewed cases awaiting Tribunal Hearing will also be cascaded and embedded nationally (my emphasis).’ I can provide more evidence on request.

Disability rights vs criminal law rights

There are some alarming contrasts between how disabled people on benefits are treated compared to people who are suspected of committing crimes. This is my understanding of criminal law; I am happy to be corrected if necessary.

<table>
<thead>
<tr>
<th>Criminal suspect</th>
<th>Benefit claimant</th>
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<tbody>
<tr>
<td>Investigation should be carried out before charging/imprisonment can occur.</td>
<td>Benefits are automatically stopped before investigation, even if said investigation is triggered by DWP error.</td>
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<tr>
<td>Right to free legal representation by a qualified lawyer.</td>
<td>Free representation available but harder to come by and is seldom a lawyer - also no legal right to a free lawyer. Even harder to get now that funding has been cut and many support services have been lost.</td>
</tr>
<tr>
<td>Police interviewers not allowed to ask leading or misleading questions.</td>
<td>ATOS interviewers allowed to ask leading and misleading questions.</td>
</tr>
<tr>
<td>Interviews recorded - police do not have the right to refuse this.</td>
<td>ATOS assessor has the right to refuse interview recording, and even if they agree, the DWP insist on claimants providing so much technology and expertise (e.g. sound engineer present) it's often impossible for claimants to comply.</td>
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Innocent until proven guilty.  Guilty until proven innocent?

**How the changes affect my right to independent living.**

Chances are high that I will fail the new WCA despite being too ill to work, for the reasons stated above and more. If that happens, it is likely that my DLA will also be reassessed and stopped/reduced, and I will no longer be able to live independently and will become dependent on the charity of others. I explain further below.

My disability costs are as follows:

- Therapy to aid with the depression that often comes with having a long-term illness (not available to me on the NHS)
- Taxi fares so I can be more mobile and independent, since I’m often unable to use public transport or walk very far
- Pain treatments such as massage
- Ready meals because I often can’t cook for myself, and which cost a lot more than buying the raw ingredients, and paying online supermarket delivery charges of £5-6 a time since I can no longer do a supermarket shop (my food bill has almost tripled since I became too ill to work)
- A cleaner
- Higher heating bills due to my body’s inability to adequately control my temperature, and not being able to move around as much to keep warm

My Severe Disability Premium also goes towards topping up my rent (my Housing Benefit has a shortfall of £20 a week) and allowing me an occasional social life when I’m well enough—an important aspect of equality, as disabled people should not be expected to survive on a mere subsistence existence on top of everything else.

The bulleted list alone comes to at least £475 a month—£475 I wouldn’t need to spend if I were not disabled. I am fortunate in that my current benefits allow for me to pay this. If they were stopped or much reduced, I’d be financially much worse off: losing a huge chunk of my income, with less independence, less mobility, more pain, and a far worse quality of life which would increase my depression - which I’d no longer be able to afford to treat. I’d likely lose my home too since I’d no longer be able to pay the full rent.

The government can argue that I wouldn’t be affected because the ‘genuinely disabled’ will still get support. However, one only has to look at the vast amounts of seriously ill people being found ‘fit for work’ and the huge increase in appeals to know that this isn’t true. Their reforms are not fit for purpose, and are damaging our right to independent living. I could write so much more about many other issues regarding the Convention, but I lack the physical and mental energy. It has taken me several sittings over a few weeks to even write this.
Conclusion

We are human beings, and our basic human rights are being eroded, by this government and the last. When people who are terminally ill are being declared fit for work, and the President of Appeals Tribunals himself blasted the DWP and ATOS for wrongly denying too many claims (and this was before the reforms which have made things worse), we know we have a broken system.

In a civilised society the more vulnerable members should not be afraid of poverty, public scorn and homelessness. And yet I have never felt so frightened for my future.
We welcome your inquiry and in particular that you are extending it beyond article 19 to article 4.3, as well as considering Article 31.

Let us start with the good news:

First, the Pensions Service (of the DWP) is now using recycled grey paper which is far closer to universal design standards and cheaper in its communications.

As pointed out, it could be cheaper still AND MUCH MORE ACCESSIBLE by using 75% dark grey type.

Second, the British Standards Institution (BSi) is progressing, albeit very slowly, with support from the Equality and Human Rights Commission (EHRC) Disability Policy Team, and specifically its member Aidan Toomey, with the Neurodiversity and Cognitive Impairment Task Group on Access to the Built Environment.

This has already highlighted a great deal the need to consider “virtual” and “outreach” (defined as bringing the services which buildings have to people by visiting them physically and/or by letter and other non-electronic communication).

It is essential that the next stage of this, likely to be the development of a “good practice” Publically Available Specification (PAS) document.

This is a world first and has only happened because all the neurodiverse including autistic-led organisations in the Coalition of Neurodiverse Organisations remain “Fifth Sector” organisations (truly independent of Government and any control by individuals and outside bodies) which are self-funded and have in no way been co-opted through grant or other mechanisms. We are 100% neurodiverse led and controlled civil rights organisations.

However we have recently had a problem with the web host for Neurodiversity International and the Mental Health Action Group (MHAG) going bankrupt and therefore the following link for the key documents of the Disability Rights Commission’s Neurodiversity & Autism Action Group, including the most advanced statement on the needs of disabled people in general, the Disabled People’s Charter of Essential Needs to be Met, signed off by your committee member Baroness Jane Campbell of Surbiton, on behalf of the DRC in September 2007, are included as an attachment on a page on the following website:http://adrianwhyattswebsite.yolasite.com/adrian-whyatt-web-page-1.php

You may need to complete the login and password process to access this:

Login: adw24
Password: hesychia
Written Evidence submitted by the Coalition of Neurodiverse Organisations including Neurodiversity International, the Autistic Rights Movement United Kingdom (ARMUK), and the London Autistic Rights Movement (LARM) (IL 71)

This builds on top of the Southampton Centre for Independent Living’s 12 Needs of Independent Living and expands it out to 21 Needs. It also greatly strengthens some of those needs, with an emphasis on outcomes, e.g. recognising that employment must be guaranteed.

This has been brought to the attention of NCIL, who welcome and support it.

The Charter is cut and pasted below. The NAS referred to is the National Autistic Society (NAS). Additional comments are added in blue, which are further explanations on the website:

This Disabled People’s Charter was approved unanimously by the Disability Rights Commission Neurodiversity & Autism Action Group in September 2007 and was part of the documents signed off by DRC CEO Bob Niven, the Chair of the Action Group, and Baroness Jane Campbell. Additional explanation and details are given here.

As part of the human rights agenda, the Implementation of the Disabled People’s Charter for Essential Needs to be Met, produced by the Mental Health Action Group (MHAG) [Hull and East Riding] and agreed by the Disability Rights Commission (DRC) Neurodiversity & Autism Action Group. This expands the Southampton Centre for Independent Living 12 Needs to 21.

This tackles the inadequacies of raw neoliberalism, replacing it with an advanced Scandinavian style fully socially inclusive model.

**Disabled Peoples’ Charter for Essential Needs to be Fully Met**

1. Full accessible environment.
2. Full accessible transport system.
3. Technical aids, equipment and assistive technology.
4. Accessible housing, including funding for adaptation.
5. Personal assistants.
6. Inclusive education and training.
7. Adequate income.
8. Equal opportunities and guaranteed employment.
9. Appropriate accessible information.
10. Advocacy
   a. Independent Advocacy.
   b. Self-advocacy
   c. Peer Advocacy
Written Evidence submitted by the Coalition of Neurodiverse Organisations including Neurodiversity International, the Autistic Rights Movement United Kingdom (ARMUK), and the London Autistic Rights Movement (LARM) (IL 71)

d. Citizen advocacy

e. Legal advocacy

11. Counselling.

12. Appropriate and accessible health and social care provision including diagnosis, treatment and support, which includes appropriate Mental Health services and treatment taking into account the nature of individuals’ disabilities including their diagnoses and how they are affected.

13. Coaching

14. Individual style of social interaction accepted and supported.

15. Fully accessible legal systems, this includes judicial civil and criminal systems. This includes mediation and arbitration systems, comment, liaison and complaint systems, tribunals and all other forums.

16. Fully accessible police and law enforcement system.

17. Effective and Fully Funded Access to all stages of the legal system from informal dispute resolution onwards. As part of this a Disability Courts structure.

18. Extension of and effective enforcement of the Disability Equality Duty (DED) throughout the legal system, as part of its extension through all sectors of society: public, private, voluntary and mixed. Including all legal and law enforcement processes. This includes private security guards. And compulsory and comprehensive training in the DED for all.

19. The Right to have religious, spiritual, other belief and cultural needs met in full.

20. Court decisions to be made fully compliant with the Disability Discrimination Act (DDA). All participants in the legal system, including judges, to be held fully and personally liable under the DDA and other legislation for any breaches of disabled people’s rights. To support this they are to have unlimited scope to order disabled people’s needs to be met.

21. The right to an Individually Controlled Environment (ICE). This includes measures to ensure that a person can avoid sensory overload.

This Charter is based upon the Southampton Centre for Independent Living’s 12 Needs of Independent Living, with additions by the Mental Health Action Group, based in Hull and the East Riding of Yorkshire, in 2007.

Notes on MHAG and its concerns

Disability Rights Commission (DRC) established a DRC Neurodiversity Group followed by the DRC Neurodiversity & Autism Action Group following effective lobbying at the DRC AGM in 2003 by Mr Colin Revell, MHAG volunteer, and NAS Councillor, Mr Russell Stronach, as well as concerted and continuous pressure from many others, notably his fellow
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NAS Councillors Adrian Whyatt (mainly in his capacity as Co-Chair of DANDA: Developmental Adult Neuro-Diversity Association, but also through his involvement in other organisations) and Larry Arnold (who is also an NAS Board member). This is to be included in part of its final report of September 2007 before the DRC is replaced by the CEHR.

However, overall the UK has failed miserably and is going backwards in terms of independent living.

We concur with the analysis of the Public and Commercial Services Union—collect the taxes and that way eliminate the deficit, don’t cut services. Also institute anti-tax dumping against tax havens and low tax regimes.

The Government needs to change course and follow the PCS alternative broadly.

If it won’t then it should be replaced by a Government which will as soon as possible.

The current arrangements are not working for involvement or taking disabled people’s views into account. The UN Paris Principles must be accepted and followed in full. Unlike at present.

Universal design and scientific principles (i.e. how common is a need) as envisaged by the Disability Convention (especially in its definitions) must be followed in full.

This includes forcing DPOs to become fully representative and to represent people in proportion to how common their needs are in the population (using a block vote system) and thus to tackle the hierarchy of impairments. This must include massive capacity building for common but non-represented groups such as neurodiverse people and our organisations.

We are still awaiting for example, the Access statement as part of the Autism Strategy First Year Development Plan from the ODI and the Department of Health, which should have been produced by December of last year and which has still not happened to our knowledge and has failed to involve neurodiverse including autistic-led representative organisation in any way whatsoever.

We are the biggest group of disabled people in terms of lifelong disability in percentage terms. In fact, if you use the broadest definition, and include a key element of neurodiversity, visual stress to black type on a white background, the late Dave Morris claimed publically on a number of occasions that 95% of the population prefers (and very often needs) something else.

We welcome the support of the EHRC to try to get access to this.

See our reply to the Network of Networks Consultation (via People First below):

Network of Networks—UN Convention on the Rights of Disabled People—Second Round of Questions—Statement on the Exclusion of
Open Letter about the Exclusion of Neurodiverse People and our Representative Organisations from Representative Structures, such as the Network of Networks, amounting to systemic exclusion contrary to the UN Convention on the Rights of Disabled People

Dear all,

Despite one group of neurodiverse people, those who are developmentally diverse alone, being the largest group of Disabled People in terms of numbers with a lifelong disability from before, at or soon after birth or so early in childhood that we cannot remember any other way of being, unlike deaf people, blind people, mental health users and survivors, organisations representing people with physical disabilities, organisations representing people with HIV and organisations representing people with global learning difficulties and other organisations, neurodiverse including autistic people and our organisations continue to be excluded from direct representation on the Network of Networks and all other Government pan-disability initiatives. This includes organisations representing people with types of acquired neurodiversity (after brain injury).

This, despite having expressed a repeated willingness and indeed eagerness to serve and despite the Disability Rights Commission (DRC) having set up a Neurodiversity Group followed by a Neurodiversity & Autism Action Group.

Just one type of neurodiversity, dyslexia, was highlighted in a parliamentary question by David Cameron in 2005 as being identified in over 22% of school pupils in the independent sector, but only 2% in the state sector. Best estimates are that over 10% of the population has another type, dyspraxia, 5% Attention Deficit Hyperactivity Disorder (ADHD), up to 5% dyscalculia, 1% Tourette's Syndrome, 1% autism. And there are a million brain injuries a year, many resulting in long-term disability, especially of a neurodiverse type.

Our needs (e.g. quiet non-open plan environments, gluten and casein free food for some people) and even having information on different coloured paper, are routinely ignored and even denigrated.

Despite, or maybe because of, the fact that we were the first (and so far only) organisations in the UK to use the UN reporting mechanism (on 01 September 2009), we have been deliberately excluded as organisations and/or as activists from representation on Equality 2025, Network of Networks, Government Electronic Access Committees, as Commissioners of the DRC and its successor, the EHRC (as well as its Disability Committee), the Autism Programme Board, all All-Party Parliamentary Group executives, etc.

Excluding us is more expensive than including us: over two thirds of people in jails and young
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offender institutions have the above disabilities or similar and are almost always undiagnosed. This has long been known. This criminalisation results in the UK competing with Portugal to have the highest level of prison inmates in the population in the European Union.

We were also not informed of the first round of questions of the Network of Networks. If we had been we would have said that an absolutely key area of the Convention is the involvement of us through our representative organisations under articles 4.3 and 33 especially, and that this is every bit as important as the five areas outlined as areas of interest, if not even more so. Linked to this is the need to ensure, under article 2, that design is universal, and that there is proportional representation of disabled people according to how common our impairments are in the whole population, as well as how common our access needs are, where accessibility is concerned. This is blatantly not happening.

Also, the forms for the response, despite highlighting accessibility, took absolutely no account whatsoever of neurodiverse needs in their design including the provision of dyslexia-friendly formats (and colours) (grey type on a light blue background and other alternatives (e.g. brown type on a dark yellow background) as well as dark grey type on a light grey background for your default universal design versions. This is always the case with Government consultations.

For example, for the Network of Networks, it has been extremely difficult to download forms and to cut and paste them into an editable version. The consultations themselves do not give anywhere to respond to, no central point.

We demand an end to our exclusion and the proper, proportionate inclusion of disabled people of all types on everything which affects us, broadly in line in terms of voting power in such organisations with our proportion in the overall population of disabled people in percentage terms.

Yours sincerely

The Coalition of Neurodiverse Organisations

Conclusion

A scientific approach, looking at percentages and need must be adopted, including in representation requirements of disabled people’s organisations.

This means capacity building for traditionally excluded groups (above all neurodiverse including autistic-led organisations.

And the observance in full of the Paris Principles.
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It also means massive increases on grounds of historical justice and comprehensive training of the whole population in all aspects of neurodiversity.

It will be paid for out of invest to save provisions which will reduce the prison population from the extremely high levels it has to the European average or less.
Introduction

The United Kingdom’s welfare system was designed in the 1930’s and implemented after World War II. It was an important achievement that created entitlements to income security, health care and education for all. However its design was constrained by thinking that now seems out of date.

In particular:

**Key groups were excluded**: disabled people, older people, people with mental health problems, people with long-term conditions were not considered in the fundamental design of the system.

**Paternalistic solutions were accepted**: schools, hospitals, institutions and centres were accepted as good practice, community alternatives went unrecognised, the idea of independent living not considered and the negative impact of provider interests went unrecognised.

**Communities and families were taken for granted**: little thought was given to the impact of welfare systems on family life or upon the fabric of existing community structures.

At the most general level this has meant that welfare solutions for everyone often discourage citizenship, can undermine family structures and weaken community involvement. However, for older and disabled people and all those who need longer-term support, the impact of the current system has been much more negative: any support has been largely mean-spirited and institutional in character.

Since the 1960’s, there have been efforts to amend this post-war settlement and to ensure that older and disabled people are included in ways that better reflect their true needs. But the impact of these changes has been limited and incoherent. Today it is still the case that:

- Older people who need support and disabled people are much more likely to live in poverty
- People who want to work cannot access work (7% of people with learning disabilities work—65% want to work)
- People often lose their homes or cannot access real homes of their own
- People are subject to hate crimes and abuse—older people are more than 10 times likely to be abused in residential care than in their own home (Duffy, 2010a)
- Discrimination is still very real (92% of unborn children with Downs Syndrome are aborted in the UK.)

But perhaps one of the most striking instances of the underlying systemic weakness of the welfare state is that, during the current financial crisis, it is the services, income and support for older and disabled people that are being subject to the most severe cuts. The current
Written Evidence submitted by Campaign for a Fair Society (IL 72)

round of unfair cuts demonstrates that these supports have not been established as universal rights—in instead they are being treated as marginal and optional 'gifts'.

1. Unfair cuts

The current cuts in public spending target older and disabled people. Our current estimate is that at least 25% of the government’s cuts will fall on 3% of the population, those with the most significant disabilities.

Our fullest analysis to date is set out on the Campaign’s website and two papers drawn from the website have been enclosed with our submission—Unfair Cuts and Unfair Cuts in Detail [Not printed].

If we just focus on the 3% of the population with the most significant disabilities—those entitled to some level of social care—cuts will come in the following areas:

- **Social care funding**—cumulative cuts of £4.6 billion, 20% of the CSR Target (Comprehensive Spending Review, 2010).
- **Disability benefits**—cumulative cuts of £4 billion, 17% of CSR target.
- **Social housing**—cuts to social housing will also fall particularly on those older and disabled people who are not in residential care.

However this is to understate the level of unfairness. Additional cuts target other groups with important needs that just happen to fall outside the mainstream public services that have been largely protected, for example: older and disabled people who are not eligible for social care, people with mental health problems, women and families experiencing domestic violence, refugees and many other minority disadvantaged groups.

2. Weak entitlements

As well as noting the severity and unfairness of these cuts it is important to note the reasons why the cuts target older and disabled people.

To begin with it is easier to target cuts on older and disabled people because the infrastructure for meeting the rights of disabled people is so fragile, complex and incoherent.

There are multiple disability benefits—but there is no clear logic to their organisation and no clear principle defining either:

- sufficient personal income for a disabled person or
- extra income necessary to meet the costs of disability

The benefit system has developed incrementally and it needs fundamental reform. However the lack of any underlying framework of rights, and the lack of any public principles that can be used to define levels of entitlement, means that the reforms planned by the current government can be made without any reference to principles of fairness or sufficiency.

Additionally social care has been made the responsibility of local government and local government is subject to a set of complex and overlapping legislative instruments that do not
provide a strong guarantee of any right to support. As the Law Commission has noted, social care law is a “a confused patchwork” of measures.

Furthermore the relationship between local and central government in the UK has declined to the point that local government has progressively lost control and influence over most local services - whilst funding for centralised services like the NHS or local services with central funding, like schools, continues to strengthen (even in the current difficult economic climate). Despite the rhetoric of localism (from the current and previous government) the real power of local communities has weakened. This only serves to further weaken the rights of older and disabled people who rely upon locally funded and locally organised services.

3. Public confusion

In addition this pattern of underfunding and inadequate legal protection is part of a long-term pattern where funding for education and healthcare has been prioritised by successive governments. Education and healthcare are perceived as universal services that benefit all of us. Whilst social care and disability benefits are treated as marginal services benefiting minority groups. This perception of marginal status thereby helps to undermine the political will to treat older and disabled people fairly.

This perception marks a fundamental weakness in the current welfare settlement. Moreover this perception is also an illusion - on-going support, the kind of essential support necessary for independent living, is a fundamental and universal right and it is relevant to all of us:

- If we are born with a disability
- If we grow frail in later life
- If we acquire a disability through illness or accident
- If this happens to our family, friends or neighbours
- Or even if we just fear we might experience such an impairment

There is nothing marginal about the right to on-going support. In fact many of the public are quite surprised to find that the right to such support is as weak and fragile as it is. The public often imagine that such support is an essential part of the welfare settlement and are rightly upset and concerned when they find that there is in fact no significant right to such support.

In fact the creation of the concept of social care (as distinct from healthcare) may have played an important part in adding to public confusion. As Nigel Crisp—ex-CEO of the NHS—rightly says, the principles of independent living should be at the heart of all future healthcare provision: “in health the goal for people is independence and the freedom to live a life that they have reason to value” (Crisp, 2009).

Moreover, as personalisation and individual budgets are progressively extended into healthcare, including mental health services, many citizens and professionals begin to understand that the idea of a health-social care divide is incoherent and will need to be fundamentally reviewed (Duffy, 2010b).
This suggests that ultimately the NHS itself will need to fully embrace the principles of independent living and enable us to end the nonsense of generously funding healthcare while tightly rationing social care. Revisiting the health and social care divide would be one sensible strategy for radically rethinking the current welfare settlement.

4. Lack of objective entitlements

One of the other reasons that entitlements to support have been weak is that in the past public responses to disability have been in the form of concrete services—not financial entitlements. However the development of personalisation and the use of individual budgets to meet successfully meet needs has demonstrated that support can often be more usefully framed in terms of money—and that defining a fair budget can be clarified according to public principles—that is, as a matter of right.

Of course the notion that an impairment, and any disability it causes, gives rise to an entitlement has been long been recognised in Tort law where calculating the ‘cost of a disability’ is normal practice. And, although the duty to meet this cost in Tort law lies with anyone who is appropriately culpable, the size of the ‘award’ is defined only by the level of disability in accordance with principles of natural justice (rather than by the level of blame).

However the UK welfare system does not currently operate according to principles of natural justice, and this is wrong and incoherent.

In fact the recent shift to personalisation in social care has not been supported by any coherent account of the principles that should underpin the allocation of budgets and there is some reason to fear that new ideas like ‘resource allocation systems’ are now being used as a smokescreen behind which significant cuts can be made without adequate legal protection (Naysmith, 2011).

The principle that should underpin the right to support is that any such support should be sufficient to enable the individual to achieve full and active citizenship. In addition we need to identify a model of citizenship that should include:

1. The right to be in control of one’s life and to have the necessary support to make this possible.

2. The right to direction and a life of meaning, to be able to set personal goals and the freedom to try and achieve those goals.

3. The right to sufficient money so as to avoid undue dependence on others and to enable independent living.

4. The right to a home where one can have privacy, safety and live with those you have chosen to live with.

5. The right to decent help which enables and supports independence and the pursuit of personal goals.

6. The right to active involvement in the life of the community, including access to work and volunteering, the opportunity to form relationships and the chance to have a family.
This model of citizenship could be built into UK law (with full allowance for the differing legal structures of the four home countries). Although it may seem ambitious it is in fact the minimum requirement of a decent society.

And, rather than being costly, it is in fact the most economically sustainable model—for it ensures the **full use of the whole community's talents**.

5. ‘Charging’—the disability super-tax

It has also become widely accepted that social care must be subsidised by charging. However the word ‘charge’ is misleading. Charging is actually a super-tax that targets older and disabled people. Its impact is to lock disabled people into poverty and to encourage older people with modest savings to transfer property to their families far earlier than necessary—further promoting dependency and poverty.

There is no moral case for this super-tax on those in greatest need. The only reason for levying this tax on this group is that social care was not built into the initial welfare settlement and older and disabled people have never exercised sufficient political influence to resist this hidden tax.

In fact our approach to taxation or means-testing for services is entirely incoherent: people with substantially similar needs can find themselves in very different situations simply because of how their need was generated:

- Someone born with Down’s Syndrome will be super-taxed
- Someone who has worked through all their life but who then becomes frail in their old age will be super-taxed
- But, someone who acquires a long-term health condition or experiences mental illness may not be super-taxed

The substantial need—the need to live with dignity and to be able to make an active contribution to community life—is identical in every case.

Charging, or super-taxing, disabled people is not only unfair it is expensive. Each local authority sets up its own distinct means-testing system (not one integrated into the tax or benefit systems) and the cost of collecting the relatively modest charges (less than 10% of social care funding) is high. Often disabled people or older people find themselves first assessed for a service, they are then means-tested and finally they can then be told that the cost of their putative service is equal to the charges they have to pay. This process can take months to complete.

Recent reviews of social care funding have encouraged the idea that we cannot afford to provide sufficient support. This is despite the fact that almost all paid social care is already publicly funded (about 2% of GDP and 4% of government spending) yet most care and support is provided by families—not funded by the taxpayer.

Proposals to encourage private saving or insurance for social care in old age seem particularly unrealistic given the fact that social care for older people is usually only received by a minority of people for a very short period. Currently most people seem unwilling to
make proper provision for their own pension—something that will be of benefit to most people for a significant period of their life. So, it seems highly implausible that we can also be persuaded to take out social care insurance. Moreover creating government subsidies in this field is fraught with moral hazards and is likely to further encourage unattractive institutional solutions which are easier for insurance providers to cost control. Such arrangements are most to lead to a repeat of the disastrous public policy of the 1980s which saw massive growth in residential care—funded by central government though Board & Lodgings payments to service providers.

The pressure to introduce new insurance funding for social care has been fuelled by a fear of demographic change. But the fear of some ‘demographic time-bomb’ seems highly exaggerated. Any increase in the population of older people will be relative to a reduction in the population of younger people. And, as a society, we spend significantly more on younger people than we do on older people. Taking a broader view there is no reason to fear that a shift in the demographic profile of the UK demands some new private-insurance model of funding for on-going support.

The real threat emerges if we continue to fail to focus on how to strengthen and support the much more significant network of care and support that already exists in our community. It is by better supporting families, enabling citizenship and strengthening local communities that we will build a society where people will be protected from isolation, abuse, institutionalisation and dependency.

It would be fairer, more efficient and more realistic to abandon this incoherent model of super-taxation for older people and disabled people and to return to the principles that have been successfully enshrined in our health and education systems: support according to need, taxation according to means.

### 6. Prevention and eligibility

Current government policy demonstrates a deep confusion about prevention and eligibility. On the one hand local authorities are exhorted to prevent need, to provide reablement services and to build community capacity. These are good and sensible measures. However, and at the same time, local authorities are also told that their responsibility to local citizens can be terminated if people are not eligible for support. This policy—paradoxically named Fair Access to Care Services—allows at its most extreme local authorities to only provide support to people who are in critical need and this explicitly excludes people in any or all of the following circumstances:

- you have only partial choice and control over your immediate environment
- you have been abused or neglected, or will be abused or neglected
- you cannot carry out the majority of your personal care or domestic routines
- you cannot sustain involvement in work, education or learning
- you cannot sustain the majority of your social supports and relationships
- you cannot fulfil the majority of your family roles or other social roles
This level of entitlement is inconsistent with the UN Convention. But it is also inconsistent and incoherent with a policy that promotes prevention. In fact Fair Access to Care Services promotes personal and family crises, creates additional needs for support and discourages early intervention.

We need to shift to a model of support where anyone who is at risk of failing to achieve active citizenship may be entitled to support. But where support is proportionate to need and focused on strengthening:

- individual capacity
- social networks
- community opportunities, and
- income—where necessary

This approach is capability-focused and acknowledges that building a good and decent life for a citizen is only partly about having sufficient income. Real wealth is not just financial—it also has internal and social dimensions (Murray, 2011)

7. Personalisation

This government, just like the previous government, has placed considerable emphasis upon what can be achieved through increased personalisation of health and social care. Personalisation is a broad term but might be thought to include:

- The use of direct payments
- Individual budgets and self-directed support
- Peer support
- Personal assistance

All of these ideas were first developed by disabled people and their allies and were first tested and developed in local communities without the support of central government. Over time, as central government was slowly persuaded of the benefits these ideas, they have been appropriated by policy-makers. However, there has often been a failure to fully consider the real meaning and consequence of these ideas and this is then reflected in poorly thought-through implementation strategies from central government:

The focus of central government effort has been to spend money on consultancy, provide extra funding, offer its own guidance (rarely rooted in good practice) and to set targets for others to achieve. All of these measures are better achieved by communities themselves.

Instead central government has failed to do the very things that only central government can do. It has not created the right legal and economic conditions to promote success nor has it helped define the central rights that personalisation is supposed to realise.
The thinking behind personalisation, like the thinking behind independent living, is that mostly people and local agencies are the best agents for positive change in their own lives and the lives of others. These values have not been reflected in recent change efforts.

The results of this incoherent policy initiative are therefore patchy and inconclusive. In some areas:

- People have budgets on paper, but often have no meaningful control or influence over how those budgets are spent
- People have some control, but are then told—often in retrospect—that they cannot spend that money as they see fit
- People are told that they must live in groups, with people they do not know or like because there is insufficient money to meet ordinary human rights
- People have some money, but not enough, and the individual budget has been used a crude means for cutting funding.

Personalisation offers hope. But it is not a solution for the underlying problems that were created by the old welfare system; personalisation and technologies such as individual budgets were adaptations - designed to bring about positive change within a poorly functioning system. But, in the long-run, it will be necessary to create the right legal and economic changes to properly embed personalised practices.

**Key Recommendations**

The promotion of independent living within the older welfare system has been piecemeal and often incoherent. The Campaign for a Fair Society believes that the time has come for a much more fundamental review of the rights of older and disabled people and for a much more radical redesign of the whole welfare state.

Progressive governments have failed to respond to this challenge. However the the implementation of the right to independent living for disabled people, as guaranteed by Article 19, UN Convention on the Rights of Persons with Disabilities creates an ideal opportunity to develop a more wide-ranging and radical approach to establishing independent living for all.

The Campaign for a Fair Society is currently working with its members across the UK to develop a set of practical policy proposals which will transform the experiences of older and disabled people. In summary the current seven proposals seem to offer a strong basis for positive reform:

1. **A commitment to human rights**: this means fully embracing the European Convention on Human Rights and building the UN Convention on Rights of Disabled people into UK law in order to safeguard the full citizenship of older and disabled people.

2. **A commitment to make the right to support an objective right defined in law**: this will remove the dependency of older and disabled people on “gifts” from professionals.
3. **A commitment to provide families and individuals with early support:** this will prevent crises, reduce the need for expensive interventions, and end the indignity of eligibility thresholds.

4. **A commitment to put people back in control of their own lives:** this will enhance personal autonomy and dignity by restoring people’s right to control their lives and any support they need.

5. **A commitment to good housing:** this will give people the right to go on living in their own accessible homes, with a choice of the full range of different types of tenure.

6. **A commitment to a guaranteed minimum income free from means-testing:** this will create the necessary incentives for people to work and make contributions to civic life.

7. **A commitment to end the current super-tax on older and disabled people levied through local authority charges:** this will end the indignity of older people having to spend or give away all their savings just to get minimal support.

**References**


Duffy, Simon (2010b) Resource Allocation in Mental Health.

Naysmith, Stephen (12.04.2011) Glasgow Herald: This time it’s personal.

Department of Health: Fair Access to Care Services.

HM Treasury: Comprehensive Spending Review, October 2010

Murray, Pippa (2011) A Fair Start.

**Published documents—to be provided**

Unfair Cuts.

Unfair Cuts in Detail.

Fair Society and the Limits of Personalisation

**28 April 2011**
I am a disabled person who currently receives a Local Authority Direct Payment and ILF funding to enable me to live independently and work.

I would like to add my comments to some of the questions you have asked.

**Question 1.**

I believe that the right to independent living should continue to be the basis for UK Government policy. It should be something that everyone is entitled to.

**Question 2**

The Independent Living Strategy contains all the elements to implement a coherent policy towards implementing Article 19. If needs political will and funding to embed it.

**Question 4**

- The right to independent living should be enshrined in UK law.

- Recent changes in funding put this right in jeopardy because more emphasis will be put on volunteering and charitable organisations to cover areas previously funded by local authorities. There is a real danger that this will undermine the rights of choice and control disabled people can gain from employing their own Pas or choosing services most appropriate for themselves.

- The changes to the independent living fund are also going to undermine this principle. The national scheme took out local issues and provided a consistent national policy. Local Authorities implementing the full package will be distorted by post code lottery.

- It would easily be dependent on local funding issues.

- Any money given to Local Authorities for social care should be ring-fenced to ensure it is used in the intended way.

- National guidance should be applied to social care funding with budgets centrally to give consistency. However the local element of supporting disabled people to find the people or organisations to provide their support should be a user led organisation who can bring together support and experience not available in any other setting.

- A nationally funded consistently applied scheme will enable mobility of disabled people around the country without being restricted by differing local authority assessment and funding criteria.

I believe the above points are fundamental to disabled people gaining independent living.
I am a disabled man living as Independently as I can with support from the local Social Services in South Wales. I have been assessed as needing certain care/support and choose to take this support as a direct payment which gives me control over my life.

I am currently facing a cut in the hours I receive based upon a change in Social Services which I can only assume is financial in Nature, my needs have certainly not changed and I know will increase rather than decrease over years.

My independence is threatened by such proposed financial cuts, particularly my ability to go out and be part of the ‘big society’ so popularised by David Cameron Prime Minister. I will not be able to volunteer without the hour’s support I receive, is this an assumption that Disabled People are not counted as Citizens within our ‘big society’.

I believe Disabled People are paying the price of inappropriate support over the last fifty years. The support provided has come about without the involvement of Disabled people in the way we live our lives. Support has been targeted at propping up a ‘care’ industry that medicalises Disabled people and keeps us dependent on an army of care professionals.

True involvement must involve Disabled service users in an emancipatory process of service planning as well as delivery of services, run by and for Disabled people.

Disabled people are not yet ready to be involved in planning services without much training and access to learning support.

We need negotiation and not consultation with government departments to move towards more equality in deciding how our own lives are managed.

The UN in article 19 does not stipulate that our human rights depend on whether our support needs are critical or substantial. Be using these assessment criteria many local authorities are discriminating against independence of many disabled people, particularly those with sensory impairments and those with mental health impairment.

For a valid and effective decision making process individual people must be present, or be represented when decisions are being made.

If participation in decision making is to mean anything beyond tokenism then the three core principles need to be in place:

Disabled people, service user, need to have the power to exercise choice and understand the consequences of that choice.

Disabled people need to be in the role of decision makers, and the role of disabled people in decision making must be in a network of links and similar interest groups, such as an Independent Living Organisation.

The future of Social Care provision must involve Disabled people in a co partnership between service planning and service provision.
Written Evidence submitted by the Walsall Alliance for Independent Living (IL 77)

Introduction

1. The Evidence that we are submitting may be unusual in one sense. It comes from an Organisation of Disabled People whose main purpose is promoting amongst Civil Society the idea of Independent Living by Disabled People. Independent Living is a Basic Idea behind the United Nations’ Convention on the Rights of Disabled People. Independent Living, however, is not just a disabled person having a home of their own. That is condensing the idea too much and making it too simple. We consider Independent Living to involve anything which non-disabled people take for granted. The compiler—our Interim Secretary, Mr John Cresswell-Plant—has taken great care to anonymise the evidence as much as possible.

EVIDENCE

2. One of our founder members trained at a National Disability College for a Specialist Career despite being born severely disabled. When he returned home, he attempted to get a job in his field. He experienced very negative and hostile attitudes from staff of the Relevant Central Government Department. He has not worked since returning home from College over 10 years ago.

3. Another founder member has only held 4 jobs—3 under Community Programmes and 1 under Permitted Earnings—in the whole of his working life of over 30 years.

4. A third founder member held a job as a Local Employee in Crown Service but was forced to leave owing to what she perceived as lack of understanding by her employers.

5. One of our associate members has 3 children—1 daughter (who lives elsewhere in the U.K.) and 2 sons. The 2 sons constantly get into trouble. Our associate member has learned that the youngest son—who gets into the most trouble—probably has a mental age of 8 despite being in his 20s. However, he is still held fully responsible for his actions. When the youngest son is accused of something, he is told firstly not to answer any questions then to admit to doing something (even if he hasn’t done it) to avoid harsher punishment.

6. The associate member in question accepts that her youngest son will never be able to live independently; she has tried to get him formally assessed but this seems to meet with official resistance. It seems that relevant organisations believe it would go against the best interests of the community as a whole.

7. The associate member in question has even come across attitudes that are hostile and bigoted not only in the wider community but also in relevant organisations. These attitudes have led to her son being demonised rather than classified and treated as a disabled person. (This case has caused us to view some of the attitudes as more in keeping with those of Nazi Germany rather than the United Kingdom. Certain elements also draw a parallel—although not as serious—with R v Bentley.

[Lord Chief Justice Wolff said Bentley had been:—
“[...] Denied that fair trial which is the birth right of every British Citizen [...]”

and we believe this could possibly have been the case here because of this young man’s likely condition. N.B. As far as we are aware no proceedings are imminent or pending.]

8. Two of our founder members have found that accessing civil justice is more difficult than it would be for people without disabilities or sufficient means. They have experienced the fact of organisations attempting to exhaust their determination to pursue a case. They have also found that the civil justice system expects them to behave as if they were lawyers in presenting any case. The alternative is to rely on the Official Solicitor when they are both competent.

9. The Civil Justice System does not recognise the difficulties it places on people with severe disabilities who are competent. The legal profession also does not seem to recognise this; similarly, Appeals Tribunals and Inquests have similar recognition difficulties.

10. Two of our founder members have suffered abuse etc. based on their disabilities. One—a whole-time wheelchair user—suffered what is considered a targeted assault and both are now considered victims of Hate Crime. At the time the issues were raised, they were not generally taken seriously and—when they were—standard “Means of Assurance” were used rather than letting the members know (as much as possible) what was being done.

11. This caused the members’ faith in the police and the criminal justice system to become so badly damaged that it nearly reached breaking point. This issue has been resolved but we felt it should be included for purposes of evidence and context. On a positive note, praise is due to the Independent Police Complaints Commission for their instruction to investigate the matter and to extend its scope.

12. One of our founder members attempted to stand in a local by-election. As a Benefit Claimant, she attempted to get clearance whilst meeting the Statutory Deadlines imposed under Election law. Whilst the Electoral Commission and other agencies were helpful, the Benefit Bodies would not meet the requirements laid down for clarifying the questions as to whether or not she could stand. As a direct result, she was unable to stand.

13. One of our founder members has experienced very negative attitudes from the educational establishment in her role as Guardian for her younger brother. When her brother—a second generation Pakistani Muslim—has suffered bullying etc., she has attempted to complain. She suffers a spinal form of Chronic Pain Syndrome and so finds attending school in person very difficult, costly, time-consuming and stressful.

14. When she has attempted to make complaints by telephone, she has been told she must attend in person. She does not feel that the relevant agencies take acknowledge either her disability or their duty to make reasonable alterations to how they deal with matters (duties which are under UK and International Law). This has impacted on her ability to trust them and rely on how they deal with her concerns.

15. One of our founder members has great intellect yet cannot use standard methods to obtain qualifications. He seeks to be recognised for what he has learned but would need things differently structured. He is told that Examining Bodies will not make adjustments or that Educational Institutions will not permit him to attend because of his specialist needs.
16. A Member suffered a major mental health crisis that put her safety and well being—and that of her family—at risk. Her medication had failed to work properly and she was unable to get her concerns taken seriously. She was subsequently admitted for treatment as a voluntary patient.

17. However, the almost rigid application of the “Catch-22” rule is becoming too much of a risk.

(The “Catch 22” rule basically is: “A person cannot be treated for a mental health problem if they don’t admit they have a mental health problem; once they admit they have a mental health problem then treatment isn’t urgent.”)

**RECOMMENDATIONS FOR ACTION BY GOVERNMENT**

18. To enable disabled people to achieve their goals IF NECESSARY BY “SLOPING THE PLAYING FIELD” IN THEIR FAVOUR.

19. Ensuring that adjustments are made in the Judicial System not only for Prosecution Witnesses in Criminal Cases but also for Defence witnesses and Defendants; for Plaintiffs and Defendants in Civil Cases; for Participants in Tribunal Cases; and at Inquests.

20. That all bodies—public and private—must have a Statutory Duty to comply with the rights of Disabled People.

21. That any organisation that chooses to place its own interpretation on the law—and therefore places itself above the law—can be punished as having committed a serious criminal offence and is dealt with accordingly.

22. That parents and guardians be accorded the same disability rights as pupils/students when being dealt with by educational establishments.

23. Where there is an Inspecting or Oversight Body, ALL disability matters should be made Inspection Criteria and they should have jurisdiction in ALL disability complaints.

24. Ensure that rules that apply do not put society at risk or disadvantage the severely disabled members of the community.

25. Ensure that the whole of Civil Society is aware that they are all bound by the Convention.

26. To finally have the courage to tackle HEAD ON (by confrontation if necessary) the prevailing attitudes in society against Disabled People. Especially by letting people—including those in public life—understand that this is NOT Political Correctness but Justice!

27. That instead of Guidance or Advice the Government issues Directions or Instructions so that no organisation can escape compliance.

28. In the case of elections (including questions of approval for candidacy), that ALL Government agencies be bound by Election law and be required to give straight and immediate answers to questions. Where this states a person cannot stand for election, they must justify this decision at once in writing.
29. That if the Equality & Human Rights Commission is abolished, that a stronger body relating to Disability Rights is put in its place BEFORE ITS ABOLITION. Also that this body has “TEETH” including the power to compel public and private bodies to behave properly towards disabled people.

8 May 2011
Written Evidence submitted by the College of Occupational Therapists, Specialist Section-Housing (IL 78)

Written Evidence submitted by the College of Occupational Therapists, Specialist Section-Housing (IL 78)

Introduction

The College of Occupational Therapists Specialist Section-Housing (COTSS-Housing) is pleased to provide a response to request for evidence for this inquiry.

The College of Occupational Therapists (COT) is the professional body for occupational therapists and represents about 28,000 occupational therapists, support workers and students from across the United Kingdom. Occupational therapists work in local authority social services, the NHS, housing, schools, prisons, voluntary and independent sectors, and vocational and employment rehabilitation services.

Occupational therapists are regulated by the Health Professions Council, and work with people of all ages with a wide range of occupational problems resulting from physical, mental, social or developmental difficulties.

The philosophy of occupational therapy is founded on the knowledge that occupation is essential to human existence and good health and wellbeing. Occupation includes all the things that people do or participate in. For example, caring for themselves and others, working, learning, playing and interacting with others. Being deprived of or having limited access to occupation affects physical and psychological health.

The College of Occupational Therapists (COT) has 11 Specialist Sections which are branches of the College and cover a range of clinical specialities. The COT Specialist Section- Housing is one of these clinical interest groups and is particularly interested in the contribution of accessible housing to independent living for disabled people.

General comments

COTSS-Housing wishes to respond to this Inquiry because appropriate and accessible housing is a key requirement for optimising independent living for disabled adults and children. Inappropriate housing is a major barrier to personal independence in the home. It also bars disabled people “full inclusion and participation in the community” (Article 19 preamble, p13), and from developing and using their skills and potential to the fullest degree.

COTSS-Housing welcomes the Joint Committee’s aim to consider contributing factors to independent living in the round, but is concerned about the timing of this enquiry. Many changes proposed and implemented by the current government for housing, social care, planning and welfare benefits will have a significant cumulative effect on disabled people, but full evidence of these impacts will not be clear before the end of this enquiry period due to implementation timetables: a review in one year’s time is likely to give a clearer picture.

The framework today and what is at risk

The UK should be proud of the national framework of legislation and practice guidance that has developed over the decades to support accessible housing for people with disabilities. This includes national legislation since the 1948 National Assistance Act to provide for full
Written Evidence submitted by the College of Occupational Therapists, Specialist Section-Housing (IL 78)

assessment of needs and adequate accessible housing provision. It also includes Planning guidance to ensure adequate social housing, on which disabled people remain disproportionately dependent: 2011 Census figures show 42% social housing households with a person with a disability or long-term illness, compared with a national rate of 17%. The discrepancy is even higher when households with more than one disabled person are added in, and also in different regions (Northern Ireland Housing Executive households reported in 2009 63% containing a disabled or longterm ill member).

COTSS-H notes that all of the legislation and guidance marked with an asterisk below is identified for review in the current Department for Communities and Local Government (DCLG) public consultation on “unnecessary” local authority burdens that should potentially be removed or reduced if there is sufficient public support. In addition, those marked with double asterisks are being reviewed by the Law Commission. Much of the current planning legislation and guidance may also be removed under the Treasury’s Plan for Growth (March 2011) and replaced by a single ‘inherently pro-growth’ Planning Policy Framework.

Key legislation and guidance governing appropriate assessment of and provision for needs:

- Chronically Sick and Disabled Persons act 1970**;
- Disabled Persons (Services, Consultation and Representation) Act 1986**;
- NHS and Community Care Act 1990**;
- Carers and Disabled Children Act 2000 **;
- Carers (Recognition and Services) Act 1995**;
- Community Care (Delayed Discharges etc) Act (Qualifying Services) England) Regs 2003**;
- Fair Access to Care Services 2003.

Key legislation and guidance governing adequate housing and provision of adaptations:

- Housing Renewal Grants Regulations 1996*;
- Housing Renewal Grants (Service and Charges) Order (1996, introduced disabled facilities Grant - DFG- to fund adaptations)*;
- Disabled Facilities Grant (Maximum Amounts and Additional Purposes) (England) Order 2008*;
- Regulatory Reform (Housing Assistance-England and. Wales) Order 2002;
- DFG- The Package of Changes to Modernise the Programme Feb 2008;
- DCLG- Housing Adaptations for Disabled People: a good practice guide 2006*;
- Housing Corporation and COT Minor Adapts Without Delay good practice guide 2006.

Key legislation and guidance governing planning provision for social and purpose-built housing:

- Town & Country Planning Act 1990 (in particular Section 106);
- HCA-Planning and Access for Disabled people— a good practice guide 2006;
- CLG-Code for Sustainable Homes and technical guide 2009 (inc Lifetime Homes);
- DCLG-The Building Regulations 2000: Approved document M: access to and use of buildings 2006;
- Allocation of Accommodation: Code of Guidance for Local Housing Authorities 2002*;
- HCA - Delivering Quality Places guidance Nov 2007;
- Lifetime Homes, Lifetime Neighbourhoods— a National Strategy for an Ageing Society 2008;
- DCLG Choice Based Lettings—Code of Guidance for Local Housing Authorities 2008;
- Equalities Act 2010 (superseding the DDA 2006)*

Local frameworks building on national

The national legislative framework has enabled occupational therapists to work creatively with different local authorities to develop local initiatives that further support provision of appropriate accessible housing. For example, occupational therapists have been involved in
Written Evidence submitted by the College of Occupational Therapists, Specialist Section-Housing (IL 78)

working with Greater London Authority (GLA), national and sub-regional housing partnerships and departments elsewhere to develop the following:

London Accessible Housing Register (LAHR): a tool that enables local authorities to consistently assess the accessibility of their housing stock pre- and post-adaptation, to support best use of accessible housing for disabled tenants. This has recently been evaluated by Herriot-Watt University (2011, pending publication)

— GLA LAHR good practice guide (2010)
— Northern Ireland Housing Executive (NIHE) Wheelchair Housing Study (2006)
— SE London Housing Partnership Programme (SELHP) wheelchair design guide (2010)

Concerns

This legislation and guidance has achieved a degree of national consistency in access to assessment for adaptations, equipment, telecare and housing provision, improved consistency in the design of newbuild housing to accommodate disability needs and recognition that disability needs must be considered in housing developments, and improved consistency in the allocation of accessible social housing.

However, despite this, in 2007–2008 900,000 disabled people in England (20% of those who identified themselves as such) remained living in accommodation unsuitable for their needs, with 53% of disabled children under 15 living in unsuitable accommodation (Survey of English Housing 2007/08, quoted in Office for Disability Issues website facts and figures).

The areas of legislation and practice guidance affecting the housing situation and rights of disabled people are multi-factored, and removing such legislation, or elements of it, under the banner of reducing regulation burdens, supporting localism or cutting general public sector costs runs the risk of substantially reducing the rights of disabled people to independent living through the possibly unintended consequences of interacting cumulative impacts.

Health and housing departments have historically worked poorly together at all levels to recognise and address the health impact of poor housing for disabled people. This may hopefully improve with the transfer of public health responsibilities to local authorities.

COTSS-Housing has further concerns regarding the interaction and impact of planned cuts or limits to benefits and Local Authority budgets, for example:

1) Changes and reductions in local Disabled Facilities Grant (DFG) funding:

Many COTSS-H members report that their local authorities have reduced or ceased to provide DFG funds additional to the central DCLG allocation since this legal duty was
removed from them in 2008, resulting in severe delays in DFG provision following assessment and recommendations.

These member experiences were confirmed in the 2010 Foundations report *Adapting for a Lifetime*: at Oct 2009, 54% of Home Improvement Agencies reported nationally that their local authority was overspent or overcommitted on their annual DFG budget for 2009–10, and 71% reported increased demand for DFG adaptations from 2008–09.

With local authority budgets increasingly under pressure, this DFG funding will come under further pressure, reducing access to necessary adaptations. Cuts to the private sector renewal funding stream will also put other related and innovative ways of meeting need at risk, such as emergency repairs grants and assistance to move where a property is unsuitable to adapt using DFG funds.

2) Unequal access to adaptations funding for social housing tenants:

The inequity of adaptations provision and monitoring across tenures (that has been recognised in all DCLG DFG reviews) has been amplified by the increase in registered social landlords (RSLs) that own social housing, following large-scale stock transfers from local housing authorities to registered social landlords in the wake of the Decent Homes programme. Proposed social housing changes under the Localism Bill may further increase this inequity, especially if the Equalities Act (2010) requirement for RSLs to provide and report on a Disability Equality Scheme is removed under the DCLG burdens review.

Recent reductions in the Social Housing Grant are also likely to increase confusion and conflict about funding for adaptations in social housing.

3) Difficulty navigating systems and knowing rights across multiple housing providers:

COTSS-Housing members often report difficulty knowing the duties of the multifarious housing providers, and negotiating between different ways in which they provide and manage adaptations and rehousing. It cannot be any easier for disabled people themselves: service user choice without certain basic regulation means confusion and lack of choice and control. This will only be exacerbated if NHS reform plans result in removing co-terminosity between health and social care provision.

4) Housing benefit caps affecting disabled people’s housing access and choice:

Disabled people are sometimes assessed as needing an extra bedroom when applying for re-housing, due to carer or medical equipment needs. Planned changes to housing benefit rules that would reduce benefit paid to those identified as under occupiers may penalise these disabled people unless the reasons for their “under occupying” are recognised and taken into account. Benefit caps may make appropriate adapted housing in expensive areas financially inaccessible for disabled people.

5) Local authority budget reductions and access to specialist occupational therapist assessment:

Members are reporting already that in some local authorities specialist assessment by occupational therapists for housing and adaptations is either being removed or outsourced.
as a way to achieve budget cuts. This potentially puts disabled service users at risk of having inappropriate adaptations made to their homes, which may prove costly and risky in the longer term.

6) Localism and the Big Society:

The Big Society purports to be about increasing the range of small local social enterprises and mutual or co-operative service providers. The push for local authorities as commissioners to achieve efficiencies through block-contracting acts against this, and runs the risk of social enterprises etc becoming nothing more than a “socially acceptable stepping stone to privatisation”.

Members already report an increase in larger, sometimes multinational, companies promoting and winning block contracts across multiple local authorities. There is a real risk of cartels developing in the long run that will reduce choice and control for disabled people.

With service provision increasingly delegated, how will there be redress for the disabled service user when things go wrong? This is proving an issue already in the Stafford Hospital Trust case.

Members are concerned that accessible housing provision is already challenging to secure in agreements with and compliance from developers, due to the increased footprint and development costs needed to meet Lifetime Homes standards and purpose-built wheelchair housing standards. They already report some local planning authority decisions on new housing that contain reduced proportions of social housing, and no provision for wheelchair-accessible housing.

The Treasury’s Plan for Growth 2011 indicates that government will encourage local authorities to review existing Section 106 and other planning agreements where these are delaying development, with “the Government’s clear expectation that the default answer to development and growth should be ‘yes’, except where this would compromise the key sustainable development principles set out in national planning policy” (paragraph 2.10). Will these key sustainable development principles continue to include accessible housing and Lifetime Homes? Failure to include these as key principles will seriously hinder continued provision of suitable housing to meet the rising needs of the UK’s disabled citizens, with the associated impact on their ability to enjoy independent living and full community participation.

REFERENCES:

LAHR:

http://legacy.london.gov.uk/mayor/housing/docs/housing-choice-for-disabled-londoners.pdf

LAHR good practice guide:

http://www.london.gov.uk/sites/default/files/2010.03.03%20LAHR%20Good%20practice%20guide%202010.pdf
Written Evidence submitted by the College of Occupational Therapists, Specialist Section-Housing (IL 78)

GLA Accessible London:
http://legacy.london.gov.uk/mayor/strategies/sds/accessible_london.jsp

London Design Guide:

NIHE Wheelchair housing study:
http://www.nihe.gov.uk/wheelchairreport.pdf

SELHPP wheelchair design guide:

Waltham Forest inclusive Design Guide:

Foundations: Adapting for a lifetime:
http://www.foundations.uk.com/pictures/content400/
major_adaptations_final_hi_res270110.pdf

HM Treasury Department for Business and Skills The Plan for Growth

20 April 2011
COTSS-Housing wishes to present the following additional evidence following our invitation to present oral evidence to the Joint Committee. It covers:

— more detail on cumulative impacts of cuts, including material published since the hearing

— evidence on the limitations of consumer choice in securing rights to independence

— evidence on the role of adaptations in supporting independent living

— impact of removing duties from local authorities

— working smarter to achieve more with the same money

**Cumulative impacts of planned changes and cuts:**

Over this year and up to 2014, households with a disabled member may find themselves losing income and housing choice in the following ways:

— Housing Benefit (HB) + Council Tax Benefit (CTB) penalty for the carer of a disabled person occupying separate bed space except in very specific cases

— HB + CTB deduction for any disabled adult deemed to be non-dependent

— HB penalty for under-occupying if disabled partner/child is not accepted as needing their own bedroom

— reduced HB due to the 4 bed cap if their household needs more than 4 bedrooms due to disability or medical needs of a family member

— loss of Severe Disability Premium element of Income Support under Universal Credit if there is a young carer (the 2001 census identified 175,000 young carers under the age of 18 in the UK, but 2010 BBC figures suggest the number could be as high as 700,000)

— 10% reduced HB if a disabled claimant is assessed as capable of work via WCA and unable to find employment within 12 months

At the same time they may incur increased costs in the following ways:

— increased rent if they have to move to a new adapted property with Affordable Rent

— Increased rent premiums in the private sector as demands increase

— severely increased fuel and heating costs of up to 19% depending on supplier
Additional Written Evidence submitted by the College of Occupational Therapists Specialist Section-Housing (IL 78A)

— generally increased costs of food and other basic necessities due to inflation
— Increased cost of ‘disability’ related equipment eg incontinence pads

The impact of planned government cuts will vary widely across the country in terms of both local direct care provision and other services that enable disabled people to access work and education, as shown by a recent DEMOS report Coping with the Cuts (Sept 2011)

All the above has an impact on an individual’s mental health and there is evidence that poor housing and concerns over money create anxiety and depression. A 2007 Office for Disability Issues study identified several international studies showing the impact of poor housing and adaptations or their lack on the mental health of disabled people (Better outcomes, Lower Costs 2007, pp 43–53).

We provide further detail of these interactions below.

**Housing Benefit (HB) changes + availability/ affordability of accessible housing**

**Non-dependent claimant penalty**

The Department of Work and Pensions (DWP) has indicated that Housing Benefit (HB)—and Council Tax Benefit—will be reduced by fixed amounts where there is a non-dependent claimant living in the household of the benefit claimant (ie an adult child, or other adult relative). This will apply where the benefit claimant is the carer for a disabled adult, or another adult child in the household is the carer for their sibling.

In addition, households deemed to be using more bedrooms than they are entitled to will have their HB cut. The government has now accepted the need for an additional bedroom in some circumstances, which may address the additional space needs of up to 10,000 disabled people and their carers, but the Work and Pensions Select Committee noted in December 2010 that it still fails to address the needs of other households with disabled members such as:

— parents of disabled children who need an extra bedroom to care for their disabled child (of whatever age)
— pensioner and other couples who need an extra room due to their medical needs
— disabled people requiring extra space for wheelchair use, dialysis and other medical equipment or a guide dog
— adult children caring for disabled parents in their own homes

The committee recommended that these groups should be included but it is not clear whether the recommendations will be followed. These families are at risk of incurring a HB penalty under current HB rules. Evidence submitted to the committee also criticised DWP’s own Equality Impact Assessment as failing to adequately assess the impact of LHA/ HB changes on disabled people.
Additional Written Evidence submitted by the College of Occupational Therapists Specialist Section-Housing (IL 78A)

There appears to have been little if no work carried out on how much additional adaptation cost will be incurred if disabled people are forced to move from adapted to smaller properties: a lady in a Housing Association home has had £20,000 of adaptations completed on her two bedroom property; if she moved this level of work would need to be considered again as adapted properties are in limited supply, and therefore the cost savings would not be gained.

**Interaction of housing and employment benefit changes**

The government aims to move a substantial number of disabled people from Incapacity Benefit to Jobseeker’s Allowance (JSA) using the Work Capacity Assessment (WCA) as administered by ATOS Healthcare. From April 2013, those on JSA will have their HB reduced by 10% if still on JSA 12 months after their assessment. There is no consideration or allowance made as yet by the government of the additional difficulties faced by disabled people in obtaining accessible employment. Disabled people’s forums, and organisations such as RNIB, the Disability Alliance, MIND and the MS Society, are reporting that people with significant disabilities are being assessed as both capable of work and not needing support to find employment. This runs counter to the rationale for establishing Disability Employment Advisor posts in Job Centres: that disabled people face additional barriers and discrimination when seeking and keeping employment. Evidence shows that disabled people face significant discrimination in the job market. Demos *(Coping with the Cuts, Sept 2011)* cites the statistic in Equality and Human Rights Commission’s 2009 review *How Fair is Britain?* that the chances of low-qualified British disabled men having a job halved from 77% in the 1970s to 38% in the 2000s.

We note the concerns raised in Professor Malcolm Harrington’s November 2010 review of WCA, in addition to those raised by numerous disability organisations. He recommended work to:

— examine the descriptors, in particular how they account for other fluctuating conditions and generalised pain, and provide any recommendations necessary.

— incorporate advice from MIND, Mencap and National Autistic Society on refining the mental, intellectual and cognitive descriptors

— understand whether the assessment could and should incorporate more “real world” or work-focused elements

WCA descriptors were revised in April 2011, but we note the continued high number of successful appeals against WCA assessments, and the criticism of WCA expressed in the Work & Pensions Select Committee’s 6th report *(July 2011)* on the role of Incapacity Benefit reassessment in helping claimants into employment. We find it extremely worrying that the Select Committee looks forward in its report summary to Prof. Harrington’s 2nd review “*assessing whether the WCA could contribute more to establishing an individual’s employment capability*”: if WCA currently broadly fails to identify the employment capability of a disabled person, it is failing in its assessment function and is in itself discriminatory.

**Young carers, disabled parents and removal of Income Support Severe Disability Premium (SDP)**
Additional Written Evidence submitted by the College of Occupational Therapists Specialist Section-Housing (IL 78A)

The Children’s Society’s report of 30.8.11 estimates that the families of up to 15,000 young carers will be affected by this change. The SDP currently recognises that a parent with a disability may be cared for by someone who is not entitled to Carer’s Allowance, eg their child. Caring has a significant impact on a young person’s access to education. The Children’s Society have had to develop an e-learning module to help teachers recognise the impact of caring on young people’s ability to attend and achieve at school.

The Localism Bill + Affordable Rent offer

Despite this being a question in DCLG’s national consultation, there is currently no central guidance to social housing providers on whether any tenant groups should be exempted from the proposed freedom for social landlords to charge up to 80% of local market rents.

In one Southeast London LA, most local RSLs have decided that charging this level of rent for new-build properties of 3 beds and more will not be realistic, and they will mostly be setting those rents at around 60% of the local market rate. For 1-2 bed properties, the picture is more variable, and all new tenants may be subject to higher levels of rent closer to the 80% level.

In this London LA, the majority of disabled people awaiting adapted accessible housing are waiting for 2 bed properties, often because one half of a couple needs their own bedroom. They may be most affected by the potential level of Affordable Rent if their HB is also capped due to their being deemed to occupy one more bedroom than they need. This may affect their ability to move to accessible housing from an unsuitable and unadaptable property if they fear being unable to cover the increase in their rent. As yet there has been indication in the this London borough that disabled people will be exempted from the affordable rent offer when moving to 1 or 2 bed new adapted housing.

Rising fuel costs and fuel poverty

There have been recent reports on the impact of increased fuel prices on fuel poverty in low income households from Consumer Focus’s July 2011 report, commissioned a report from the Institute of Fiscal Studies, published in July 2011: Fuel Price Inflation and Low Income Consumers. The report’s summary notes that from 2001–11, the poorest 20% of households have tended to respond to a 10% rise in fuel costs by reducing their heating by 6%. Many disabled people, especially those who are older, will be in this 20% : disabled people are more than twice as likely to live in poverty as non-disabled people. (quoted in “Coping With The Cuts” p18, statistic based on the Joseph Rowntree Trust 2004 report on disabled people’s cost of living).

Consumer Focus estimates (17.8.11) that, if all of the ‘Big Six’ fuel suppliers put prices up by the same amount as Scottish Power (19% for gas and 10% for electricity), the number of households facing fuel poverty (defined as spending more than 10% of their income on fuel) may rise next year from 5.1 million to 6.4 million in Britain (a 25% increase), and the number of individuals living in fuel poverty may rise from 9.16 million to 11.93 million (a 30% increase).

Choice and treating disabled people as consumers

Rights (including consumer rights) only have status when enforceable in law. The current central approach to localism risks diluting this, and introducing consumer choice will not
necessarily improve quality of life or independence for disabled people if there is inadequate information upon which to base choices. Some disabled people will welcome the chance to do their own research and choose providers of equipment and adaptations, but many will find it confusing and impossible to make decisions, and where do they obtain reliable information and consumer assessment?

The Office of Fair Trading (OFT) November 2010 Mobility Aids Market Study found that disabled people were often subject to unfair trading practices and are not always able to access accurate information on the products they need. They are therefore at risk of “paying very high prices and […] purchasing products that may be inappropriate to their needs”, with product prices varying in some cases by up to £3,000.

This applies also particularly to adaptation services. Nationally, Trading Standards structures are breaking down, with local departments reduced in size and remit, and consumers now directed to Trustmark sites that can only offer limited guarantees of reliability. Is it ethical or effective to devolve what are in effect commissioning functions to the disabled individual? In terms of power, disabled consumers and their carers are not on a level playing field with businesses providing services to them, as the OFT report demonstrates. They do not necessarily have the same levels of time or energy as other consumers to be able to exercise their consumer power to choose alternative providers when let down or dissatisfied, and the services/products they are sourcing are not simply switchable. The failure of IB pilots to integrate DFG adaptations partly reflects this problem, as reported in the evaluation in 2008.

Role of adaptations + increasing their effectiveness

COTSS-Housing was not asked to speak to this at the Committee hearing, and submits the following information:

Impact of reduced Local Authority funding for adaptations

We reported previously on the impact of the government’s removal of the mandatory 40% local/60% central funding responsibility split for Disabled Facilities Grant (DFG) funding. One impact of this already being noted by COTSS-Housing members is the attempt by some Local Authorities to manage the DFG budget reduction caused by reducing their notional 40% contribution by refusing DFG funding to local Registered Social Landlords (RSLs), although this is actually illegal. As social housing stock ownership shifts increasingly to RSLs, a greater proportion of disabled people will be affected by this development: there is no statutory obligation for RSLs to fund adaptations, many smaller specialist RSLs do not hold funds for this and the funding stream they previously applied to for their own adaptations was consolidated with the DFG in 2006.

Local Authorities may also seek to manage reduced budgets by delaying formal application and approval, but this is often a false saving, as was noted in Better Outcomes, Lower Costs (p13): “One local authority spent £89,000 in one year on adaptations for applicants who, because of long delays, died before they could obtain any real benefit from them”

The All Party Parliamentary Group on Housing and Care for Older People produced a report in August 2011 that recommended inter alia (regarding housing and adaptations):
That Government should reconsider the abolition of Private Sector Renewal funding for home improvements that make the homes of low income elderly owner occupiers fit to live in.

That local authorities should make full use of central government funding for Disabled Facilities Grants and, as appropriate, work with Health Trusts to secure additional resources for aids and adaptations that can save NHS funds.

That Government should encourage local authorities and the NHS strategically to commission integrated community based support, Home Improvement Agency and handy-person services for older people across housing, health and social care, thereby combatting fuel poverty, and reducing excess winter deaths, accidents in the home, and longer stays in hospital.

**Impact of timely adaptations**

*Better Outcomes, Lower Costs* and the Audit Commission report *Fully Equipped* have marshalled some of the evidence for the effectiveness of timely equipment provision and adaptations in reducing costs in other areas of public expenditure such as physical and mental health services, social care and benefits. They also identify these as ways to achieve greater quality of life for the same level of spend as other pre-existing approaches.

**Increasing the effectiveness of adaptations—accessible housing registers**

Rolling out accessible housing registers would have a major national impact on making the most of money spent on adaptations through recycling, and ensuring that the level of accessible housing stock is maintained in the face of increasing demand. Too often, housing providers do not know where their adapted stock is, and cannot therefore allocate it appropriately to disabled housing applicants. Heriott Watt University recently evaluated the London Accessible Housing Register (LAHR) pilots and found that:

- less than half of all London’s housing association lettings involving accessible homes go to households containing a wheelchair user or other disabled person.
- Kensington & Chelsea more than doubled the number of lettings involving disabled people appropriately rehoused from 5% of total council lets in 2007-08 to 12% in 2009/10.
- running cost-savings would include meeting need through existing rather than new adaptations, reducing the need for other costly support services through providing suitable adapted homes, better use of housing OT expertise in assessing applicant needs rather than accessibility of properties.

It recommended the LAHR model as a way to meet ministerial priorities to maximise the effective use of social housing stock and minimise unfairness to disadvantaged groups, and suggested seeking support from DCLG and DWP (where the Minister for Disabled People sits).

**References:**

Demos: Coping with the Cuts, (Sept 2011)
Additional Written Evidence submitted by the College of Occupational Therapists Specialist Section-Housing (IL 78A)

http://www.demos.co.uk/files/Coping_web.pdf?1315593443


Work & Pensions Select Committee report HC469 : Changes to Housing benefit announced in June 2010 (Dec 2010)

http://www.publications.parliament.uk/pa/cm201011/cmselect/cmworpen/469/469.pdf

Equality and Human Rights Commission: How Fair is Britain?( 2009)

http://www.equalityhumanrights.com/key-projects/how-fair-is-britain/

Work & Pensions Select Committee’s 6th report (13.7.11) on the role of Incapacity Benefit Reassessment:

http://www.publications.parliament.uk/pa/cm201012/cmselect/cmworpen/1015/101502.htm

Summary

http://www.publications.parliament.uk/pa/cm201012/cmselect/cmworpen/1015/101503.htm

An Independent Review of the Work Capability Assessment, M Harrington (Nov 2010)

http://www.dwp.gov.uk/docs/wca-review-2010.pdf

Harrington WCA Review Yr 2 recommendations

http://www.dwp.gov.uk/docs/wca-review-timeline.pdf

Children’s Society report on Young Carers and benefit changes:


Children’s Society Healthy Schools e-learning module

http://www.childrenssociety.org.uk/what-you-can-do/resources/school-resources/supporting-young-carers
Additional Written Evidence submitted by the College of Occupational Therapists Specialist Section-Housing (IL 78A)


Office of Fair Trading: Mobility Aids Market Report Nov 2010
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APPG Housing and Care for Older People: Living Well at Home Inquiry, ed J Porteous (2011)

Evaluation of London Accessible Housing Register, Herriott Watt University March 2011 (F Pawson, J Sosenko & J Atkins)
http://www.rbkc.gov.uk/pdf/Evaluation%20of%20the%20LAHR%20March%202011.pdf
Should the right to independent living continue to form the basis for Government policy on disability in the UK?

The right to independent living should definitely be the basis for government policy on disability in the UK. UK disability legislation is regarded as one of the best in Europe, if not the best. I feel we are now threatened of losing these high standards and progress with the current government who do not seem to be promoting independent living robustly. The Improving the Life Chances Report (2005) made a great difference in changing policies in local government and supporting ULOs. The government should continue to strengthen these policies. The government should use such policies along with Article 19 of the Convention to measure its effectiveness in developing right to independent living.

Do existing policy statements, including the Independent Living Strategy, represent a coherent policy towards the implementation of the obligations in Article 19 of the UN Disability Rights Convention? Could current policy be improved? If so, how?

I think the Independent living strategy needs to be developed more since the ratification of Article 19 of the UN Convention. The government does not seem to be taking it seriously enough. It should make its position clear on what they are going to do with the Independent living strategy particularly given its importance in Article 19. The strategy could represent a coherent policy towards the implementation of the obligations of Article 19 but I think it needs to be improved to include other aspects of the Article like for instance "choice of residence in where one lives" because at the moment it is not possible for people to take their personal budgets and direct payments to live in other areas. There needs to be freedom of movement for independent living to be truly successful.

What steps, if any, should the coalition Government, the Scottish Government or other work to public agencies take better to meet the obligations in Article 19 and to secure the right to independent living for all disabled people in the UK?

It should actively encourage local authorities to meet the obligations in Article 19. Many local authorities are still not very aware of the obligations of Article 19. Government should promote and publicise this important Article more robustly. The government should encourage more local and national coproduction work with disability organisations to help secure the right to independent living for all disabled people, otherwise some groups might well be marginalised. There needs to be a more holistic approach both locally and nationally. The government should be developing policies which categorically intrinsically include the Convention in them. We need to be sure the Articles are fully enshrined in our legislation.

Impact of funding on the right to independent living

The Committee would particularly welcome evidence on these recent developments:
I think the recent announcement by the government to abolish the Independent Living Fund in 2015 would have disastrous effects on the right to independent living. It would in fact be in violation of Article 19 and this very regressive move would endanger disabled pupils independence. They would not be able to afford personal assistants and others to support them to live independently. Local authorities could not possibly replace the funding if the ILF was withdrawn as they have enough budgetary pressures now.

It has changed my life enormously living independently for more than 20 years and enabled me to work in the end with the support of my personal assistants. It would threaten my life and work like many other thousands of disabled people.

I think this country could end up going back 30 years as a result of some other proposals AND cuts being made. Local authorities are under enormous pressure to maintain front-line services the current drastic cutbacks in the budget would inhibit them being able to support disabled people live independently. This along with changes to the DLA would have detrimental effects for disabled people in restricting the level of choice, control and freedom in the daily lives.

Disabled people are already being reassessed in many instances throughout the country and are losing the services and funding of personal budgets changes to the Independent Living Fund; this is going to have a very bad impact on the quality of lives, independence of a choice and control of disabled people. It would also inhibit their ability to travel around with the cutbacks suggested for the DLA.

**What impact does funding have on the ability of the UK to secure the right to independent living protected by Article 19 of the UN Disability Rights Convention?**

**How will recent policy and budgetary decisions impact on the ability of the UK to meet its obligation under Article 19 to protect the right of all persons to independent living?**

I think the impact of funding has a primary importance of securing rights to disabled people in the UK and those rights are being currently threatened by the recent public expenditure cuts that have decreased front-line services. There have not been any new applicants for the ILF since the moratorium in June so this has already affected the ability of new applicants with a right to independent living. It is very much against Article 19 which is why it needs to be strengthened within the framework of UK legislation otherwise it is worthless and disabled people at the end of the day will suffer. The budgetary decisions are impacting very negatively on people’s lives and will make it very difficult to meet the obligations under Article 19.

**What steps should Government take to ensure that disabled people’s views are taken into account when drafting their reports to the UN under the UNCRPD?**

**As part of the national monitoring mechanism, what steps should the EHRC, NIHRC and SHRC take to ensure that the Convention is implemented effectively?**
The Government needs to involve disabled people to determine meaningful outcomes and appropriate indicators of the UK’s performance in securing the right to independent living. It is important that we do not exclusively rely on the UN reporting procedure as it can take years for the UN Disability Committee to consider the UK Government and shadow reports. In order to keep the momentum going, the Government should commit to an independent living strategy, backed-up by a range of domestic reports which would strengthen the UK’s credibility towards the UN. To this end, findings at local level should be linked back to changes at the national policy level and vice versa. Focusing instead solely on either local or national level risks to obscure the root causes to real life experiences of disabled people and renders any strategy meaningless.

Any such input needs to be funded and research commissioned, for instance on the tensions between choice and control and cutting back on the welfare state. Research designs need to be robust. For instance, to explore geographical variations in physical access it is not sufficient to rely on just a focus group in the North and another one in the South. Finally, these reports need to identify action points and disabled people must be given a fair chance to keep momentum during the period of consideration of the reports by the UN Disability Committee which can take a few years.

They should make their report available to the main disability organisations. They should be as transparent as possible in making their reports public before submitting to the UN. They should have disabled people as experts by experience working alongside civil servants in coproduction producing reports. This would provide an ideal working group.
INTRODUCTION

The Government welcomes the inquiry by the Joint Committee on Human Rights into the implementation of the right of disabled people to independent living, which is at the heart of the United Nations (UN) Convention on the Rights of Disabled People.

The Coalition Government supports independent living and the rights of disabled people as set out in the UN Convention. We are committed to removing barriers to opportunity, to empowering disabled people and to ensuring that government supports disabled people’s positive choices so that they can participate fully in their communities and wider society.

Work is critical in finding a route out of poverty. To this end the Government is also committed to an ambitious programme of welfare reform, which will support those who can work to do so, as well as providing unconditional support for those who can’t work, ensuring that everyone who can work gets the support they need to do so.

“Disabled People aren’t limited by a lack of aspiration, or will, or talent. These people are limited by a system that isn’t equipped to deal with their needs [...] Disabled People should have the same choice, control and freedom as any other citizen. This to me seems evident.” Maria Miller, Minister for Disabled People

At present, disabled people do not have the same opportunities as others. We know that:

- disabled people are more likely to be without work and dependent upon the welfare state
- disabled people are more likely to live in income poverty than others
- disabled people fare worse, on average, in the education system

Facts:

- 23 per cent of individuals living in low income are in families where at least one member is disabled, compared to 16 percent of individuals living in low income in families where no one is disabled

- The employment rate for disabled people in the United Kingdom is around 46% compared with 77% for non-disabled people.

236 Source: Family Resources Survey 2008/09 - figures are based on a before housing costs basis.

237 Based on the new ONS definition of working age; 16-64 years for both men and women.

238 Labour Force Survey, Quarter 4, 2010
• Parents of disabled children\textsuperscript{239} were more likely to say their child experienced barriers to education than parents of non-disabled children (30\% compared with 3\% respectively).

We also know that disabled people identify a lack of choice and control over their lives as a key driver of these disadvantages, and that disabled people are not currently able to participate equally in our society.

This government’s approach to transforming the lives of disabled people is underpinned by a commitment to social justice, freedom, fairness and responsibility. We want a future for disabled people free from discrimination, where disabled people have equal access to education, work and community life, and where disabled people are able to contribute to our society on an equal basis with non-disabled people.

This government’s approach to independent living for disabled people comprises:

• removing barriers to give disabled people the opportunity to fulfil their potential and be fully participating members of society by:
  
  o involving disabled people in developing and designing the services they need
  
  o changing the way people receive support, joining up support provided by different areas where possible so that it makes sense, and is easier, for people needing support
  
  o enabling disabled people to live in the way they choose, and which avoids people being institutionalised

• increasing choice and control—at the heart of the government’s approach is placing the power and choice, on how to live one’s life, with individual disabled people—and transferring the power to make those choices away from government departments and local authorities

• communities that include disabled people - where disabled people participate in public life, are free from prejudice and can receive the information they need to participate fully and make choices about how they live their lives

All this is underpinned by a commitment to the civil rights of disabled people, and fair and equal access to justice.

Equally, this government is committed to reducing the fiscal deficit. The action we are taking to bring spending under control is essential to ensure we can continue to provide support for those who need it most. Tough decisions are being made about how to reduce spending but the Government is clear that we must more effectively support disabled people into work while providing unconditional support to disabled people with the most difficulties in living an independent life. We are also clear that whilst money is important, empowering disabled people and removing barriers to participating in society is not just about money.

\textsuperscript{239} ‘Disabled children’ refers to children aged 11 to 15, using the DDA definition of disability. Life Opportunities Survey. ONS 2010.
Written Evidence submitted by the Department for Work and Pensions (IL 80)

Transparent, accountable, joined-up public services which are shaped by individuals’ choices not providers’ convenience must remain a priority.

This memorandum to the call for evidence from the Joint Committee on Human Rights will explain how the government is supporting the right to independent living.

SECTION 1: REMOVING BARRIERS

This section addresses the following JCHR question:

Should the right to independent living continue to form the basis for government policy on disability in the UK?

Giving disabled people a fair chance to improve their living standards is at the heart of this government’s thinking. At the moment we know that disabled people do not have a fair chance in education, and are more likely to experience low levels of employment and welfare dependency than others. This section sets out how the government intends to help disabled people have a fair chance to live the lives they choose and to be independent of the welfare state where this is right for them. It starts with supporting disabled people into and helping them remain in employment, and also considers:

- education
- housing
- health and social care
- transport
- the welfare system

1.1 Employment

Half of disabled people work and many more want to. We need to look at what people can do, not what they can’t do. The Government is committed to supporting disabled people to enjoy the same right to work as others. Supporting disabled people to seek, retain and progress in work is a key part of the Government’s approach to improving the quality of life for disabled people and to ensuring that they live independently and not consigned to a life on benefits through a lack of effective support.

Having the capacity to earn one’s own income gives greater choice and control to disabled people over decisions that affect their own lives, and provides a route out of poverty. The Government wants to address the particular needs of those furthest from the labour market, and acknowledges that there are substantial barriers to overcome for many.

Facts:
In the United Kingdom there are over 10 million disabled people.\textsuperscript{240} The employment rate\textsuperscript{241} for disabled people in the United Kingdom is around 46\% compared with 77\% for non-disabled people.\textsuperscript{242} This gap is broadly in line with the average for OECD countries. Within the disability employment rate, the employment rate for some groups of disabled people is far lower e.g. people with learning disabilities, autism or severe mental health conditions.\textsuperscript{243}

Adults with impairments were more than twice as likely as adults without impairments to say they experienced barriers to employment opportunities. Among all unemployed adults, a perceived lack of job opportunities was the most commonly stated barrier to employment. Among unemployed adults with impairments, other common barriers included: difficulty with transport, anxiety or lack of confidence, the attitudes of employers and a lack of skills, qualifications or experience.\textsuperscript{244}

**Effective Government Support**

The *Work Programme* is the biggest single welfare to work programme the UK has ever seen, and out of work benefit claimants will be able to access the programme at a time that is right for them. It will provide personalised back to work support and conditionality, including taking account of barriers to work faced by disabled people. The payment by results tariff ensures that the highest payments to providers are for customers receiving Employment and Support Allowance who had previously been in receipt of Incapacity Benefit.

*Work Choice* was launched across England, Scotland and Wales in October 2010. It will ensure that disabled people with more complex disability related barriers to obtaining employment have access to the right support to help them prepare for, enter and retain employment, with the aim of progressing into unsupported employment where possible.

It is a voluntary pan-disability employment programme available regardless of any benefits being claimed and is being delivered across the UK. 9,000 disabled people per annum will be enabled to enter work through our Third Sector and Private Sector provider partners. Success will depend on good and effective working with employers to help disabled people access work opportunities to achieve their full potential.

*Access to Work* is a specialist disability programme available to support disabled people to take up or retain paid work. It pays for an adjustment or support, such as wheelchair access,

\begin{footnotes}
\item Source: Family Resources Survey 2008/09; the estimate covers the number of people with longstanding illness, disability or infirmity, and who have a significant difficulty with day-to-day activities. Everyone in this group would meet the definition of disability in the Disability Discrimination Act (DDA); however, these estimates do not reflect the total number of people covered by the DDA.
\item Based on the new ONS definition of working age; 16–64 years for both men and women.
\item Labour Force Survey, Quarter 4, 2010
\item NHS Information Centre, Social Care and Mental Health Indicators from the National Indicator Set—further analysis 2009–10; Fulfilling and rewarding lives: the strategy for adults with autism in England, DH, 2010
\item Life Opportunities Survey—Interim Wave 1 results - ONS (2010).
\end{footnotes}
or travel to work costs, over and above the support an employer would be expected to provide.

37,290 disabled people were supported by Access to Work to get or keep employment during 2009–10, up from 27,720 in 2007/08, and the total programme spend was £98m. Latest figures show 29,040 people have been helped up to September 2010.

Both Work Choice and Access to Work are included within the Right to Control funding streams, testing choice and control over support that disabled people receive.

The Government is working closely to embed fully the learning from cross-government initiatives such as the Valuing People Now, employment work which focused on paid full time jobs for people with learning difficulties, to close the employment gap between people with learning disabilities and that of the disabled population as a whole. New best practice standards on supported employment were published in March 2010 as part of this work.

Residential Training Provision is another pan-disability programme that delivers vocational training to unemployed disabled adults. The nine residential training providers focus their support on individuals whose needs cannot be met through any other Government funded programmes. The expenditure on the programme in 2009–10 was £18m.

The DWP has commissioned Liz Sayce, Chief Executive of RADAR, to undertake an independent review of the specialist disability employment programmes, to consider whether they provide the most effective support possible. A call for evidence ran from December 2010 to February 2011, and Liz Sayce has spoken to a wide range of stakeholders including disabled people’s organisations, charities, providers, employers etc. A final report on the findings will be published in summer 2011.

Welfare to Work Programmes will continue to be reviewed to ensure the support they provide remains appropriate, effective and value for money.

Other activities:

To encourage businesses to become more accessible BIS and ODI commissioned a report “2012 Legacy for Disabled People: Inclusive and Accessible Business” setting out the opportunities that disabled customers bring. The initiative focused on improving the way businesses engage with disability issues. Disabled consumers are a sizeable yet poorly addressed segment of the consumer market.

- For an average business disabled customers may account for up to 20% of the customer base;

245 http://www.valuingpeoplenow.dh.gov.uk/webfm_send/469

The risk of losing custom to a more accessible competitor is high as consumer experiences of disabled people affect the choices of families and friends.\textsuperscript{247}

London 2012’s official education programme, \textit{Get Set}, is encouraging schools and colleges across the UK to learn about and live the Olympic and Paralympic values and to celebrate key London 2012 milestones. Over 17,000 schools have so far signed up. The \textit{Cultural Olympiad} will produce the largest arts, cultural and sporting programme of work by disabled people ever seen in the UK. The \textit{Paralympic Torch Relay} will give the public a chance to support the Paralympic Games on the streets of the UK.

January 2011 saw the launch of two \textit{sponsored Small Business Research Initiative} competitions designed to promote independent learning, with a specific focus on digital information. The competitions are being run by the leading UK educational advisory service in the fields of technology and inclusion. More details are available on the competition website\textsuperscript{248}

The UK recognises that online and web-based access is increasingly important as, on average, 1 in 5 of the consumer population is disabled. A key element of the UK Government’s work to improve access to services and products for disabled and older people is the work we are doing to implement the revised \textit{EU Framework on Electronic Communications Networks and Services} in UK law by May 2011. The Framework introduces new provisions, particularly in the Universal Service Directive, on equivalence of access and choice for disabled people.

There is also a new provision that will place a duty on Member States to encourage the availability of terminal equipment suitable for disabled people. This work is being taken forward by the \textit{e-Accessibility Forum} and the \textit{e-Accessibility Action plan} which aims to end the exclusion of UK citizens who are unable to take advantage of the benefits that digital technologies bring to our everyday lives. The design of public sector websites is being improved to make them more accessible to disabled users. Previously inaccessible online and television content is being made accessible to disabled people, such as e-books for those with visual impairments. Awareness of the issues facing disabled people in the digital economy will be promoted in order to help achieve a more inclusive society.

\textbf{1.2 Education}

The shared goal across Government is for disabled young people to have the best opportunities and support so that, as far as possible, they can make a successful transition from education to adult working life.

Too many disabled people hold low aspirations for their futures whilst at school. Disabled people will be supported to realise their true potential and rebuild their confidence to be able to participate in the labour market in a way that is appropriate to each individual.

\textbf{Facts:}

\textsuperscript{247} [http://www.bis.gov.uk/assets/biscore/business-sectors/docs/0-9/10-1126-2012-legacy-for-disabled-people-case-for-the-disabled-customer]

\textsuperscript{248} [http://www.jisctechdis.ac.uk/sbricompetitions]
Around 85%\textsuperscript{249} of pupils without Special Educational Needs\textsuperscript{250} achieve 5 or more GCSE (or equivalent qualifications) at grades A*-C compared with around 51% of pupils with Special Educational Needs without a statement and around 20% of pupils with Special Educational Needs with a statement.\textsuperscript{251}

Around 12% of 16–18 year olds with learning difficulties and/or disabilities (LDD) are not in education, employment or training compared to around 6% of young people with no learning difficulties and/or disabilities.\textsuperscript{252}

59%\textsuperscript{253} of disabled students who completed their first degree attained a first class or upper second class degree in comparison to 63% of non-disabled students.

10.3%\textsuperscript{254} of adult learners declare a learning difficulty and/or disability. This is significantly lower than the equivalent proportion of 16–18 learners (17%) and lower than the estimated proportion of disabled people in the working population (19%).\textsuperscript{255}

In 2009, the former Learning and Skills Council published research on Apprenticeships from the Institute for Employment Studies using 2008/09 data, which found that: learners with learning difficulties and/or disabilities were significantly under represented in some sectors.\textsuperscript{256}

**Effective Government Support**

Key programmes being undertaken by government departments to promote more access to education include:

The *Green Paper ‘Support and aspiration: A new approach to special educational needs and disability’*\textsuperscript{257} sets out comprehensive proposals for reform of the Special Educational Needs (SEN) System.

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\textsuperscript{249} National pupil database 2009/10

\textsuperscript{250} Special Educational Needs provides a limited proxy for disability; there are both disabled children who do not have SEN and non-disabled children who do have SEN.

\textsuperscript{251} A pupil has a statement of Special Educational Needs when a formal assessment has been made. A document setting out the child’s needs and the extra help they should receive is in place.

\textsuperscript{252} Connexions Services 2009

\textsuperscript{253} Data from 2009/10; Higher Education Statistics Agency

\textsuperscript{254} http://www.thedataservice.org.uk/NR/rdonlyres/18BD9C2A-BA99-4B6F-AF77-575A3463CFC9/0/MarchSFRSupplementaryTableS31OverallFEandSkillsParticipationVALUESREVISEDBACKTO0203vs.xls

\textsuperscript{255} Office for National Statistics Labour Force Survey, Jan - March 2009

\textsuperscript{256} http://www.employment-studies.co.uk/pdflibrary/lsc_1109.pdf

\textsuperscript{257} http://www.education.gov.uk/publications/eOrderingDownload/Green-Paper-SEN.pdf
The call for views that informed the Green Paper, included responses from parents of disabled children and children with SEN, professionals from health, education social care, representative bodies, the voluntary and community sector, and young people and their families and organisations who represent them. Areas of concern included: overly complex system, need for better information on services available and choices of schools, better training for school staff, and education, health and social care services working better together to identify and deliver the needs of children and young people.

The Green Paper proposes to:

- Introduce a single assessment process and combined education, health and care plan
- Include parents in the assessment process and introduce a legal right to give them control of funding for their child’s support needs.
- Ensure the assessment and plans run from birth to 25 years of age
- Replace existing complicated categorisation systems with a new school-based category to help teachers to focus on raising attainment
- Overhaul teacher training and professional development
- Look at how voluntary groups might coordinate the package of support
- Give parents greater choice of school

Further Education and Skills:

In 2010/11 the Adult Foundation Learning Curriculum replaced the Foundation Learning Tier. Adults with learning disabilities, aged over 25 who follow this curriculum, will be offered personalised learning programmes that support progression to appropriate destinations and agreed outcomes, for example, a Level 2 qualification, employment or independent living.

The Next Step careers service, operational since August 2010, provides advice on careers, skills and jobs for all adults, both in and out of work. It is accessible on-line, by telephone and face to face. People with learning difficulties and/or disabilities are prioritised for intensive face to face guidance. Jobcentre Plus customers may be referred or signposted to Next Step.

The Department for Business, Innovation and Skills (BIS) will continue to fund a high quality online and helpline service for adults. From September 2011 these will be linked to similar services for young people, so there is a single point of access for all users of each service. BIS will also continue to fund a network of public, private and voluntary sector organisations to provide face to face careers guidance to adults. The single points of access to online and helpline services, and the network of organisations funded by BIS, will be known as the National Careers Service from April 2012. As well as providing free face to face guidance to

258 https://nextstep.direct.gov.uk
priority groups, the network of organisations funded by BIS will be able to offer services on the open market to those individuals/organisations which are willing to pay.

**Apprenticeships** are open to all suitably qualified people aged 16 and over. Apprenticeships are jobs, with training to industry standards, and as such entry requirements and access are largely dictated by employers and the labour market. Within these parameters the Government is working towards widening access to apprenticeships and identifying and removing barriers to entry and progression, for example, developing arrangements that will enable disabled people to submit alternative evidence, if needed, to demonstrate their suitability for, and capacity to complete, an apprenticeship.

Through the Education Bill a duty is being placed on the Chief Executive of Skills Funding to prioritise funding for apprenticeship training for certain groups of young people, including disabled people aged 16-24, when they have secured an apprenticeship place.

The SEN Green Paper commits to exploring **supported internships** for disabled people for whom an apprenticeship may not be a realistic aim. The Government is already evaluating the ‘Project Search’ internship model, of particular benefit to people with learning disabilities and autism, in 14 demonstration sites in the current academic year. This evidence will inform development of how a workplace based pre apprenticeship service might look.

**Higher Education and Skills:**

The Higher Education Funding Council for England and Wales has undertaken a recent review of its policies to support disabled students. The review showed the significant progress made by the sector in supporting disabled students but also identified key areas for improvement. The result was more updated guidance issued to institutions, in December 2009, which reflects the outcomes of the review highlighting where services could be improved e.g. developing an inclusive, anticipatory approach to disability equality, paying more attention to the end of the student life-cycle to support graduates into employment amongst other recommendations.

1.3 Housing

The Government appreciates and supports the importance of disabled people being able to remain in their homes, and having the choice of home ownership where this is sustainable, as an integral part of living an independent life.

**Facts:**

80% of disabled people requiring adaptations to their home felt their accommodation was suitable for their needs.

For both households with a disabled person and households with no disabled person 33% live in non-decent accommodation.

259 [http://www.hefce.ac.uk/widen/slld/](http://www.hefce.ac.uk/widen/slld/)

260 Data from 2007/08; Survey of English Housing
8%\textsuperscript{263} of adults with impairments experienced difficulty getting into at least one room within their own home compared with less than 1 per cent of adults without impairments.

**Effective Government Support**

There are two key funding streams that offer assistance to disabled people to live independently. These are:

The **Disabled Facilities Grant (DFG)** is a mandatory grant that helps to fund provision of adaptations that enable disabled people to live as comfortably and independently as possible in their homes. The grant is subject to a maximum limit of £30,000 in England and a means test to ensure that funding goes to those most in need, although children and younger people under the age of 19 are exempt.

This programme is crucial in delivering the Government’s objective to support independent living for disabled people. The eligible work is wide ranging, providing for access to the basic facilities within a home, including ramps, door-widening, stair-lifts and walk in showers. The funding for DFG has been protected within the 2010 Spending Review, with the national allocation to local authorities increasing from £169 million in 2010–11 to £185 million in 2014–15.\textsuperscript{264}

**Housing related support services** (also known as **Supporting People**) enable disabled people and people in vulnerable situations to live independently in their own homes. These services work with individuals to help them gain the skills needed to live more independently, with ongoing support where this is needed, and to find and keep their own homes. Approximately 1 million people receive support at any one time. A £6.5 billion investment was secured for the Spending Review period, which equates to an average annual reduction over the four years of less than 1% in cash terms. By including this funding into the main formula grants, local authorities have been given the maximum flexibility to meet their local needs in the best way.

Both Disabled Facilities Grant and Supporting People are included within the Right to Control funding streams, testing choice and control over the support that disabled people receive.

**Other programmes:**

**Housing Benefit** is an income-related benefit that helps low-income households with the costs of rent. It is administered by local authorities. Around 60% of families in receipt of

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\textsuperscript{261} Data from 2008; English House Condition Survey 2003-2007, English Housing Survey 2008

\textsuperscript{262} Definition of decent accommodation comprises of the following criteria 1) satisfactory state of repair 2) modern facilities and services 3) an adequate level of thermal comfort and the Housing Health and Safety Rating System.

\textsuperscript{263} Life Opportunities Survey—Interim Wave 1 results - ONS (2010).

\textsuperscript{264} http://www.communities.gov.uk/documents/localgovernment/pdf/1745945.pdf
Written Evidence submitted by the Department for Work and Pensions (IL 80)

Housing Benefit have at least one disabled member.\textsuperscript{265} The Government is taking steps to manage Housing Benefit expenditure, and additional support is being given by trebling the Discretionary Housing Payment budget, an additional room allowance for non-resident carers and exemption from the cap on total benefit income for those in receipt of Disability Living Allowance (DLA) or Constant Attendance Allowance (CAA).

\textit{Home Improvement Agencies (HIA)} advise homeowners and private sector tenants on improvements and adaptations that disabled people may need in their homes, helping them to apply for grants and identify reputable contractors. The Department for Communities and Local Government (DCLG) sponsor Foundations, the national body for HIAs\textsuperscript{266}.

\textit{Handypersons funding (Housing Strategy for Older People)} provides services such as small home repairs and minor adaptations to help older and disabled people to remain living independently in their own home. These services are delivered by a range of providers including HIAs and voluntary sector organisations. From April 2011 handypersons funding will be rolled into the Formula Grant with a national allocation of £15.5 million.

\textit{FirstStop}\textsuperscript{267} is a free independent national information and advice service for older people, their families and carers, funded by DCLG. It provides joined-up advice across a range of housing care and finance issues, and is also investing in the development of local FirstStop partnerships to offer more intensive local support and advocacy services.

\textit{Extra Care Housing} gives older and disabled people access to specialist accommodation with access to person-centred care and support that facilitates their independent living.

Between 2004 and 2010, Department of Health allocated capital grants to Councils with Adult Social Care responsibility (CASC\textsuperscript{R}) £227 million to enhance the housing with care choices available in their localities. Working with the Homes and Communities Agency and DCLG, over 5,000 new purpose-built Extra Care Housing units of accommodation have been built. An evaluation is being undertaken to determine the cost-effectiveness of Extra Care Housing as an alternative to residential care and to measure the health and wellbeing outcomes of residents, funded by the Department of Health.

A further £251 million was recently allocated to CASC\textsuperscript{R} until 2013 to support wider capital investment priorities determined locally, including preventative approaches such as Extra Care Housing, aids, adaptations or telecare services. Emerging evidence shows that such investment can avoid unnecessary hospital admissions or facilitate a speedy hospital discharge home, thereby enabling older and disabled people to move to appropriate accommodation that meets their need or supports their independence or recovery at home.

\subsection*{1.4 Health and Social Care}

The Government believes that all disabled people deserve to be treated with dignity and respect. The principle of improving outcomes and giving people more choice and control

\textsuperscript{265} Family Resource Survey 2008/09

\textsuperscript{266} Details about Foundations can be found at www.foundations.uk.com

\textsuperscript{267} Details about FirstStop can be found at www.firststopadvice.org.uk
and purchasing power over the services they receive underpins all our health and social care reforms.

The commitment remains to improve outcomes for people with learning disabilities and delivering the vision of inclusion and equality set out in *Valuing People Now*. The Department of Health announced on 4 March that contracts for the learning disability Public Health Observatory and the Confidential Inquiry into premature and avoidable deaths of people with learning disabilities will run for a further two years to March 2013. Annual health checks for people with learning disabilities also remain a priority.

A library of resources and toolkits is available on the valuing people website. This ensures that people with learning disabilities and their families can be involved with local service delivery and development, and have the opportunity to hold services to account.

**Facts:**

81\%\textsuperscript{268} of people with a long-term condition reported that they had sufficient support from local services or organisations to help manage their long-term health condition(s).

30\%\textsuperscript{269} of the general population believe older people in their local area receive the support they need to live independently at home for as long as they want to.

**Effective Government Support**

The Department of Health (DH) have published their vision for social care which is the first of three pieces of work (along with the Law Commission Report in the spring and the independent Commission on the funding of care and support in the summer) that will feed into the development of a White Paper on social care in autumn 2011 and ultimately to legislation in 2012.

It will lead an information revolution enabling disabled people to take informed decisions and choices on their care and to hold local services to account. Linked to this, on 18 November 2010, DH and ODI published good practice guidance so public services can improve provision of easy read information for people with learning disabilities\textsuperscript{270}.

**Health**

The NHS White Paper *Equity and excellence: Liberating the NHS*\textsuperscript{271} sets out the Government’s long-term vision for the future of the NHS. This builds on the core values and principles of the NHS—a comprehensive service, available to all, free at the point of use, based on need, not ability to pay. For disabled people this will:

\textsuperscript{268} Data from 2009/10; Healthcare Commission Primary Care Trusts Patient Survey 2007–08 and GP patient survey (DH/Ipos-MORI) 2009–10

\textsuperscript{269} Data from 2008; Place Survey

\textsuperscript{270} [http://www.valuingpeoplenow.dh.gov.uk/webfm_send/377](http://www.valuingpeoplenow.dh.gov.uk/webfm_send/377)

• put them at the heart of everything the NHS does – nothing about me without me, and
• put the focus on continuously improving the outcome of their healthcare

The vision for health set out in the White Paper strongly supports the wider aspirations of the Government to build a Big Society, which will draw on the strength and capabilities of active citizens and communities. Disability charities, especially user-led groups, social enterprises and mutuals are ideally placed to help mobilise local communities and ensure that the voices of disabled people are heard and acted on.

**Information Revolution for Health and Social Care**

In October 2010, the Government published a consultation on an Information Revolution in health and social care272. The views and direct involvement of disabled people are helping shape an information strategy that will deliver and support choice and control, as well as promoting and advancing equality and patients’ rights.

**Proposed duty to reduce health inequalities in access**

Through the Health and Social Care Bill, the Government has proposed a Duty specific to reducing health inequalities in access and outcomes. This complements the Duty under the Equality Act 2010 as well as the European Convention of Human Rights.

The (public health) White Paper *Healthy Lives, Healthy People* set out the practical steps intended to tackle health inequalities across the life course and across the social determinants of health that shape people’s lives.

**Social Care Vision**

The Coalition Programme committed the Government to reforming the system of social care in England to provide much more control to individuals and their carers. Personalisation of services for disabled people has been identified as a priority for the Government.

*A Vision for Adult Social Care: Capable Communities and Active Citizens*, published on 16 November 2010, is grounded in the Government’s values of freedom, fairness and responsibility.

As part of this Vision, the Government expects councils to provide personal budgets to 1 million eligible people, preferably as a direct payment, by 2013, and develop the Big Society, with more local preventative activity to support people’s independence. The Vision encourages care and support to be delivered in partnership between individuals, communities, the voluntary sector, the NHS and councils—including wider support services, such as housing.

The Spending Review allocated an additional £2bn a year by 2014/15 to support the delivery of social care which will directly benefit disabled people.

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On 25 November 2010 the Government published an update to the Carers Strategy—
Recognised, valued and supported: Next steps for the Carers Strategy—setting out the
following priorities for action:

- supporting those with caring responsibilities to identify themselves as carers at an
  early stage
- enabling those with caring responsibilities to fulfil their educational and employment
  potential
- personalised support both for carers and those they support, and
- supporting carers to remain mentally and physically well

**Social care reform**

The Government recognises that urgent reform of the social care system is needed to
provide much more control to individuals and their carers, and to reduce the insecurity that
they and their families face.

That is why we have established an independent Commission to consider how to ensure
affordable and sustainable funding for care and support for all adults in England, both in the
home and other settings. The Commission on the Funding of Care and Support has been
asked to deliver practical and deliverable recommendations by July 2011.

In its terms of reference, the Commission is asked to take account of evidence from
stakeholders, including people with disabilities.

**Portability of assessments**

The Vision sets out that we want to see greater portability of assessments, and will consider
how to pursue this in the light of the work of the Law Commission in the spring and the
independent Commission on the Funding of Care and Support in the summer. These
reports will feed into the development of the White Paper on social care.

**1.5 Transport**

Funding schemes that provide travel concessions can help to reduce the constraint of extra
transport costs for disabled people and give them greater access to transport.

**Facts:**

There has been an improvement in the proportion of disabled people who report having
difficulties in using transport from 25% to 22% between 2005 and 2009.

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Disabled adults are less likely to use all modes of transport compared with non-disabled adults. This was particularly marked for local trains, the underground, long distance trains and motor vehicles.\(^{275}\)

**Effective Government Support**

The Department for Transport will continue to ensure transport policies promote equality. Schemes such as *Blue Badge* help disabled people stay independent and *concessionary travel* ensures fair and equal access to public transport.

The *concessionary bus scheme* provides a higher level of access to bus travel at off-peak times for disabled people, reducing constraints caused by cost. The statutory concession offers free travel for eligible older and disabled people on any local bus service in England at off-peak times.

The Government recently announced plans for modernising the *Blue Badge* scheme, to tackle rising levels of fraud and abuse, and to ensure badges are issued more fairly and consistently across the country giving the correct people the capacity to maintain their independence.

For some disabled people their car is a vital means of maintaining independence and quality of life, and provides them with the opportunity to actively participate in society. The Department has just made available £3m over the next three years in grant funding to 12 accredited *mobility centres*, who will give advice to disabled drivers. The funding will continue to help disabled drivers maintain their independence.

*Community transport* is local passenger transport provision which is not provided through scheduled bus or rail services, and which is organised on a non-profit basis by voluntary organisations, community transport groups, and other non-statutory bodies. Community transport can be flexible and demand responsive, so it is ideal for dispersed rural communities, where buses have fewer passengers and destinations can be more diverse. The Government has just announced £10m for rural English local authorities to kick-start community transport in their areas.

**1.6 Welfare Reform**

The *Welfare Reform Bill* contains important provisions to reform disability benefits. The changes will ensure that support is targeted at those who have most difficulty living an independent life whilst making the system more affordable. In addition, wider welfare reforms with the introduction of Universal Credit will see significant improvement in work incentives. This, combined with the Work Programme, will help support many more disabled people into work.

*Universal Credit* is intended to reduce the financial barriers to work faced by disabled people including where they can only do small or fluctuating amounts of work. Under Universal Credit we currently envisage that disabled people will be able to earn between £2,080 and £7,000 a year before the standard Universal Credit taper applies. In addition the Universal Credit calculation will include additional amounts for disabled people to reflect the extra

\(^{275}\) Life Opportunities Survey—Interim Wave 1 results. By ONS (2010).
costs of longer durations on benefits. Disabled people, as part of the harder to help customer group, will have priority access to the Work Programme after three months, on a voluntary basis.

*Personal Independence Payment* will replace Disability Living Allowance, to build a new, more transparent and sustainable benefit. As a result of these reforms and focussing resources on those who have the greatest barriers to participation, the Department will continue to provide essential support whilst delivering savings in expenditure for working-age customers by bringing the level of spending to a more sustainable level. DLA expenditure is expected to return to roughly 2009/10 levels by 2015/16.

The design of the new Personal Independence Payment will also now include any subsequent changes that may be made to the mobility component of the Disability Living Allowance for people in residential care. These changes will not remove disabled people’s mobility, but should remove any overlaps in provision. The government wishes to ensure that the help available is properly targeted to reflect the different circumstances in which disabled people live.

A cap on total benefit income will also be introduced in April 2013. Recipients of Disability Living Allowance will be exempt from this. *Contributory Employment and Support Allowance* will be time limited to a maximum of one year, mitigated by exemption for Support Group plus income related benefit safety net.

*Housing Benefit* reforms started from 1 April 2011 with changes to the Local Housing Allowance. These reforms include restricting the maximum Local Housing Allowance level to the four bedroom rate, applying overall weekly caps to and setting Local Housing Allowance rates so that 3 in 10 properties are affordable to Housing Benefit customers rather than 5 in 10 as is currently the case.

To help those in the most vulnerable circumstances who could be affected by these changes, we are tripling expenditure on Discretionary Housing Payments.

From April 2011 there will also be staged increases in the level of non-dependant deductions so that by April 2014 they reflect growth in rents since 2001. Non-dependant deductions are not applied if the claimant or their partner is blind or in receipt of Attendance Allowance or the care component of Disability Living Allowance.

From January 2012 the shared accommodation rate will apply to customers under 35 years instead of under 25 years as now. But we will keep the current exemptions, so that people who receive the severe disability premium retain entitlement to the rate for one bedroom self contained accommodation.

From April 2013, Local Housing Allowance rates will be uprated on the basis of the Consumer Prices Index, rather than on the basis of local rents and Housing Benefit for working age social rented sector customers will be restricted for those who are occupying a larger property than their household size and structure warrants.

We recognise the important work done by carers up and down the country and so we are putting in an extra £60 million by 2015 to help fund an additional room for disabled people who have live-in but non-resident carers.
1.7 Independent Living Fund

The Independent Living Fund (ILF) was set up in 1988, with an intended lifespan of five years to provide transitional protection for disabled people at risk of losing domestic assistance as a result of the replacement of supplementary benefit with Income Support. The fund currently operates as a Non Departmental Public Body, overseen by a board of independent trustees.

The fund grew very significantly from 400 users in 1989 to 16,000 in 1997 when the direct payments act was passed, rising to 21,000 users in 2010. This growth partly reflects the growing popularity of the ‘cash-for-care’ model and the increasing demand from disabled people to live independently and exercise greater choice and control over their lives.

In 2007 the ILF was subject to an independent review. The report, while recognising the contribution that the ILF had made since it was created, recommended that the fund be closed in the medium term, reflecting the subsequent development of the policy framework around individualisation of care and support. While the previous Government acknowledged these conclusions, no firm decision was taken on the future role of the fund.

In December 2010, following a decision to temporarily close the fund in June of that year due to pressure on the 2010/11 funding allowance, the Government announced that the fund would close permanently to new users. In a Written Ministerial Statement on 13 December 2010 the Minister for Disabled People stated that while the fund would be closed to new users, it remains the priority of the Government to safeguard the position of the existing recipients of the ILF by fully protecting the programme budget for existing users throughout this Parliament. We also announced that, following the publication of the report by the Commission on the Funding of Care and Support, we will carry out a formal consultation to determine how best to continue to support people now receiving support from the ILF.

SECTION 2: CHOICE AND CONTROL

This section addresses the following JCHR question:

Do existing policy statements, including the Independent Living Strategy, represent a coherent policy towards the implementation of the obligations in Article 19 of the UN Disability Rights Convention?

The Government believes that disabled people should have choice and control over their lives and the opportunity to live more independently. As part of the wider cross-government strategy on independent living, the Government has identified personalisation of services for disabled people as a priority in giving disabled people greater choice over the support they need and the resources available to them.

CASE STUDY 1

Michael was born profoundly deaf, and lost his eyesight at the age of 16. He uses his personal budget to employ a personal assistant. Michael’s PA assists him to communicate using “hands-on” sign language. Thanks to his personal budget, Michael enjoys a full social life and is able to work:

“Now things are on the up for me, and things are really exciting—I’ve got PAs who help me and my life is much better. I get to choose, the time, the number of times and also
the people who work with me. The personal assistants gave me a lot of confidence that I went out so much more. Regularly I go and watch football. My PA also helps me to go clothes shopping. The deaf club is what I enjoy the most. I meet all my friends there and we have a social life altogether and it's a really good time for me. I can go out and do anything in my time, when I want to do it.

I have a job as a lecturer for a company called Hear First, they're a training company who run training courses for social workers. I talk to them about my life and I explain to them about individual budgets and direct payments. The feedback's been really, really good. They say they've enjoyed it a lot, and it gives me confidence."

Michael's video story is at: www.puttingpeoplefirst.org.uk/Topics/Latest/Resource/?cid=7713

Facts:

- A key barrier to disabled people being able to participate and contribute as equal citizens is a lack of choice and control over the support they need to lead independent lives. Over 23% of disabled people believe that they do not frequently have choice and control over their lives.²⁷⁶

- Whilst 3/5 of adults with impairments say they do have a say over the assistance that they receive to live their daily lives, 1/5 reported that they have a say 'sometimes', 'rarely' or 'never'. (Life Opportunities Survey—LOS).²⁷⁷

- Adults with impairments are almost twice as likely as those without impairments to say they do not have a choice over how they spent their free time (26% and 15% respectively).²⁷⁸

Effective Government Support

The Government is taking forward four key programmes to increase the choice and control that disabled people have over their lives:

- Independent living
- Personal budgets and direct payments
- Right to Control
- Personal health budgets

2.1 Independent Living

Disabled people say that independent living is fundamental to achieving disability equality, enabling them to fulfil the roles and responsibilities of citizenship.

²⁷⁶ ONS Opinions Survey 2010

²⁷⁷ Life Opportunities Survey—Interim Wave 1 results. By ONS (2010).

²⁷⁸ Life Opportunities Survey—Interim Wave 1 results. By ONS (2010).
The UK’s approach to independent living is therefore a broad one. It looks to deliver the right to live independently and be included in the community—as described in Article 19 of the UN Convention. It also recognises that disabled people should have the same level of choice, control and freedom as non-disabled people and underpins the rights set out for many of the other Convention articles covering different aspects of life.

The Academic Network of European Disability experts (ANED) in their report The Implementation of Policies Supporting Independent Living for Disabled People in Europe (amended January 2010) placed the UK within the top six European countries where “policy and practice focuses on independent living.” Stating that in the UK, “there had been significant movement towards policy support for independent living in recent years” and that the policy framework in the UK “provides a range of support to allow the majority of disabled people choices to live in the community.”

The UK is also mentioned within the report as one of only nine countries who use a system where personal assistance can be funded via a personal budget or a direct cash payment.

The Independent Living Strategy (ILS) published with cross-party support in 2008 set out actions aimed at improving the choice and control disabled people have over the services they need to live their daily lives. The ILS also highlighted what independent living means to disabled people.

“Disabled people have challenged the meaning of ‘independence’. Independent living does not mean doing things yourself, or living on your own. It means having choice and control over the assistance and/or equipment needed to go about daily life, and having equal access to housing, transport and mobility, health, employment and education and training needs.” Independent Living Strategy 2008

The strategy contributes towards the Government’s work to implement the UN Convention, particularly Article 19, living independently and being included in the community.

Choice and control practitioners’ project—This aims to improve the capability of social workers and GPs to offer greater choice to disabled people. The project has created a stakeholder engagement programme which shares good practice examples of how professionals can give disabled people more choice and control. It also directs them to government resources and tools which enable them to support disabled people more effectively.

Demonstration projects—showing the effectiveness of user-led support planning and brokerage; and promoting choice and control for older people in or about to move into residential care. The outcomes and lessons from these projects are being used to inform policy development and delivery across and beyond government

2.2 Personal Budgets


Personal Budgets are money apportioned to individuals to manage their costs in line with an agreed support plan, following a full community care assessment and financial allocation by the council. Personal budgets give a person the opportunity to procure (either themselves or through others) the services they want and that are specifically tailored to their needs. This significantly increases their prospects for living their lives in the way they choose. An individual can take a personal budget in the following different ways:

- As a direct (cash) payment
- An account held and managed by the council in line with the individual’s wishes, or placed with a third party (provider) and called off by the individual in agreement with the provider
- As a mixture of both

**CASE STUDY 2 (Further revision)**

Lewis, who has learning disabilities, lives with his family but wants more independence. His family have built him his own flat as an extension to the family home.

Lewis’s social worker explains: “Lewis left college about a year ago, and he was fortunate enough to be one of the first service users who went through the self directed support scheme. Lewis was quite clear when we did the assessment for him that we wasn’t interested in going to the County Council’s day service but he wanted to have more choice and control over what he did. Lewis has experienced a range of activities some that he’s decided not to continue with and some that he has. He’s also doing some voluntary work at a local museum, and also has some one to one support where he goes out one day a week to do some physical activity at the gym.”

Lewis’s mother speaks of the difference that the personal budget is making: “We’re building Lewis a little flat on the side of his bedroom. It was the suddenly the realisation when Lewis left college that Lewis was an adult. It’s totally life changing really isn’t it? Because once this place is finished we can phone up the agency and get someone in, can’t we, and we could go away or go out for the day, which is something we’ve never done before really. We’re at the very early stages, but I can see it will change our life quite a lot, won’t it? As time goes on and as Lewis gets more used to going out with different people and you know out and about you know, independently.”

Lewis’s story is available at: [www.puttingpeoplefirst.org.uk/Topics/Latest/Resource/?cid=7707](http://www.puttingpeoplefirst.org.uk/Topics/Latest/Resource/?cid=7707)

**2.3 Right to Control**

Right to Control takes this a step further, trailblazing a new form of service delivery over six separate funding streams which will provide disabled adults with even greater choice and control over how public money is spent to meet their individual needs and ambitions. It gives disabled adults a legal entitlement to choose how to use money available for their support across housing, employment and personal care.
This Right has been implemented across seven pilot areas in England for an initial period of two years. These Trailblazers are a partnership between local authorities and Jobcentre Plus, and disabled people’s organisations.

The majority of disabled adults in these Trailblazer areas will have a legal right to:

- Be told the monetary value of the resources available to them;
- Decide and agree, with the public body, the outcomes they want to achieve based on the objectives of the publicly funded services they access;
- Have choice and control over how resources are used to meet agreed outcomes;
- Be able to choose how they receive that support; by a direct payment, by services commissioned on their behalf or a mixture of both.

**CASE STUDY 3**

Michael is a 25 year-old man with learning disabilities and has been supported to design a business plan to set up his own business. He plans to exercise his Right to Control in respect of Work Choice and use the money to buy the support he needs to start his business. He also plans to use some social care funding alongside this to help cover these costs. His plan is to be able to work full time, and his Disability Employment Adviser (DEA) is working with him on his business plan for his request to be considered under the Right to Control.

**2.4 Personal Health Budgets**

Personal Health Budgets give people more control over how money is spent on their health care. They allow someone with a long-term condition (e.g. diabetes, stroke) or a learning disability, or someone receiving NHS continuing healthcare or with a mental health condition, to have more choice and control over the services and care they receive.

Individuals can use their budget in flexible, innovative ways to meet agreed health outcomes; they can use them on services and care not traditionally provided by the NHS. A personal health budget could be spent on any service, as long as it is legal and appropriate for government to fund, and agreed in a care plan as meeting the patient’s health needs.

Personal Health Budgets are new to the NHS and are currently being piloted. The pilots are due to run until October 2012, when an independent evaluation report will inform their wider rollout.

**The results:**

The *National Personal Budgets Survey* a questionnaire provided by the Association of Directors of Adult Social Services (ADASS) working together with In Control and Lancaster University. It will provide local authorities with data they need to find out how personal budgets and direct payments are working. Early findings already show that:

- Two thirds (66%) of personal budget recipients and family carers said their quality of life had improved.
More than half (55%) of personal budget recipients said the level of dignity in their support had improved.

Over two thirds reported an increase in control over their support.

“The use of Direct Payments and Personal Budgets has really made a difference and has provided greater choice and control for disabled people. It is therefore important that the drive to personalisation must continue.” Independent Living Scrutiny Group 2nd Annual Report

2.5 Other activities

Equity and Excellence: Liberating the NHS

The NHS White Paper, Equity and Excellence: Liberating the NHS, set out the Government’s long-term vision for the future of the NHS. The vision builds on the core values and principles of the NHS, a comprehensive service, available to all, free at the point of use, based on need, not ability to pay. The objectives are to:

- Put patients at the heart of everything the NHS does
- Focus on continuously improving those things that really matter to patients – the outcome of their healthcare
- Empower and liberate clinicians to innovate, with the freedom to focus on improving healthcare services

From July to October 2010 the Government consulted on how best to implement the White Paper reforms and undertook nationwide engagement with key partners. Findings of the consultation helped inform the Health and Social Care Bill presented to Parliament on 19 January 2011.

The proposed changes in the Health and Social Care Bill will help to make sure that there are better outcomes for patients and service users including people with disabilities, their families and carers.

Membership of Health and Wellbeing Boards, set up under the Bill, will include HealthWatch and members from councils, NHS Commissioning Board, GP Consortia and others. The Bill will place local authorities and GP Consortia under a new duty to agree a Joint Health and Wellbeing Strategy and to agree commissioning strategy based on an assessment of local need.

All of this amounts to a strengthening of duties and requirements on local organisations to work together, not just on the needs assessment, but also in turning that assessment into a shared commissioning strategy that should underpin their own plans.

Building Capacity of User Led Organisations (ULOs)

Local disability organisations can play an important role in providing the assistance that disabled people may need to exercise choice and control over their lives, ensuring that sufficient information, advice and advocacy is available.
ULOs are already very involved with developing and implementing policies that support disabled people achieving more choice and control. For example the Right to Control policy was developed in co-production with disabled people and their organisations. This partnership between local authorities and local ULOs continues during development and testing of the Right in the Trailblazer sites.

The Department of Health is expanding the role of the ULOs, by creating an Order under the Deregulation and Contracting-Out Act that will allow Trailblazer sites to delegate Adult Social Care reviews to third party organisations, including ULOs. The Order will also enable local authorities to delegate certain other functions, including assessments, to social work practices that can work closely with ULOs and organisations providing peer support.

The Minister for Disabled people will be announcing in early May a package of measures that the Government is developing with disabled people. The package will be worth around £3 million over the next four years. It will include help for disabled people’s user-led organisations to acquire the skills and expertise they may lack—for example around human resources or business planning. The package will also help organisations to demonstrate their role and value to commissioners. All of this will be underpinned by a fund that organisations can bid to for specific items that will help them to grow and flourish.

**Adult social care sector partnership**

The adult social care sector published a partnership agreement, ‘Think Local, Act Personal’, published in January 2011, following a period of consultation. The agreement recommends how councils, health bodies and providers need to work more efficiently to personalise, integrate service delivery across health and adult social care and provide more comprehensive information for people who need advice on care and support services.

Over 30 organisations across the sector, including local government, health, private, independent and community organisations, have signed up to the key principles underpinning it.  

Best practice documents on different aspects of personalisation were published at the same time as the vision for adult social care.

**Carers**

The role of carers, and government’s support for carers, in developing more personalised, preventative services, delivered in partnership with the NHS and voluntary and user-led groups, is vital.

On 25th November 2010, the Government published an update to the Carers Strategy—Recognised, valued and supported: Next steps for the Carers Strategy, setting out the priorities

281 www.puttingpeoplefirst.org.uk

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for action over the next four years focusing on what will have the biggest impact on carer’s lives.

Pilots and Studies—promoting what works

There have been a range of pilot initiatives exploring choice and control. These include ‘Getting a Life’, ‘Project Search’ and independent living demonstration projects. To promote what works, the Government will pull together the practical learning from these initiatives and publicise the findings for local commissioners and providers. The aim is to ensure that good ideas don’t gather dust on shelves but that policy design and implementation on the ground is as effective as possible in promoting choice and control.

The costs for delivering Project Search in each site at an average of £26,000 per place are met by the partnership in that site, through existing funding streams including education, adult social care and contributions from the host employer. In most cases the supported employment partner provides funding for the job coach. As part of the ongoing evaluation detailed information is collected about the costs involved in running the model and how these costs are met in each site. We will carefully look at cost effectiveness in the light of job outcomes from Project Search, as well as benefits to businesses, alongside other support.

The findings from two independent living projects (to be published May 2011) demonstrates that changing the way services are delivered to disabled people can lead to increased levels of choice and control and better outcomes, for little additional cost.

The Support, Advocacy and Brokerage (SAB) project was set up to demonstrate how resources could be transferred from traditional, local authority, care-management systems to user-led support, advocacy and brokerage to give disabled people more choice and control. The demonstrations found that user led organisations (ULOs) were able to successfully deliver support planning and brokerage to a wide range of service users.

The South East Regional Initiative (SERI) project was designed to demonstrate and measure the effectiveness of investing in independent living for older people with high support needs. The SERI aimed to increase the voice, choice and control of older people living in care homes and those at risk of moving into care. Several initiatives were carried out in three local authority areas, all of which relied on local authorities working in partnership with other organisations to deliver services differently in residential care, accessible transport, reablement and hospital discharge. A key message is that new approaches do not have to cost additional money but require changes in how that money is allocated and used.

SECTION 3: INCLUSION IN OUR COMMUNITIES

This section addresses the following JCHR questions:
What steps should the Government take to meet its obligations under the Disability Rights Convention to involve disabled people in policy development and decision-making, including in budget decisions such as the Comprehensive Spending Review?

Are the current arrangements for involvement of disabled people in policy development and decision-making working?

Putting power into the hands of local people is at the heart of the government’s policy. We will ensure disabled people, along with everyone, have the opportunity to directly influence the decisions made about the public services available to them, and to shape the opportunities available to them. We do recognise that we need to take special steps to ensure that any additional barriers that disabled people face are addressed so they can fully participate. Consequently, our overarching policies are also backed up by policies and rights specific to disabled people—for example, the equality duty, measures to increase participation in public life, and measures to ensure that policies are backed up by strong co-production and advice from disabled people.

3.1 Big Society

At its heart, the Big Society is about putting more power in people’s hands—a massive transfer of power from Whitehall to local communities.

There are three key parts of the Big Society policy agenda:

- **Community empowerment**: giving local councils and neighbourhoods more power to take decisions and shape their area

- **Opening up public services**: our public service reforms will enable charities, social enterprises, private companies and employee-owned co-operatives to compete to offer people high quality services

- **Social action**: encouraging and enabling people to play a more active part in society

The Big Society vision therefore supports this Government’s ambition to provide the opportunity for disabled people to have more choice and control over their lives; to have a greater voice in deciding how their local communities are run and to hold local services to account.

The Big Society approach can be seen throughout this paper, for instance in measures to encourage peer support through user led organisations and other groups; through a range of measures to enable disabled people to influence policy that affects them; and through the support for personal budgets and the Right to Control to give people more power over their public services.

For example, the London 2012 Olympic Games and Paralympic Games will be an extraordinary sporting and cultural event with a global audience of billions. Disabled people have played and will play a fundamental part in every aspect of the Games, from planning to construction and staging, as volunteers and as world class athletes. The Games’ legacy offers an opportunity to make a lasting difference for over 10 million disabled people in the UK as
well to the disabled people visiting in 2012. London 2012: a legacy for disabled people\textsuperscript{284} was published in April 2011.

The Big Society also presents some real opportunities for disabled people to have a greater influence in their communities for example, to improve accessibility of public transport.

Transport needs and continues to be planned with all users in mind, including those with disabilities or reduced mobility. The Department for Transport will continue to work with key disabled groups to encourage disabled people to have the right to independent living which means the same level of choice and freedom over the way transport services are planned and delivered.

### 3.2 Decentralisation and the Localism Bill

The Localism Bill contains a wide range of measures to devolve more powers from the central state back into the hands of individuals, communities and councils.

- It frees local government so that they can ensure services are delivered according to local needs
- It will give local people more power over local government and over how public money is spent in their area
- It enables and encourages local people (inc. disabled people) to get actively involved in the provision of local services.

Every policy contained within the Localism Bill underwent a comprehensive equalities screening process, designed to highlight any potential inequalities arising for all minority groups including people with disabilities during the policy development stage. Subsequently full equalities impact assessments have been completed on four key provisions where a potential impact was identified (Neighbourhood Plans, Abolition of the Standards Board, Abolition of the Tenant Services Authority and discharging the main homelessness duty). These full equality impact assessments are available to view on the DCLG website.\textsuperscript{285}

### 3.3 Participation and consultation

The coalition Government’s Equality strategy makes a commitment to “promoting greater participation and inclusion in public, political and community life”.

The Government supports the principle underpinning the United Nation’s Convention that disabled people must be involved in decisions that affect them so that their views, experience and expectations can be taken into account as policies and programmes are developed and delivered.

\textsuperscript{284} http://odi.dwp.gov.uk/docs/wo/leg/legacy-full.pdf

\textsuperscript{285} http://www.communities.gov.uk/localgovernment/decentralisation/localismbill
The Disability Equality Duty under the Disability Discrimination Act 1995 was groundbreaking and has increased disabled people’s involvement with Government and public authorities. Examples of how involvement is becoming more embedded in Government are:

**Spending Review 2010**

At the Spending Review, the Coalition Government adopted a new approach to public engagement when making decisions on spending allocations. The Government invited people to contribute ideas and suggestions, and consulted experts and the public through discussions and regional events. These discussions informed the decisions made for the Spending Review.

**Public sector Equality Duty**

One of the key ways for the Government to embed disability equality into its policies and delivery of services is through the public sector Equality Duty, contained in the Equality Act 2010. This came into force on 5 April 2011. The duty requires public bodies to have due regard to the need to eliminate discrimination against disabled people, and to advance equality of opportunity for them. The Act makes clear that this may involve taking steps to meet disabled people’s needs, and that, public bodies should consider how to remove or minimise the disadvantages that disabled people face. It also makes clear that complying with the duty may involve treating some people more favourably than others.

Compliance with duty helps improve the quality of the decision making processes, support risk management frameworks and avoid element of potential discrimination or exclusion of disabled groups. To be able to demonstrate that they have had due regard to the aims of the Equality Duty, public bodies need to consider these before and at the time that particular policies are under consideration or decisions are being taken. They should do this when new policies are being developed or revisions are being made to current policies or activities.

Public bodies need to show that their consideration was exercised in substance, with rigour, and with an open mind, and that sufficient information was available to them in order to give proper consideration, so that it might influence their final decision. One way in which they can do this is through the involvement of disabled people. This brings the voice of disabled people and information about their experiences into the decision making process, thereby breaking down barriers and developing inclusion.

**Equality 2025**

Equality 2025 is a Non-Departmental Public Body of publicly appointed disabled people. The group offers strategic, confidential advice to government on issues that affect disabled people, including participation in the very early stages of policy development or in depth examination of existing policy.

The group advises ministers and officials across government, but is responsible to the Minister for Disabled People.

**Right to Control co-production**
An Advisory Group made up of disabled people, disability groups and government officials, was set up in May 2008 to consider proposals that would give disabled people greater choice and control over the way that public funds are spent to meet their needs.

The Right to Control was co-produced, developed in partnership, with disabled people and the Advisory Group ensuring that the Right was shaped by experience of disabled people. We are committed to continue developing the Right in partnership with disabled people.

We are seeing the Big Society in action in the central role that disabled people’s organisations are playing in the planning, design and implementation of Trailblazers and in the development of the legislation required to support them. Disabled People and their organisations will continue to work in partnership in each Trailblazer over the two year testing period. Its success will therefore rely heavily on commitment from all local partners working collaboratively with the trailblazing authorities.

**Network of Networks**

The Government has worked with Equality 2025 and 12 partner disabled people’s organisations to create a more efficient two-way communication between disabled people and government, consulting on the two key policy areas of independent living and the UN Convention.

This network was a pilot scheme, and we are now looking at the lessons learnt from this work to see how it might be taken forward in the future.

**Making the Most of Partnership Boards**

All local authorities are advised by groups of local people and community groups organised into local partnership boards. ‘Making the most of partnership boards’ is a guide aimed at local authorities, disabled people and their organisations explaining how disabled people and groups can get involved.

**Facts:**

Figures from 2009–10 show that disabled people are less likely to engage in formal volunteering; 22% of disabled people engaged in formal volunteering at least once a month compared with 26% of non-disabled people.

**Access to Volunteering** was a £2 million pilot fund set up in response to a recommendation from the 2008 Commission on the Future of Volunteering.

The aim of the fund was to reduce barriers to disabled people volunteering and explore the feasibility of a national Access to Volunteering fund. Volunteer involving organisations were able to apply for grants of up to £5,000 to support disabled people to volunteer in their organisations, and the programme was delivered by a consortium of Digital Public, Charities Aid Foundation and RNIB and ran in North West, West Midlands and London.

286 Citizenship Survey 2009-10
Five grant waves for the pilot in December 2009, February, April, June and September 2010, provide funding to 389 organisations. An evaluation is due to be published in April 2011.

**Participation in public life**

The Government is committed to providing extra support to disabled people seeking elected office, as well removing legislative barriers that hinder disabled people’s participation in public and civil roles.

The Coalition Government has made a commitment to introduce “extra support” for disabled people “who want to become MPs, councillors or other elected officials”. Disabled people who want to become councillors or MPs will have access to a fund to help them overcome the barriers they face. The fund is part of a planned £1 million package aimed at improving Access to Elected Office for Disabled People. Proposals also include the creation of new training and development opportunities and the introduction of a mentoring programme that will allow aspiring disabled politicians to learn from people who have already made it to the top.

"By supporting more disabled people who want to take leadership positions in politics we can help change those perceptions and make people see that when it comes to disability it's not what someone can't do but what they can." Minister for Disabled People, Maria Miller

The Government is seeking views from across the community on this issue, including disabled people and those involved in the political process at all levels. The consultation will conclude on 11 May 2011, with the scheme expected to launch in late 2011.

Her Majesty’s Courts and Tribunals Service have published *Reasonable Adjustment guidance* for staff working with the public and other service users. The guide stresses the needs to involve disabled people in decision making in order to help meets their needs and expectations. The guidance also addresses the types of facilities and “reasonable adjustment” measures to ensure effective participation of disabled people in the justice system. These may include disabled parking spaces near to a courthouse, hearing aid induction loops, information in alternative formats or provision of BSL interpreters for certain types of cases.

*National Citizen Service (NCS)* pilots, which will be launched in summer 2011, bring together disabled and non-disabled people from all walks of life, enabling them to develop the skills needed to be active citizens and to get involved in their communities. NCS offers young people the opportunity and skills to engage in social action and other civil roles.

A new generation of *Community Organisers* will be trained to support the creation of neighbourhood groups across the UK, especially in under-represented and disadvantaged groups and individuals in the most deprived areas. Community Organisers are individuals who will act as a catalyst for more social action in communities, reflecting the vision of Big Society and will be representative of the communities they are representing. They will support new and existing neighbourhood groups and help communities express their needs, and be inclusive of and accessible to disabled people.

**Special Educational Needs Green Paper**
To help shape the Green Paper ‘Support and aspiration: A new approach to special educational needs and disability’ and ensure that the proposals put forward reflect the experience and expertise of families and those supporting them, the Department for Education issued a call for views. We received over 1,800 responses, 40 per cent of which came from parents of disabled children and children with SEN. We also heard from a range of professionals from health, education, social care and other areas, representative bodies, the voluntary and community sector, and talked to children and young people and their families and organisations that represent them.

The Learners with Learning Difficulties and/or Disabilities (LLDD) Advisory Group has been valuable in informing policy development. It includes members that represent the concerns of young people with SEN/LLDD and disabled young people for example NATSPEC and SKILL.

The Getting a Life demonstration sites (part of Valuing People Now work) have put people with learning disabilities and their families at the heart of redesigning local transition systems to improve employment and other life outcomes. They have used person-centred planning to bring together support from across children’s and adult social care, education, health and employment support to enable young people with severe learning difficulties leaving education to achieve paid employment and fulfilling lives. The learning from Getting a Life closely informed the Green Paper.

**Higher Education and Skills**

The *Student Finance Stakeholder Interest Group (SFSIG)* advises the Government on the development and implementation of policy on financial support for students in Higher Education, including both mainstream student finance available to all students and targeted student finance for students with additional needs such as disabled students.

Applications for higher education student finance are administered in England by the Student Loans Company (SLC). The *Disabled Students Stakeholder Group (DSSG)* reviews the SLC’s application arrangements and advises on the specific needs of disabled students. SKILL and the NUS are also represented on the DSSG.

**Further Education and Skills**

The BIS/DfE Apprenticeships Unit has commissioned an expert group of disability organisations to advise on implementation of the flexibility to demonstrate suitability for an Apprenticeship through alternative evidence, and on the definition of disability to be used to establish eligibility for this, and for the prioritised funding we propose to introduce through the Education Bill.

**Skills for Sustainable Growth: the National Skills Strategy**287 outlines the vision and key elements for skills and the strategy for delivering it for the next five years. Disabled people were consulted when developing this strategy. It highlighted the importance of participation in education and community learning and how this may help engage disabled people when

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287 [http://www.bis.gov.uk/skillsforgrowth](http://www.bis.gov.uk/skillsforgrowth)
there is evidence that raising the skills of under-represented and under-achieving groups could have a significant impact on economic growth.

The European Social Fund (ESF) will contribute to the UK’s sustainable economic growth and social inclusion agenda. In each region, the Department for Business, Innovation and Skills (BIS) works with partners, including local authorities and the Young Person’s Learning Agency, to develop a co-financing plan for 2011-2013. This plan sets out priorities and initiatives over and above the mainstream programmes. In line with ESF priorities, BIS will focus on helping people who are unemployed or inactive in the labour market and in particular those who are most likely to face disadvantage or discrimination.

The Skills Funding Agency worked with the Young People’s Learning Agency and the Learning and Skills Improvement Service to deliver a range of projects to improve opportunities and outcomes for Deaf and hearing impaired learners. One of these projects is a learner voice conference held in March 2011. It aimed to: enable the voices of d/Deaf learners to be heard by the learning and skills sector, in particular those with power to influence change; and to raise awareness of the challenges experienced by d/Deaf learners and identify potential solutions. The conference was designed and led by D/deaf learners from both mainstream and specialist organisations. It was bi-lingual, held in British Sign Language and in English.

The Skills Funding Agency is developing a Single Equality Scheme to set out its equality objectives. As part of its wide-ranging public consultation on the Scheme in summer 2010, the Agency took particular steps to involve disabled people. In particular, the Agency: commissioned the Learner Panel to conduct an online focus group with ten disabled adult learners; it met with BIS Disability Advisory Group; and commissioned Mencap to produce an ‘Easy Read’ version of the Scheme’s consultation document, to ensure it would be accessible to all.

Business

A group of over 60 experts from Government, including the devolved administrations, industry and disability organisations work together to explore issues surrounding e-accessibility so that better and more inclusive services and products can be developed for both business and consumer benefit. A key element of this is the RaceOnline2012 campaign which aims to make the UK the first nation where everyone can use the web bringing the 10 million people who have never been online, into the Information Age.

SECTION 4: JUSTICE AND RIGHTS

This section addresses the following JCHR questions:

- **What steps should the Government take to ensure that disabled people’s views are taken into account when drafting their reports to the UN under the UNCRPD?**

- **As part of the national monitoring mechanism, what steps should the EHRC, NIHRC and SHRC take to ensure that the Convention is implemented effectively?**

4.1 Justice

There are a number of measures in place to ensure that disabled people have the support they need to ensure effective access to justice at all stages of the legal process, exercise their legal rights as defendants and victims and to fulfil their responsibilities as witnesses and jurors.

In addition, in order to live independently, disabled people should not only feel a valued member of society, but also feel safe in their communities.

Facts

Disabled people are more likely to be victims of crime than non-disabled people at all age groups apart from those aged over 65.\(^{289}\)

Effective Government Support

Courts and Tribunals

In addition to the Reasonable Adjustment guidance mentioned in the previous section, other support enabling disabled people to participate effectively within the justice system has been made available.

In certain circumstances disabled witnesses are supported under the Youth Justice and Criminal Evidence Act 1999 e.g. using video recorded evidence, live links and assistance with communication through a registered intermediary or communications aid, to help them give the best evidence possible when being interviewed by the police and at court.

Disabled Prisoners

Policies and programmes are in place to help meet the needs of disabled prisoners in England and Wales. Prison Service Instructions mandates compliance with equality legislation, including requiring prison staff to be proactive in identifying disabled prisoners, recording information about disability and ensuring reasonable adjustments are made.

Hate Crime

We recognise that disability hate crime is an issue that is under reported and an issue we must take action on. In England, the Association of Chief Police Officers published in 2009, for the first time, figures on crimes motivated by prejudice (hate crimes) in Great Britain. Out of the 52,028 such crimes recorded, 1,402 were perceived to be about the victim’s impairment.

The Government is developing a new work programme to tackle hate crime. This work programme will take into account the findings from the EHRC’s Inquiry into disability-related harassment to ensure that the actions already underway in this area are the most effective way to combat disability hate crime, and that there are no significant gaps in action being taken.

\(^{289}\) Data from 2009-10; British Crime Survey
ACPO (Association of Chief Constables & Police Officers), supported by the Ministry of Justice, re-launched the public-facing True Vision hate crime website in February 2011 which provides hate crime information, including information packs on disability hate crime. The website includes a new online reporting facility as an alternative route to reporting directly to the police.

The Government is working with a national disability organisation and other relevant government departments to empower disabled people and their organisations to increase reporting of disability hate crime. Together we are developing a national, independent disability hate crime reporting centre; providing guidance on minimum standards for such reporting centres, empowering disabled people and their organisations to set up their own reporting centre; and raising disabled people’s awareness of disability hate crime and incidents and how to report them.

The Government maintains an overview on disability hate crime and individual departments lead on specific areas relevant to their areas of responsibility. DH has focused on hate crime at several meetings led by the National Forum of People with Learning Difficulties and has fed in their expertise into the Cross Government Hate Crime Action Plan.

The Coalition’s Programme for Government includes a commitment to improve the recording of hate crime offences against disabled people which are frequently not centrally recorded. This commitment has been implemented and from April 2011 police forces will formally collect and report to the Home Office the number of offences that are motivated by hostility towards disabled people. This data will allow the Government and local areas to better tailor their response to victims of disability hate crime and to ensure that we properly meet their needs.

4.2 Rights

The UN Convention on the Rights of Disabled People

The Government is committed to the rights set out in the UN Convention, and to the need to have processes in place for implementation, monitoring and reporting that will involve disabled people themselves, and include a robust independent mechanism.

The participation of disabled people in these processes is an important principle underpinning the Convention as whole, and section 3 described how disabled people are involved in the development and delivery of policies that affect them.

The Government is preparing a report, through a focal point, co-ordinating work in respect of the Convention—including reporting arrangements—as required by Article 33(1). Within each of the devolved administrations in Scotland, Wales and Northern Ireland there are focal points which lead on the Convention within those administrations. The UK Government and the devolved administration focal points are working together on preparation of the UK-wide report. The Government has involved disabled people in the preparation of this report.

Article 33 (2) of the UN Convention requires that there is an independent mechanism to monitor implementation. In the UK the four equality and human rights commissions— the Equality and Human Rights Commission (EHRC), the Scottish Human Rights Commission...
The Commissions are working together on the Convention, as well as having particular regard to their remits for England and Wales, Scotland and Northern Ireland.

Article 33 (2) expects the Commissions, as the independent mechanism, to ‘promote, protect and monitor’ implementation of the Convention. How they interpret these obligations is for their discretion. It is clearly important that they are seen to be independent of Government and that they adopt a balanced and impartial approach to the work.

The Commissions have chosen to take steps in a number of ways under each of the obligations to ‘promote, protect and monitor’. Under promotion the Commissions have undertaken a number of awareness-raising events for disabled people and their organisations, and have produced a range of guidance materials.

Protection involves scrutiny of UK legislation by the Commissions to see if it complies with Convention obligations, and providing advice on the equality legislation that underpins the Convention.

Monitoring involves examining how the UK is implementing the Convention, including the reservations that were entered on ratification. We understand that the Commissions will submit their own ‘shadow report’ to the United Nations Committee that monitors the Convention as a response to the report that the UK Government must make later this year. This will set out the Commissions’ analysis of implementation of the Convention in the UK and help inform the Committee’s assessment of progress made.

Across the whole range of work that the Commissions are doing on the Convention the Government has made clear its expectation that they will have regard to Article 33 (3) and must work with disabled people and their representative organisations. This applies, for example, in terms of raising awareness through accessible guidance and events, and in collecting views from disabled people to inform the monitoring role and the ‘shadow report’.

Whilst recognising the independence of the Commissions, the Office for Disability Issues as UK government’s and the devolved administrations’ focal point for the Convention, has formal and informal discussions about work that is happening and the approach to be taken to what is still a new Convention.

This constructive co-operation will continue as implementation of the Convention goes forward. Government would expect the work of the Commissions to continue to evolve in response to their evaluation of the need for different types of activity.

SECTION 5: THE ECONOMIC PICTURE

This section addresses the following JCHR questions:

- What impact does funding have on the ability of the UK to secure the right to independent living protected by Article 19 of the UN Disability Rights Convention?

- How will recent policy and budgetary decisions impact on the ability of the UK to meet its obligation under Article 19 to protect the right of all persons to independent living
There has been, and continues to be, substantial investment by Government in services and financial support for disabled people and we have emphasised our commitment to those most in need and removing the barriers experienced by disabled people.

Reducing the fiscal deficit is essential and tough decisions are inevitable. The Government is clear that we must continue to support disabled people into work while providing unconditional support to disabled people with the highest support needs.

This Government strongly believes in the social justice agenda and is working to support the outcomes it believes should be possible for all citizens, including disabled people: being productive and respected members of society contributing to personal, family and wider collective wellbeing. We are determined that those not currently achieving those outcomes be supported to do so rather than “written off”.

We endeavour to look beyond purely financial measures to address the root causes of entrenched disadvantage—like poor educational achievement and worklessness,—and by tackling them, level the playing field.

Whilst there are great opportunities afforded by the transfer of power from government to communities and individuals, we recognise that funding is important, and cuts in funding inevitably seen as negative. However, we also recognise that the way in which money is spent including personalisation, transparency, and the emphasis on better value for money are as important and can themselves remove barriers to inclusion and independence.

We know from our discussions with disabled people that the extra costs incurred by disabled people are often very specific and individual. There is "no one size fits all" solution. We are therefore working to ensure that potential barriers to inclusion are identified at as early a stage as possible and wherever possible, removed. Personalisation has a key role to play in this, together with choice and control. This is why the Government has made a commitment to extend the greater roll-out of personal budgets to give people and their carers more control and purchasing power, use direct payments to carers and better community-based provision to improve access to respite care. From 9 December 2010, disabled job seekers have been able to find out immediately if they are eligible for Access to Work support by completing a short on-line questionnaire at Directgov. If eligible, they can then print a "Pre-Employment Eligibility Letter" to show to prospective employers.

The principle of improving outcomes and giving people more choice and control over the services they receive also underpins all the health and social care reforms. Personalised services for those for whom barriers still remain then become crucial, and we continue to work with partners in all sectors—public, private and in the community to achieve this.

The Coalition Government therefore took a new approach to the Spending Review allocation, based on openness, innovation and consultation. It invited people to contribute ideas and suggestions, and consulted with experts and the public through roundtable discussions and regional events. These events included a roundtable meeting on the issue of equalities, which was attended by representatives from disability and equality organisations. It is for each Department to decide how they will allocate resources within their budgets. Potential impacts on disabled people will be considered by departments as they develop their policies and services.
Disabled people use some public services more than non-disabled people, and decisions have been taken which relatively protect these services, in particular:

- **Health:** People with long-term health conditions account for around 70% of the NHS budget. Many within this group are disabled. Health spending has been protected in real terms.

- **Social care:** disabled people are more likely to be users of social care. In recognition of the pressures on the social system in a challenging fiscal climate, the Coalition Government allocated an additional £2bn by 2014/15 to support the delivery of social care. This means, with an ambitious programme of efficiency, that there is enough funding available both to protect people’s access to services and deliver new approaches to improve quality and outcomes. Decisions on funding for social care are, however, ultimately a matter for local government.

- **Housing:** £6.5 billion investment was secured for Supporting People during the CSR period, but by including this funding into the main formula grants, local authorities have been given the maximum flexibility to meet their local needs in the best way.

- **The Disabled Facilities Grant national allocation to Local Authorities will increase from £169 million in 2010–11 to £185 million in 2014–15.**

- **Service targeted on people on low incomes:** disabled people are more likely than average to be in households on low incomes. The extension of childcare to disadvantaged two year olds and the Pupil Premium will benefit families with disabled members, who are over-represented in the target groups for these policies. The confirmed increase in funding for short breaks for disabled children will also help to improve the quality of life for disabled children and young people and their families.

### 5.1 Education

In England, disabled students in higher education (HE) are supported by the Government via (i) the institution they attend and (ii) individually through Disabled Students’ Allowances (DSAs).

The Government provides funding to HE institutions through the Higher Education Funding Council for England, to help them recruit and support disabled students; £13.2 million has been provided in academic year 2010/11, and £13 million has been allocated for 2011/12.

In addition, DSAs are available to help individual students in HE with the extra costs they may incur on their course because of disability (including a long-term health condition, mental health condition or specific learning difficulty such as dyslexia). DSAs are paid in addition to the standard student finance package. They do not depend on income and do not have to be repaid. In academic year 2008/09 49,000 students in England received DSAs and total expenditure was £109 million.

Government has also established a new £150 million National Scholarship Programme (NSP) which forms part of a package of measures to support disadvantaged young people through their education, including the introduction of the £2.5 billion pupil premium which
will support them to achieve at school and turn that into success at university. One of the national criteria for the NSP will be support for disabled students.

In the UK there is (and historically has been) a strong focus on supporting the skill needs of people with lower educational qualification, including those with learning disabilities and/or learning difficulties who would be prioritised for access to provision and support; as well as disabled learners who are a priority for funding in the further education system. The Government’s commitment to inclusive and equitable further education and skills training, which includes disabled people, is set out in the UK Skills Investment Strategy 2010/11.290

The focus on skills has been complemented by ‘A Simplified FE and Skills Funding System and Methodology’291 for Further Education colleges and training organisations. This will examine ways in which funding is allocated to support the development of skills, and how it can best be used.

Funding is available for learning provision for disabled learners. Adults with learning difficulties and/or disabilities, aged over 25, are offered a wide range of support from personalised learning programmes to specialist equipment such as talking computers or Braille printers to minimise barriers to learning. Additional Learning Support (ALS) funding is available to help all learners including those with moderate to severe disabilities, including exceptional Additional Learning Support where costs exceed £19,000. This funding is aimed to help with a wide range of support needs appropriate to individual learners, for example, in-class support, specialist staff/tutors, extra equipment, one-to-one support sessions etc. Within budget constraints, providers are able to draw the funding for as long as the additional learning needs continue. The different Learning Support budgets are currently being aligned in order to simplify and will move to a single budget in 2012/13, as part of the changes to the Skills Funding Agency’s funding system.

5.2 Transport

Concessionary Travel:

The Chancellor of the Exchequer confirmed in the Spending Review (Autumn 2010) the Government’s commitment to protect key benefits, such as free bus travel. The right to free bus travel for both older and disabled people is enshrined in Primary Legislation.

Local Authorities receive funding from Central Government for the statutory concession via a formula grant. The funding is not ring-fenced so local authorities have flexibility in how this funding is spent, so long as their statutory obligations are met.

Around £1 billion a year is spent on statutory and discretionary concessionary travel.

Local Sustainable Transport Fund: The Government published the White Paper Creating Growth, Cutting Carbon on 19th January 2011 and announced that it was making available £560m to stimulate more sustainable modes of travel at local level. The Fund supports packages of transport interventions that support economic growth and reduce carbon

290 http://www.bis.gov.uk/policies/further-education-skills/funding/skills-investment-strategy

291 http://www.bis.gov.uk/fe-funding-consultation
emissions in communities as well as delivering cleaner environments and improved air quality, enhanced safety and reduced congestion.

Proposals will be designed to enable people to make more sustainable transport choices. These are expected to encompass a wide range of measures, including packages that support the promotion of walking and cycling, initiatives to improve integration between travel modes and end-to-end journey experiences, better public transport and improved traffic management schemes. Improved public transport is expected to help provide a greater choice of travel options for all people including disabled people.

**Access for All:** The Access for All programme will help make continued improvements to rail stations, enhancing accessibility for disabled people. The UK Government will shortly be introducing a new “mid-tier” programme for station access projects requiring between £250k and £1m of Government funding. Around £17m will be available up to 2015.

The main Access for All programme includes 148 stations that will receive an accessible, step free route into the station and to and between each platform. So far 47 stations have been completed and a further 18 are in construction. The remainder will be completed by 2015. In addition, over 1,000 stations have received grants for smaller scale access improvements since 2006. The main programme will continue until at least 2015 and was not affected by the spending review. Up to £5m a year will continue to be available to train operators for smaller scale works.

Bus Subsidy: The recent announcement on bus subsidy states that, from April 2012, the rate at which Bus Service Operators Grant (BSOG) is paid will be reduced by 20%. This may have some impact on some local services, but the Department for Transport will be working with bus operators and local government to look at smarter ways of delivering this subsidy, and is keen to see what can be developed by consensus between local authorities and operators.

**SECTION 6: CONCLUSION**

The government is committed to equality for disabled people, and to empowering individuals to have greater choice and control over the support they receive, but it is clear that is not yet a reality.

Throughout this memorandum we have provided responses and evidence to the Joint Committee on Human Rights’ call for evidence on protecting the Rights of Disabled People to Independent Living. Highlighting where the government’s policy improvements have already been beneficial to disabled people, and where further actions are already being undertaken.

There are though still unacceptable gaps between the experiences of disabled people and of those who are not disabled. The government continues its work to close these gaps, and remains adamant that life chances should not be limited by disability.

**Annex A**

*Equality Act 2010: Key Disability Provisions*
The Equality Act 2010 (EA) brings together, harmonises and, in some respects, extends the existing equality law. It aims to make the legislation more consistent, clearer and easier to understand and operate for those with rights and duties under the Act.

Key disability provisions which came into force from 1 October 2010

**Definition of disability**

- The EA makes it more straightforward for some people to show that they are disabled for the purposes of the Act by removing the list of capacities. They will now only have to show that their impairment has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities. Previously under the Disability Discrimination Act (DDA) they had to show that the adversely affected activity involved something referred to as a capacity, such as mobility, speech or the ability to understand. Some people, particularly some with certain mental health conditions that were intended to be protected under the legislation, found it difficult to demonstrate the link with a capacity.

**Perception and association**

- The EA provides protection from direct disability discrimination or harassment for people who are mistakenly thought to be disabled, and people who experience discrimination/harassment because of their association with a disabled person. This will apply, for example, to carers of disabled people. This provides more consistency with protection for people with other protected characteristics. Previously under the DDA, as a consequence of a European Court of Justice judgement ("Coleman" - see background), protection from direct discrimination or harassment applied only to associates, and it was limited to the field of employment.

**Direct disability discrimination**

- The EA applies protection from direct disability discrimination more widely, including to areas like access to goods, facilities and services. Previously specific protection from direct disability discrimination only applied in relation to work.

**Discrimination arising from disability**

- The EA contains a new protection from “discrimination arising from disability”. This replaces previous protection in disability discrimination law that was not fully effective following a House of Lords’ judgment (Malcolm v Lewisham— see background). The provision provides protection from discrimination that arises where a person is treated unfavourably because of something arising in consequence of their disability. For example, it provides protection for a visually impaired person who is discriminated against because they use a guide dog, not because they have a visual impairment.

**Indirect disability discrimination**
• The EA introduces the principle of indirect discrimination for disability. Previously this protection applied to other protected characteristics, but not to disability. Indirect discrimination can occur where a policy or provision that is applied generally puts or would put people with a protected characteristic at a particular disadvantage compared with people who do not have the characteristic, and the policy, etc. cannot be objectively justified as a proportionate means of achieving a legitimate aim.

**Reasonable adjustments for disabled people**

• The EA establishes one ‘trigger’ point at which the duty to make reasonable adjustments for disabled people applies. It now applies where a disabled person is put at a substantial disadvantage compared to non-disabled people. This trigger previously applied only to the employment field. There was a separate trigger for areas beyond employment.

**Definition of discrimination**

• The EA harmonises the definition of discrimination used in areas beyond employment, such as access to services, public functions, premises and associations. Previously the DDA used a range of definitions according to different circumstances.

**Pre-employment enquiries about health or disability**

• The EA limits when somebody recruiting for work can make health or disability related enquiries before the point at which the candidate is either offered a job, or is included in a pool of successful candidates who will be offered a job when a vacancy arises. This provision meets concerns about pre-employment enquiries about disability being used to obtain information which was used to discriminate against the disabled candidate.

**Objective justification**

• The EA harmonises the way by which some discriminatory treatment can be justified. It applies the principle of “objective justification”, which is where the treatment can be justified as being “a proportionate means of achieving a legitimate aim”. The DDA applied different forms of justification according to different circumstances.
Written Evidence submitted by the Scottish Human Rights Commission (IL 81)

1. Introduction

1.01 The Commission welcomes the present Inquiry into Independent Living by the Joint Committee on Human Rights (JCHR) and the opportunity to submit evidence thereto. As one of the independent mechanisms in the UK under the Disability Convention, the Commission has a role to promote, protect and monitor the implementation of the Disability Convention in Scotland. In furtherance of this role the Commission, and the Equality and Human Rights Commission in Scotland (the Commissions) have commissioned a legal opinion, undertaken a literature review and held a number of participation events with a total of over 300 disabled people. These three sources form the evidence basis for the present submission. As the Commissions are currently in the process of synthesising information gathered to start the process of developing a parallel report to the UN Committee on the Rights of Persons with Disabilities, the present briefing represents preliminary reflections. In addition the Commission would like to acknowledge the valuable input of the Independent Living in Scotland (ILiS) project and the EHRC in the finalisation of this submission.

2. The right to independent living

Should the right to independent living continue to form the basis for Government policy on disability in the UK?

2.01 In each of the participation events which the Commissions have held in Scotland, disabled people and their representative organisations have identified independent living as an “overarching priority”. In doing so participants have referenced the broad understanding of independent living promoted by ILiS and highlighted that the realisation of Article 19 is interdependent with the realisation of several other rights guaranteed in the Disability Convention. For this reason the Commission is not limited in its submission to a strict interpretation of Article 19, but makes reference in its response to several of the


293 For more information on the Commission’s activity as an independent mechanism under the Convention see http://www.scottishhumanrights.com/ourwork/crpd/CRPDbackground

294 Supra n 1.

295 See ILiS response to UK Joint Committee for Human Rights: Inquiry into the implementation of the Right of Disabled People to Independent Living, April 2011, paras 1.4–1.5.
articles of the Disability Convention which are crucial to the full realisation of the right to independent living.\textsuperscript{296}

2.02 In June 2008, the Scottish Minister for Communities and Sport said, "Independent living is a key priority for this Government. We accept and support the social model of disability and are ambitious and aspirational in our outlook - we want to make choice and control a reality for all disabled people, not just a fortunate few."\textsuperscript{297} On 8 December 2009, the Scottish Government, the Convention of Scottish Local Authorities (COSLA) and the Independent Living in Scotland (ILiS) Steering Group signed a Shared Vision for Independent Living in Scotland.\textsuperscript{298} In 2010 NHSScotland became the fourth signatory. That Vision clarified that Independent Living is about choice, control, freedom and dignity, that it covers every aspect of an individual’s life—at work, at home and in the community, and established a model of “co-production” with each signatory an equal partner in an Independent Living Core Reference Group (CRG). The CRG operates across government and is co-chaired by the Scottish Government Director for Strategy and Performance and the Convener of the ILiS Steering Group.

2.03 Central in supporting the realisation of that Vision, and of raising awareness among disabled people of the right to independent living and of the human rights of disabled people more generally has been the ILiS project, and the Independent Living Core Reference Group more broadly. Both have consistently framed their awareness raising, advocacy and policy interventions in terms of the broader Disability Convention. A clear example of this was the Independent Living in Scotland Festival in February 2011, to which the Commission was invited to contribute multi-media resources, facilitate a workshop and give a key-note presentation.\textsuperscript{299} The Commission understands that the funding for ILiS, secured until 2012, has yet to be extended, and hopes that a solution will be found to enable the continuation beyond that date of the important work which the project has undertaken. The Independent Living Movement, and the ILiS project, and the Core Reference Group in particular, as well as the approach increasingly taken by the Scottish Government,\textsuperscript{300} recognise that independent living requires the respect, protection and fulfilment of all rights guaranteed in the Disability Convention. As such the Commission believes that the Disability Convention, should remain the primary focus to realise the rights of disabled

\textsuperscript{296} ILiS’ definition of independent living demonstrates clearly the indivisibility and interdependence of all human rights and encompasses elements which are relevant to, among others article 4 (general obligations), article 8 (awareness raising), article 9 (accessibility), article 12 (legal capacity), article 13 (access to justice), article 18 (liberty of movement), article 19 (independent living), article 20 (personal mobility), article 24 (education), article 25 (health), article 27 (work and employment), article 28 (adequate standard of living and social protection), article 29 (participation in political and public life), article 30 (participation in cultural life, recreation and sport).


\textsuperscript{298} http://www.scotland.gov.uk/Publications/2010/03/29164308/1

\textsuperscript{299} http://www.scottishhumanrights.com/ourwork/crpd/crdparticipation

\textsuperscript{300} Supra n 6, the Scottish Government is increasingly framing action to implement its Disability Equality Scheme through the lens of the Disability Convention.
people in Scotland with the Vision and structures for independent living playing a key role in realising those rights.

Do existing policy statements, including the Independent Living Strategy, represent a coherent policy towards implementing the obligations in Article 19 of the UN Disability Convention? Could the current policy be improved? If so, how?

What steps, if any, should the coalition Government, the Scottish Government and other public agencies taken better to meet the obligations in Article 19 and to secure the right to independent living for all disabled people in the UK?

If you consider changes to policies, practices or legislation in the UK are necessary, please explain.

There is no overarching strategy on independent living in Scotland, although there have been repeated calls for one. In considering the appropriateness and effectiveness of current legislation and policy to the realisation of the right to independent living, the Commission wishes to outline the following preliminary reflections based on its work to date to promote, protect and monitor the implementation of the Disability Convention in Scotland:

Legal Protection of the Rights of Disabled People

The Disability Convention, as the JCHR is aware, has not been incorporated into domestic law. While it may be seen by the courts to be “relevant rules of international law”, and therefore applicable as a lens through which to interpret European Convention rights included in the Human Rights Act 1998 and potentially also the obligations under the Equality Act 2010, the failure as yet to incorporate the Disability Convention does limit the opportunities to enforce the rights therein, including the right to independent living. It is however the experience of the Commission that there is significant scope for the Convention rights in the Human Rights Act, such as Articles 3, 8 and 14 to be more clearly communicated and applied more consistently to advance independent living. As the

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302 As Baroness Hale of Richmond observed in ZH (Tanzania) v Secretary of State for the Home Department [2011] UKSC 4, at paras 21–23 ECHR obligations should be interpreted in harmony with the general principles of international law and, per Article 31(3) of the Vienna Convention on the Law of Treaties 1969, “any relevant rules of international law applicable between the parties”, in particular the rules concerning the international protection of human rights (citing Neulinger & Shuruk v Switzerland, application 41615/07, Grand Chamber decision, 6 July 2010).

303 The European Court of Human Rights has referred to the Convention in, among others, cases involving reasonable accommodation (Glor v Switzerland, (application no. 13444/04) judgment of 30 April 2009); guardianship, legal capacity and voting rights (Aliqos Kiss v Hungary, (application no. 38832/06), decision of 20 May 2010).

304 A 2007 study for the Disability Rights Commission in Scotland stated that “Disabled people also still have few legislative rights to services, and it can be difficult to enforce existing entitlements.” Independent Living in Scotland, a policy scoping study, prepared for the Disability Rights Commission by Reid Howie Associates, 2007, p ii.
European Court of Human Rights has repeatedly stated “the very essence of the Convention is respect for human dignity and human freedom”. ³⁰⁵ As it has further clarified of the element of “private life” alone, for example, these extend to, “aspects of an individual’s physical and social identity including the right to personal autonomy, personal development and to establish and develop relationships with other human beings and the outside world”. ³⁰⁶ Or even more broadly “to conduct one’s life in a manner of one’s choosing”. ³⁰⁷ The European Court of Human Rights has for example recognised that “Article 8 is relevant to complaints about public funding to facilitate the mobility and quality of life of disabled applicants” and more broadly, that “the effective enjoyment of many of the Convention rights by disabled persons may require the adoption of various positive measures by the competent State authorities”. ³⁰⁸ In its work to date the Commission has sought to address the unfulfilled potential of the Human Rights Act to older people in particular, including older disabled people. As an example of what is possible, the Commission is currently engaged in an ambitious programme of training and capacity building for the social care sector, Care about Rights? As part of this programme the Commission has developed multi-media resources to clearly communicate the relevance of the Human Rights Act and the Disability Convention to people who use services their families and carers; care providers and care workers; and others involved in the police and practice issues of older people’s care and support. ³⁰⁹

**Legal Capacity**

2.06 The right to legal capacity (article 12 of the Disability Convention) is indispensable to the right to independent living. In Scotland the Adults with Incapacity (Scotland) Act 2000 (AWIA), takes a human rights based approach and reflects the requirement of the Disability Convention that capacity laws secure a functional, rather than a status based approach to capacity. ³¹⁰ Nevertheless, at least one study, from 2005, suggested that there may be low levels of awareness of the AWIA among health workers. ³¹¹ Article 12 also clearly requires periodic reviews in which the individual has a right to be heard, an area where some commentators have questioned law and practice in Scotland. ³¹² The Mental Health (Care and

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³⁰⁵ See *Pretty v UK* (application no. 2346/02) Grand Chamber judgment of 29 April 2002, para 65; *Christine Goodwin v. the United Kingdom*, (application no. 28957/95), Grand Chamber judgment of 11 July 2002, paras. 71 and 90.

³⁰⁶ *Evans v UK*, (application no. 6339/05), Grand Chamber judgment of 10 April 2007 at para 57; citing *Pretty v UK* (application no. 2346/02) judgment of 29 April 2002.

³⁰⁷ *Pretty v UK*, ibid, para 62.

³⁰⁸ *Mölka v Poland*, (application no. 56550/00), admissibility decision of 11 April 2006.


³¹⁰ The European Court of Human Rights has also reflected the requirement for a functional approach to capacity, referring to the Disability Convention in the cases of *Shtukaturov v Russia* (application no. 44009/05), judgment of 27 March 2008; *Alajos Kiss v Hungary*, (application no. 38832/06), decision of 20 May 2010.


Treatment) (Scotland) Act 2003 also introduces a number of steps to advance legal capacity, including advance statements, and a right to access independent advocacy. A key review of the legislation however pointed to low take up of such measures and recommended greater publicity be given to them. Likewise concerns have been raised regarding the electoral registration of older people, including those with dementia, living in care homes. In response the Commission recently launched a campaign, together with the Electoral Commission, and the Care Commission (now Social Care and Social Work Improvement Scotland). The commissions issued a leaflet stating, “It is important that you do not make an assumption about an individual’s capacity to vote or apply a “one size fits all” approach to all residents. Each individual must be assessed on a case by case basis at the time of their decision making and in relation to voting. The fact that an individual has dementia, for example, does not necessarily mean that they will lack capacity to vote on 5 May 2011.”

Access to Justice

2.07 A Justice Disability Steering Group (JDSG) was established in Scotland in 2007. The JDSG included the Scottish Government, the Association of Chief Police Officers in Scotland, the Crown Office and Procurator Fiscal Service, the Scottish Court Services, the Law Society of Scotland, the Scottish Legal Aid Board and the Scottish Prison Service. In 2009 a series of consultation events with disabled people were carried out for the JDSG by a range of civil society organisations including Capability Scotland. The results suggested a wide range of concerns remain among disabled people, including physical accessibility of court facilities and lawyers’ premises, availability of relevant information in accessible formats, and communication barriers. The report points consistently to an inability of disabled people to access justice due to, among other factors, difficulties in accessing appropriate legal representation, and problems accessing legal aid.

2.08 During the recent joint participation events, disabled people told the Commissions that people with learning disabilities are concerned about using and accessing the court system, fearing in particular that they would not be provided with the opportunity to speak for themselves. The Mental Welfare Commission for Scotland in its Justice Denied report expressed concern with the manner in which prosecution authorities may

313 Sections 275–276.
314 Section 259.
318 Supra n 1.
determine that people with learning disabilities who are victims of crime may not be competent or reliable witnesses. As the Mental Welfare Commission notes, the result can be failed prosecutions (frustrating the positive duties to investigate and prosecute sexual offences) and the subjection of the victim to restrictive protection regimes (significantly limiting her ability to live independently). The Mental Welfare Commission made several recommendations on ways in which the Scottish Government, NHS Boards, social work departments, police and professional regulatory bodies can improve protective and judicial responses to people with learning disabilities.

2.09 As the Committee will already be aware from its own Inquiry into the human rights of adults with learning disabilities, the Prison Reform Trust No-one Knows project found that learning disabled offenders experience problems understanding why they are in prison and how to adjust to the prison regime. In response to this report the Scottish Prison service did commit to sustained involvement with the work of the project.  

Accessibility

2.10 During the Commissions’ participation events disabled people told us that accessible transport is a key issue, particularly for those living in rural areas. They reported feeling “trapped” by limited public transport options and the high cost of transport when it is available. This negatively affected their ability to access services, and to participate in society. Participants also reported concerns that service level agreements between local authorities and private transport companies (including bus, ferry and taxi services) are rarely enforced to ensure accessible transport is provided, and it is difficult for disabled people to raise concerns with local authorities. One participant also raised concerns with some train companies in England, which require that she, or a companion, carry her mobility scooter onto the train as hand luggage.

2.11 A 2006 study by the Scottish Executive found that disabled people remained 50 per cent less likely to make any kind of journey than non-disabled people. The Scottish Government has since made bus accessibility a criterion for applications by providers for the Bus Route Development Grant Scheme, as have some local authorities in their contracting practice. The Government has however noted problems in tracking progress.

2.12 In the joint participation events disabled people told the Commissions that there is a need for improved steps to ensure equal access to community services, and for Access Panels to take a more consistent approach across different parts of the country. The closure of public toilets was also raised as a concern, and in particular, the failure to ensure that “comfort schemes” are accessible. These are schemes to provide public toilets through


321 Supra n 1.

322 MacLeod et al, Improved Public Transport for Disabled People, Scottish Executive, 2006.

partnership with private service providers such as hotels and pubs in areas where public toilets have been closed. In addition, participants outlined their concerns in relation to access to information, communication and the physical environment.  

“Portability” of Care

2.13 In March 2010 the Scottish Government estimated that 66,222 disabled people access home care and support in Scotland. At present the Ordinary Residence rule determines which local authority area pays for an individual’s community care package. COSLA itself has also recognised that “the level at which people begin to pay charges [for non-residential social care services] varies significantly across local authorities.” As a result COSLA has developed some guidance which attempts to develop a framework within which local authorities make decisions on charging for non-residential social care services.

2.14 Disabled people have expressed concern to both of the Commissions in Scotland and to the ILiS project about problems in the portability of care which include variations in eligibility criteria between local authorities, requirements for different assessments in different areas meaning a lack of assurance on similar level of provision and variation in charging for community care meaning that it may be financially unviable for disabled people to move. It has been suggested that this results in barriers to disabled people accessing work and higher education in other local authorities, as well as generally exercising their right to freedom of movement and choice of residence within the country. The Independent Living Movement in Scotland has called for a human rights based approach to portability of care that identifies and then removes this barrier to their right to independent living, and that this should be progressed together with disabled people.

Self Directed support

2.15 In December 2010 the Scottish Government published a draft Bill on self-directed support. The Bill is premised on principles of increased choice, control, independence and dignity. The Commission broadly welcomed the Bill, welcoming the introduction of self directed support as a positive step towards increasing independent living but reiterated that the intentions of the Bill do not overshadow the obligations of the state to respect, protect and fulfil human rights—including through adequate support and safeguards to ensure care and support is provided at a level which does not fall below minimum thresholds. The Commission recommended that the Bill include a duty on local authorities to have regard to the right to independent living, with appropriate assistance and support to make informed

324 Supra n 1.


328 Ibid.

choices. The Commission also recommended that clauses in the Bill which provided for assistance in decision making to those who may “benefit” from it due to “mental disorder” or “difficulties in communicating due to physical disability” should be clearly linked to legal protections for legal capacity in decision making. Further, concern was expressed at the proposed blanket exclusions from eligibility for self directed support and direct payments of categories of persons such as those subject to compulsion orders, emergency or short term detention certificates, supervision and treatment orders.  

People with Learning Disabilities and intellectual disorders

2.16 In 2000 the Scottish Executive reviewed services available for people with learning disabilities and autistic spectrum disorders. The Same as You? Included 29 recommendations relating to many aspects of independent living, including the right of people with learning disabilities to a voice, to support, and to live the life of their choosing. Recently the first phase of a 10 year on-going evaluation was launched. That report noted a range of improvements since 2000, including an increase in living in the community, with more than 1000 people with learning disabilities having moved from hospitals to social housing, and local area coordinators supporting community living in over 80 per cent of local authorities. However the evidence also points to areas where more progress is needed. For example the evidence gathered indicates that there is not currently enough short break provision for people with learning disabilities and their carers. In a 2008 report, the Mental Welfare Commission for Scotland considered that “there is a large group of people who could move out of hospital if appropriate support was available. There is a clear need for health boards and local authorities to agree local strategies to develop the services necessary to enable people to move on from hospital.” In addition it has been estimated that around 869 people with learning disabilities, many of whom are under 55, were resident in care homes for older people in 2009.

2.17 Scotland’s National Dementia Strategy, adopted in 2010 includes explicit commitments to apply human rights based approach principles of participation, accountability, non-discrimination, empowerment and legality (the so-called PANEL
approach which the Commission has promoted). This built on work of the Cross Party Group on Alzheimer’s at the Scottish Parliament, supported by the Commission and the organisation Alzheimer Scotland, to produce a Charter of Rights for People with Dementia and their Carers.

Summary

2.18 A range of positive steps have been taken in Scotland in respect of a range of elements of the right to independent living. Nevertheless evidence in many areas suggest progress remains necessary, and gaps remain. The Commission will seek to identify these as part of its role as an independent mechanism under the Disability Convention, and in its broader work to map the state of human rights in Scotland. The Commission will use this evidence basis to promote an inclusive process to develop Scotland’s National Action Plan on Human Rights, with the participation of the population, including disabled people, as well as the Government, Parliament and all of those who have the responsibility to realise human rights. The Commission believes all of those with responsibility for the realisation of human rights of disabled people in Scotland should support the development of a National Human Rights Action Plan to address gaps in structural steps, processes and outcomes required to realise those rights.

2.19 The Core Reference Group is an important vehicle to implement a cross-government approach to independent living, in co-production with the Independent Living Movement and other key partners such as local authorities. While a number of the strategic and policy steps taken by the Government have been impairment or context specific, the Equality Unit, as focal point for the Disability Convention in Scotland, has coordinated efforts across Government in the preparation of Scotland’s input to state reporting under the Disability Convention. It is to be hoped that this role of focal point will continue to coordinate efforts to implement the Disability Convention and ensure a coherent approach to realising the right to independent living, together with the rest of the Disability Convention.

3. Impact of funding on the right to independent living

The Committee would particularly welcome evidence on these recent developments:

- The decision, announced in the CSR, to remove the mobility component of Disability Living Allowance for all people living in residential care
- Changes to the Independent Living Fund
- "the Big Society"
- Restrictions on local authority funding, social care budgets and benefits reassessments


336 [www.dementiarights.org](http://www.dementiarights.org)

337 this is the Commission’s major research programme at present. See [http://www.scottishhumanrights.com/ourwork/mapping](http://www.scottishhumanrights.com/ourwork/mapping)
• Increased focus on localisation and its potential impact on care provision, and specifically, on portability of care and mobility for disabled people

• What impact does funding have on the ability of the UK to secure the right to independent living protected by Article 19 of the UN Disability Rights Convention?

• How will recent policy and budgetary decisions impact on the ability of the UK to meet its obligation under Article 19 to protect the right of all persons to independent living?

3.01 There is significant concern among disabled people regarding the current and future impact of the cuts introduced by the UK Government, and their impact on budgets at the Scottish and local levels. Participants at the Commissions’ involvement events have consistently expressed concerns at the impact of reductions in public spending on the rights of disabled people, both through reduced funding for disabled people’s organisations and through cuts to service provision. Participants at the Commissions’ first participation event in January 2010 felt that the positive work to achieve independent living is most at risk in the next five to ten years as a result of budget cuts. One participant spoke of an experience where a local authority had cut services for disabled people, including in-home or community care services through the night, including support for toileting and changing people who are incontinent.

3.02 According to research conducted for the EHRC in Scotland, figures which were provided by seven local authorities in Scotland showed a four per cent decrease in funding to disability groups already between 2008/2009 and 2009/2010, with most local authorities at that time predicting further decreases in funding from 2010/2011 onwards.

3.03 Participants in the Commissions’ participation events have reported a lack of information and participation for disabled people in decisions on the prioritisation of increasingly scarce resources, as well as failures to take into account the impact of decisions on the rights of disabled people, including their right to independent living. It was felt that decisions to cut services are at times being made with such haste that alternatives to stopping services outright are simply not being considered. An example was given of “lunch clubs” which provide an important opportunity for disabled people in remote areas to socialise which are being cut without considering whether they could be facilitated by voluntary groups, if the council were able simply to provide access to the facilities.

3.04 The Commission is currently pursuing the development of a human rights impact assessment process, based on a review of practice across the UK and elsewhere in the world. The intention is to pursue the development of integrated impact assessment

338 Supra n 1.


340 Supra n 1.

methodology, in partnership with EHRC and local authorities, to promote a human rights based approach to the process, and assessing the outcomes of, decision making. The Human Rights Act, the Disability Convention and other international standards can be used more effectively and consistently as a framework for decision making, helping to ensure a participatory decision making process, better human rights outcomes, and decreasing the need for and likely success of judicial challenge to those decisions. The Commission believes that the development and implementation of integrated equality and human rights impact assessment processes will provide a means to ensure that the rights of disabled people, as well as others, are taken into account in decisions on the prioritisation of resources as well as other decisions.

3.05 With respect to the “Big Society”, the emphasis on local decision making and on the role of volunteering in the delivery of services the Commission notes that States may pursue a variety of means to implement their human rights obligations, but retain obligations to respect, protect and fulfil those rights. In general, human rights law does not require the State to be the provider of services for the realisation of human rights however the State retains its obligations under the human rights framework regardless of the contracting out of services. The State must ensure that appropriate measures of monitoring and accountability are in place in order that individual’s rights are protected; and it retains the duty to provide services where individuals would not otherwise have access to sufficient services to safeguard their human rights. It is evidently the case, as ILiS notes in its submission that many disabled people will require support in order to participate in the “Big Society”. Without sufficient empowerment of people to enable exercise their rights, and sufficient accountability, including monitoring as well as inclusive models such as co-production, the “Big Society” may risk reinforcing, rather than removing, inequalities in the realisation of rights as those who face the most significant barriers to realising their rights will likely also face the most significant barriers to contributing to the “Big Society”.

3.06 Increasingly the development of the human rights framework recognises that non-state actors, such as private sector bodies, also have human rights responsibilities to respect human rights and that the State has a duty to foster such a culture of respect.

3.07 Section 6 of the Human Rights Act states “It is unlawful for a public authority to act in a way which is incompatible with a Convention right”. This applies to public authorities or

342 Lord Bingham in R (Begum) v Head Teacher and Governors of Denbigh High School [2006] UKHL at 31, “If [...] it appears that [...] a body has conscientiously paid attention to all human rights considerations, no doubt a challenger’s task will be the harder.”

343 One element of the State duty to fulfil is of course the duty to fulfil-facilitate the realisation of rights – through the creation of an enabling environment in which people can realise their own rights. On the respect, protect and fulfil typology of obligations in general see UN Committee on Economic, Social and Cultural Rights General Comments (No. 12 and onwards), available online at http://www2.ohchr.org/english/bodies/cescr/comments.htm.

344 ILiS submission, supra n 4 at paras 4.5—4.6.

to “any person certain of whose functions are functions of a public nature”. As JCHR is aware, the courts have tended to interpret the test of “functions of a public nature” narrowly.\textsuperscript{346} Nevertheless, the protection of human rights can be promoted in service provision through commissioning and procurement processes as they are undertaken by public authorities. This has been explored in Scotland in relation to social care procurement and commissioning where recent guidance makes extensive reference to human rights.\textsuperscript{347} In addition there are some specific rules in EU procurement Directives which allow Member States to reserve the right to participate in schemes to award public contracts to “sheltered workshops or provide for such contracts to be performed in the context of sheltered employment programmes”.\textsuperscript{348}

3.08 Concerns with the commissioning and procurement of social care related both to a lack of consultation and participation with the users of services, and in some cases with a driving downward, rather than upward, of standards of service provision. In response the Scottish Government and COSLA published Guidance on Social Care Procurement to address these issues.\textsuperscript{349} The Commission is pleased that, in line with its contribution to the process of developing guidance, human rights are referenced throughout. The Guidance has opened the door to human rights being incorporated into the service specifications, the selection and award criteria and contractual clauses. In this way it is a progressive piece of guidance highlighting both the relevance and the way in which human rights can be integrated and become part of the fabric of the commissioning, procurement and delivery of services. The Commission has maintained an interest in integrating human rights protections in procurement guidance, recently drafting a consultation response on behalf of the European Group of National Human Rights Institutions to the European Commission Green Paper on the modernisation of EU public procurement policy.\textsuperscript{350} The Commission believes that Government and public authorities should take effective steps to ensure the protection of human rights in the procurement of public services.

4. Participation and Consultation

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346 YL (by her litigation friend the Official Solicitor) (FC) (Appellant) v. Birmingham City Council and others (Respondents) [2007] UKHL 27.

347 Procurement of care and support services, Joint Improvement Team, COSLA, Scottish Government, 2010.


349 Guidance on Social Care Procurement in Scotland—http://www.jitscotland.org.uk/action-areas/commissioning/procurement/

\end{flushright}
What steps should the Government take to meet its obligations under the Disability Rights Convention to involve disabled people in policy development and decision-making, including in budget decisions such as the Comprehensive Spending Review?

Are the current arrangements for involvement of disabled people in policy development and decision-making working?

4.01 As indicated above, the Commission believes that the development of integrated equality and human rights impact assessment processes, as a mechanism for to ensure human rights are effectively taken into account in the prioritisation of resources, as well as in the development of law and policy, is one mechanism which should be pursued by Governments and other public authorities.

4.02 As the JCHR is aware, Article 4 of the Disability Convention requires the State to consult closely with and actively involve disabled people and their representative organisations in the development of laws and policies that implement the Disability Convention and when they are making decisions that involve issues that relate to disabled people. The mechanisms which have been developed to integrate independent living, and the participation of the Independent Living Movement across the Scottish Government represent an important element in fulfilment of that requirement.

4.03 A number of those who have taken part in the Commissions’ participation events, and others with whom the Commission has consulted, have expressed the view that participation at local levels varies across local authorities. Similarly, a national research project in 2007 concluded that, “Many local authorities had structures in place for consulting with and involving disabled people. This included forums and partnerships within the community planning partnership, or dedicated equality forums and networks. However, we received little evidence that disabled people had been involved in or consulted on funding decisions. In some (generally city) authorities, there was evidence of consultation, but this was not the norm.” In addition, participants in a series of webcast consultations which focussed on rural areas told the Commissions that they felt excluded from decision-making and advisory groups and organisations. In continuing its role as an independent mechanism under the Disability Convention the Commission will consider whether the mechanisms for consultation and participation of disabled people at local levels and those for the participation of people in rural areas are adequate.

5. Monitoring the effective implementation of the Convention

What steps should Government take to ensure that disabled people’s views are taken into account when drafting their reports to the UN under the UNCRPD?

As part of the national monitoring mechanism, what steps should the EHRC, NIHRC and SHRC take to ensure that the Convention is implemented effectively?

351 Supra, n1.

352 Supra n 47, p 50.

353 Supra n 1.
5.01 In its role as an independent mechanism under the Disability Convention, the Commission has worked jointly with the EHRC in Scotland and has commissioned a legal opinion on the compatibility of the law of Scotland with the Convention, it has undertaken a non-legal literature review, and has co-hosted a number of participation events to gather the views of disabled people in Scotland. Joint reports of these events have been provided to and publicised with disabled people and DPOs to raise awareness of the Convention and the role civil society should play in monitoring its implementation. It has also held a capacity building event for national civil society organisations on the UN treaty body system, the preparation of parallel reports and the use of individual communications mechanisms such as that in the Optional Protocol to the Disability Convention, and participated in a wide range of events to raise awareness of the Convention and its Optional Protocol. In the coming months the Commission, in partnership with the EHRC in Scotland, will draft its parallel report to the UN Committee on the Rights of Persons with Disabilities, and continue its efforts to promote, protection and monitor the implementation of the Convention. The Commission will use the information it gathers through monitoring the implementation of the Disability Convention as one element of the evidence basis to pursue the development of Scotland’s National Action Plan on Human Rights.

9 May 2011
Written Evidence submitted by the Norfolk Coalition for Disabled People (IL 82)

Background

The Norfolk Coalition of Disabled People (NCODP) is a human-rights group controlled by disabled people and their organisations. NCODP organises and takes part in campaigns and run services that promote social equality and dignity for all disabled people.

Introduction

The new Coalition Government has taken a number of decisions that will negatively affect the rights, life chances and independence of disabled people. It is for this reason that the NCODP trustees took the following decision at their meeting last July:

1. That NCODP will pursue a public campaign against cuts in service provision, and cuts in benefits, which reduce the life chances of disabled people.

2. That NCODP agrees with the approach of pursuing opportunities presented by personalisation in social and health care by negotiation with relevant providers and partners.

NCODP supports the general policy direction and drivers which create opportunities for independence, citizenship and equality for disabled people. The personalisation of services is a key policy driver which DPOs support. Disabled people do not want to be treated as ‘special cases’ or be stuck in welfare dependency or excluded from the mainstream. However, the world is not an equal or accessible place for disabled people. The policies being pursued by the coalition government will not promote or achieve disability equality. Rather it will have the opposite effect. These changes have been imposed without proper consultation or equality impact assessments that measure the cumulative effects.

Therefore the measures are discriminatory. They will disproportionately hit disabled people and if implemented will result in isolation, institutionalisation and unprecedented levels of poverty for many disabled people and their families.

In order to evidence this view NCODP commissioned Dr. Chris Edwards, Consultant and Senior Fellow of the School of International Development at the University of East Anglia to carry out an independent study of the cumulative effects of the cuts in benefits and tax changes at a national level and the cuts to local authority budgets. The following is a summary of his findings:

A report on the impact of national budget cuts, tax changes and local reductions in services on disabled people and their families in Norfolk

Background to the report

- The Coalition government has set in motion a series of severe budget cuts and tax changes.

- This has or will lead to reductions in and the tightening eligibility for a range of key benefits.
Written Evidence submitted by the Norfolk Coalition for Disabled People (IL 82)

- These include, among others, housing benefits, disability living allowance and incapacity benefit.
- In addition Norfolk County Council is proposing budget cuts of £136 million over the next three years.
- About £45 million of these cuts will directly and exclusively effect disabled people

Why the report?
- Although many people, including a government minister, have said that disabled people and their families will be hit hardest by these measures, no one has yet provided a detailed, quantified analysis of the likely impact.
- Furthermore, no one has investigated the consequences of the combination of national and local cuts.

Some key facts
- Nationally between 17% and 21% of the country’s 60 million people are disabled.
- Nationally about 7.5 million households contain at least one disabled person
- Nationally the average income of a household with a disabled person is about a fifth lower than that of other households.
- In Norfolk there are 186,00 disabled people (22% of the population)
- In Norfolk there are 100,000 households with at least one disabled person

Main findings for disabled people and their families in Norfolk
- Of Norfolk’s 186,000 disabled people, 45,000 of working age on disability benefits will lose £526 per year, 8% of income.
- Of Norfolk County Council’s proposed £136 million cuts in services over the next 3 years, £45 million will directly and exclusively effect disabled people, representing a loss of services valued at £476 per disabled person per year, or about 7% of their income.
- Disabled people will also be effected by other services cuts making the full impact greater.
- The increase in VAT is expected to add £158 to the essential bills of the average household and will mean a loss of about 2% of income for the poorest 50% of disabled people.
- As a direct consequence of the above, the poorest 53% of disabled people in Norfolk, around 100,000 people and their families, will see their living standard decline by a third over the next four years.
The conclusion is that the impact of the changes introduced by the coalition government together with the cuts proposed by Norfolk County Council will be devastating, disproportionately effecting the most vulnerable and poorest group in society.

Full Report can be found at:


Disabled People in Norfolk and our Young Disabled People’s Forum made Videos to illustrate their concerns about the threat to independent living posed by the changes to benefits and cuts to local authority services:

NCODP response to Norfolk County Council cuts consultation

[http://www.youtube.com/watch?v=Zpp4bQSLG2w]
NCODP Youth Forum response to Norfolk County Council cuts consultation

[http://www.youtube.com/watch?v=qSoWhNz8CSE]

Lived Experience and Case Studies

Disabled people’s experiences after the cuts

- hello every one i am tracy from norfolk. I am sick with worry, our housing benefits is going to be cut, my hubby is loseing his DLA, were going to be so poor i dont think we can carry on like this, our drop in centre was shut down to save money the new gov says,these people in the gov these mps who steel money for there 2nd homes. and i cant aford to put food down on the table for my kids, cos this new gov thinks i am a lay about , i dont know where the next meal is coming from. ive never heard in all my years on cut backs like this.i heard on the internet that these cutbacks to peoples DLA was against the law and human rights, our money should be going up with the cost of food and pertol. not going down, were humans but they dont listen in there comfuly houses its all wrong we need to stand up to tese bullys thank you from tracy and this is a wonderfull web site bringing us closer. 

Tracy

- hi i am so very worried to day ive told i am going to lose my mobittly , my mobittly car is my life line, but no they said its being stopped. ive got to give the car back after 18 years. where can i afford to buy one, worse still i pay my £600 a month rent out of my dla/income surport ive been told thats stoping too. il be homeless i said, the lady on the phone said tough,your have too work she said, where are these jobs? its all mixed up.i am fed up with this penny pinching government. its crazy, how we all going to live?

thanks from princess

- hi all i am john from gt,yarmouth in norfolk. i cant belive the new gov are picking on us the disabled, i got a phone call from the job centre, john your fit to work theres nothing wrong with you. i have been in and
out of hospitals all my life over 30 years with depression, the last job i had i only lasted 1 day, the boss said to me john your a danger in work place your drugged up on your meds. the ones you get from your dr thats all. I falled to get up for work this boss had to let me go, now if theres nothing wrong with me like the job centre says why has my dr been giving me all these tablets for all this time. To tell you the truth i am very worryed i cant sleep though worry, my rent is £600 a mouth my DLA nearly pays it all i am going to be homeless at my age, yes were all proply have jobs, but i dont think were keep them very long we need to stand up to these bullys the gov there picking on the wrong people the poor get poorer, the rich get richer its all wrong. and great britan is still sending millons of pounds a year in aid to other countys.

thank you John

- I am extremely concerned about the proposed cuts to Norfolk County Council services as I fear that they will have a severe impact on the independence of many disabled and elderly people in Norfolk. This concern is backed up by Norfolk's own an initial high-level impact assessment. Here it was found that the impact "...may limit disabled and older people's independence and resources, and affect their quality of life and mobility across the county. It may restrict their access to the built environment, public transport and leisure activities. It may increase their vulnerability to loneliness and social isolation, and place greater responsibilities of care on their families, friends and colleagues."

Sarah Hopkins

- Not only are my wife and myself facing a cut of about £700 a year due to the freezing of teachers' pensions, and £1000 next year [depending on inflation rates], but we are having to support a man whom my wife visits as a voluntary social worker: he has had all benefits stopped for some time since well before Christmas, he has been long term physically and mentally disabled, he is entirely supported by his GP who is driven to rage every year by the State's hectoring of this man, he has now completely used up his meagre savings, a special emergency loan and all other sources of money except what his three young children [18-24] and we can afford to give him. He would literally starve to death without this money.

He received a telephone call this Monday to tell him that there would be a delay in the meeting of a tribunal to discuss his case "due to staff shortages".

This, I take it, is the Big Society ...

Christopher Knapp

- How does the Government expect their new ideas to work?
  1. When there are not enough vacancies to cover the number of people out of work
  2. Those out of work will find their benefits stopped after 12 months unless they do voluntary work
  3. The Coalition Government clearly haven't thought through their policies and how they will reflect on them
4. This is like going back to slavery
5. How will it affect people like myself?
6. My doctor gives me a sick note every 12 months stating that I am unable to work, but they are talking about sending disabled people back to work. Also when someone is under 24 they are not experienced enough, but 10 years later they are classed as too old for the job.
7. Most vacancies in the paper state that the job requires a car/clean driving licence. I cannot drive for medical reasons so how am I expected to get a job?

Mrs M. Woods

The importance of DLA

- Dear Mr Bacon,

I have recently been in correspondence with you by e-mail about my home care provision. Despite phone calls to your office and contact from Norman Lamb, MP and Councillor Shelagh Gurney on my behalf I have received no response.

I am now extremely concerned about the consultation on Disability Living Allowance. I am in danger of losing my independence and ability to remain living in the family home due to the removal of my home care service by local government cuts; now, in addition, I face the prospect of losing my mobility when I am forced into residential care.

My condition is complex and medical constraints mean that I can only be away from home for periods of three to four hours at a time. By meticulous planning of my care provision and the use of my own transport I manage to chisel out periods of time when I interact with the world outside in a meaningful way. Removal of a flexible care service and of my own transport will destroy my life.

I say, once again, that I urgently need your understanding, representation and support.

On the DLA consultation - the Disability Living Allowance was clearly a successful benefit that enjoyed good uptake. I am shocked that the Government could consider fanning the flames of misunderstanding and prejudice against disabled people by withdrawing assistance. The Government claims to protect the most vulnerable in Society. It appears that they do not protect the second most vulnerable. Need is need and should be met with assistance in a civilized society.

The Big Consultation in Norfolk clearly showed a desire among Norfolk people to preserve a meaningful social service for its vulnerable citizens.

Disability is complex and varied and can be greatly increased by the combination of medical and social factors. The combined effect is unpredictable and difficult to quantify by objective tests alone. It is, therefore, essential to listen to the disabled person's subjective comments and place them at the centre of the decision making process. Medical staff are used to tackling individual health issues and are notoriously bad at taking a holistic and long-term approach to problems. Care must be taken not to medicalise our social service.
Caroline Fairless-Price

- I listened to your minister on Radio4 this week and wish to comment on the proposals.

1. You cannot rely on homes/local authorities to meet the mobility needs which can be covered by DLA.
2. No home/LA could possibly maintain now whatever high level of mobility previously provided.
3. If the mobility element is cut no one will assume responsibility for the damage caused to people's health (physical and mental) through reduced mobility.
4. In a care facility it probably takes a long time for slowly reducing health to translate to death which is the best way to cut DLA, of course.

Sincerely, A. Savory

- I am extremely concerned at the cuts and changes to Disability Living Allowance, Housing Benefit, Independent Living Fund and Access to Work.
I believe these cuts are targeting the most vulnerable people in society and are disproportionate and discriminatory because it will, inevitably, take away independence and dignity that disabled people are entitled too.
I have been diagnosed with Primary Progressive Multiple Sclerosis. Up to ten years ago I was an active person, working full-time and doing 'normal' things. Since then my disability has had an enormous impact on me and my family. I am confined to a wheelchair, but can walk a little; I depend on continual assistance from family and carers. I can drive and have a Motability car that I use my DLA Mobility to pay for.
I have been given early retirement from my job at Norfolk County Council; for the last two years or more I had fought to keep my job, but to no avail. So I have been cast adrift into the unsafe world of benefits that are going to be cut. This has left me feeling frightened and vulnerable; not knowing what the future holds. I feel that I am about to fall into a black-hole.
I know that there are dozens of people in the same boat, but this makes it all the more important to save these services, and make Norfolk an inclusive county.
I know the Central and Local Governments need to make savings, but the extremely drastic and severe route they are taking is wrong.

Anne Rampton

I am extremely concerned that the government, in bringing forward this policy, has failed adequately to understand the importance of this benefit to the health and mental welfare of many many Learning Disabled and severely Physically Disabled people, OF ALL AGES (not merely the elderly infirm) who live in residential care. They live in care homes not from choice, but because they are too disabled to be cared for in any other way. But “living” implies a need and an ability to access the Normal Life outside a care home.

Mr Duncan-Smith, when interviewed on the World at One when the Consultation was announced suggested that recipients of this benefit, as a general rule, did not necessarily need it to assist them to travel about, since, if they went out at all, (which many did not very often, he seemed to think) this was usually with transport arranged by the Home in which they lived, and largely catered for in the fee package paid by the relevant Social
Written Evidence submitted by the Norfolk Coalition for Disabled People (IL 82)

Services sponsor This a completely flawed assumption, and has produced an unjust proposal to withdraw this benefit in its entirety. Please reconsider it.

I am particularly concerned with its withdrawal from people on Higher Rate Mobility Allowance, and wish to suggest that, in the exceptional life circumstances they face, that they be excluded from these plans, and allowed to keep their mobility allowance in its present form, whatever name it is in future to be given!

What was the evidential basis for the Secretary of State’s assertions about the lack of continuing need for this particular benefit by severely Disabled people? All people with disabilities, needing help to get about, can’t be lumped into one category. Its withdrawal from those who are on Higher Rate DLA is exceedingly troubling, because these are the people who, by definition have no ability to get about unaided, and many of whom are forced by their grave disabilities to live in residential care for their whole lifetimes. They don’t CHOOSE this way of life. Their circumstances impose it and their choices about HOW to live their lives are severely curtailed.

What information will be before the Secretary of State about precisely how this money is used by these recipients, (who have little or no capacity at all to walk or get about unaided,) to help deal with even the simplest normal daily needs like shopping, travelling to visit family, going to church, or the pub, or going away on even the most modest of holidays?

What evidence will be before him about how the withdrawal of this benefit might affect their health, and the lives and health of those who care for them and have to assist their travel to access the normal things in life?

Does the Secretary of State understand that without the mobility component to facilitate the purchase and servicing of specially adapted vehicles, hoists, slings, and wheelchairs many people on Higher Rate DLA mobility component in Residential care COULD NOT PHYSICALLY GO OUT AT ALL, for any purpose, (whether in receipt, or not, of Social Services funding for “essential travel” — to the doctor or dentist or hospital.)

I have 31 years of first hand experience of caring for such a person. My 31 year old son Sam, (who suffers from a genetic disorder causing gross physical and mental impairment,) has no speech, no ability to weight bear on his feet, is wheelchair and hoist bound, is doubly incontinent, low intellectual capacity and has to be fed on liquidised food. However, he has a long life expectancy, lively “locked in” intelligence, is extremely sociable and attractive, and is (very happily) accommodated in a private residential care home, with (certainly not all) costs met by his sponsoring Local Authority Social Services. He is entitled to Income Support and DLA Mobility Component at—obviously—the Higher Rate.

Have people such as Sam REALLY been assessed by the DWP as unlikely to need to go out much?!, and then only for essential trips to the doctor etc?

Sam’s formal annual Care Plan states that he has a CRITICAL NEED (as might any young male of 31) to be able to access pursuits outside the care home, such as swimming, going to football, to the pub, to church, to the cinema, having a holiday, in order to ensure that he is stimulated, motivated and does not become depressed (a familial ailment). His nearest family live an hour away by car and regular trips to see them and maintain family contact are
said in his Care Plan to be essential to his welfare. He needs, of course to make regular trips for medical and dental attention and is enabled, by saving up part his Mobility benefit, to travel on holiday once a year. Not a lot to ask.

If he is no longer able to afford to access such things, or to take occasional holidays, his health will undoubtedly be affected and he will end up becoming a charge elsewhere on the system in the NHS. Those who care for him will inevitably be affected by these curtailments as well, with consequent added stress to their lives and health. HE IS VERY HARD WORK to move about. This needs financial help!

If he takes a holiday, he has to have a specially adapted motorised wheelchair and pay, not only for himself, but also for the cost of his 24 hour Carer to go as well. —Obviously.

Without saving his mobility allowance he could never do this, nor go to the Cinema or to football or to stay with a friend sometimes, or to go on a day trip to see the lights at Christmas. Things you take completely for granted however poor you may be. Not exactly a ritzy life style, but one wholly enabled by the DLA Mobility benefit.

True it is, that the costs of transport for a number of these essential activities such as doctors visits, home visits and some leisure trips out, are factored into his Fee Package and provided by the Home. But many are not, and need to be paid for by Sam himself, from his Mobility benefit. But Life is not JUST about trips to the hospital!

If this benefit is removed from him, he will no longer be able to access many of the most basic ‘travel’ needs to make the most of his otherwise very limited life, nor take holidays. There is NO QUESTION that someone as disabled as Sam, who is young and healthy save for his disabilities, must be to be able to get out and about on a daily basis. It is not a choice, or a luxury, or an option to be done without when “times are hard.” It is a very basic human necessity for someone of his vulnerability and helplessness. Many, many people in care homes have lives similar to Sam’s, and very, very similar needs. Please—you must understand a whole lot more about such people’s lives before announcing apparently arbitrary policies seriously disadvantaging them. They are disadvantaged enough already.

I fear that some very basic misunderstanding, informed only by anecdote and not by research must have occurred here, about what Mobility Allowance MEANS to its recipients especially to those who are totally disabled and on Higher Rate. I cannot believe that this Compassionate Conservative-Liberal Coalition really intends the sort of consequences implicit in withdrawing this benefit from people in THE most vulnerable section of the community it is possible to imagine.

Please reconsider this unjust policy soon. The most charitable thing that can be said of it is that it was decided on too hastily, in the context of many many other difficult decisions needing to be made at double quick speed to reduce our national deficit.

But people like Sam are absolutely the least to blame for “the state we are in” and the least able to argue their case! They deserve another thought or two.

Dont move the Mobility Component chairs around the Titanic’s deck so they just fetch up on the desks of the Social Workers, and on the Budgets of the Local Authorities. This is a
completely futile and arbitrary gesture. PLEASE MAKE AN EXCEPTION FOR HIGHER RATE MOBILITY RECIPIENTS AT THE VERY LEAST.

Mrs Jane Ridley

Sam’s Mother, he having no capacity to understand, or participate in this consultation through any means than through me.

**Transport for independent living**

- **Dear Sir/Madam,**
  I'm writing this letter as I received a letter from the Bus Pass Department on 26th March 2011 telling me all the changes of rules to our bus passes and I was in real shock and found it very disappointing.

As a Deaf/Blind person living in Norfolk I use my bus pass as it's reliable to get me about and be apart of the community on my pass I've come which it's very helpful to me as I'm not a very confident traveler and have someone with me from time to time.

In the letter it's also telling me change of times and companion is being taken away from me and in my area my buses are on the hour and I need to get to the city for 10am so I can do my volunteer work at the NNAB Magpie rd and if I can’t use it until after 9.30am it is going to make it so difficult for me even when it comes to Hospital/Appointments too.

One of the rules is saying that we’ve to pay if we travel before 9.30am and as Deaf/Blind or disabled people we can't all tell the difference between the coins in Money these days and not only that trying to find the right coins is going to hold the queue on the bus up and bus drivers are going to always be running late as they'll have to take their time for disabled people like myself to pay.

I know from experience that people in this county have different colours passes which should mean to drivers what section they can travel on which has not been done before the changes come in to action, blue and yellow were traveling at same time it should be disabled all day and the over 60's travel later in the day and as we can use our passes all over the UK we should be able to travel when needed to as a disabled person to keep our independence.

Many people in this world who are NOT Deaf/Blind don't realize what it's like for those who ARE Deaf/Blind, those who are Deaf/Blind have lost 2 major senses;
1, Sight Loss
2, Hearing Loss
This makes them one of the most vulnerable groups of people in the world.

Some Deaf/Blind and disabled people I know in the Norfolk county work full time as their health allows them to and they don't deserve to have to go through extra stress then what they have been through in the last past few months with the council's proposals and Cuts.
Above all I request that all this is to be reconsidered for Deaf/Blind and disabled people as it’s disgusting that the council’s are picking ONCE AGAIN on the most VULNERABLE PEOPLE telling them when they can travel and have to pay and their companion section is being taken away from them in my eyes it’s telling me that the councils in their wisdom know the best for us all but that is indeed NOT true as they don't have the life we've to live with at being Deaf/Blind or even disabled in this world.

I find all this very shameful that the council didn't inform me and other disabled people of the changes until one week before the changes took effect, If the Council was able to write to us and tell us, Why couldn't they write to us to consult us???

As today 1st April 2011 I found it very frustrating with some attitudes of some drivers when handling with my travel needs.

I would like a written response with answers to what can be done about the the bus passes which I do hope that the council can reverse their decisions for the disabled.

kind regards

Mrs K Monaghan

Mental Health

- My name is Pam.

I too would like to have my say about the closure of mental-health drop-in centres in Norwich.

"Mind" closed its centre a year ago. I know that former members have suffered badly because of this.

We were told to go to Rethink.

Now Rethink is down to 2 days opening per week! If you are under the care of the NHS Mental Health Trust (and they're kicking as many people off their books as they can, utterly regardless of clinical need) you can come in on the other days for groups. This involved being referred to "Quest" (an entirely useless and superfluous referral agency) and then back to Bridges. This means people who have attended groups there for years can be shut out for good: even those who can carry on attending have to wait until "the paperwork is complete."

Same building, same staff, same groups - but now you have to go through an extra tier of beaurocracy to get a very radically reduced service.

You may not enter the building until twenty minutes before your group starts!!!!!!

You are commanded to exit the premises within twenty minutes of the group ending!!!!!!
Welcome to Rethink.

I know of one group run by a member of Bridges who, if he was not running it, would not be allowed to attend because he doesn't have a social worker.

Better have your crises on Wednesdays or Sundays, people, or else you can whistle for help and support.

The changes to the Rethink centre are moronic, destructive and entirely pointless. But some people are getting a bang out of it—the extra staff they have employed to do all the paperwork! Because that's what mental health charities and NHS funding is for, isn't it? Nice jobs for nice people and to hell with those horrid mentally ill people.

No one, not one single member of the Rethink centre is as insane as the people who decided on these changes.

Get ready to pay and pay and pay for their self-centred short-sighted ignorant behaviour. The taxpayer will pay for this useless and expensive "service". And those who have mental health problems will pay—in terms of suffering.

Pam

- My name is pamella and I want to put my penniworth in about the cuts.

In the last 18 months the Mind Resource Centre closed and this has affected many people. There was a petition that went to London but they didn't listen! The people who used that centre have gone on to do different things in the Community; however I went on to the Rethnk drop in centre which has now had cuts in it's funding and is changing it's structure. This means that I won't be able to do the things I enjoy in a flexible way but that I have to attend formal groups which waste my time and with people who do not engage with me, or who misjudge me.

This Rethink centre helps vulnerable people feel better about themselves and it gives help when members are unwell. They also have a phoneline for people to ring and get advice. There has been a decision made that they don't need Bank workers who were nearly 50% of there staffing levels. I have also been told I have to go through other channels to get my needs re-assessed. This means I am going to lose out again to mixing with people who know how stressful Mental Health issues are. The general public have no idea because some would just lock them up!!!!!!

I have witnessed first hand how paramedics struggled to deal with someone with a mental health issue. If trained staff at a drop in centre are being cut this has a negative effect on the community! Enough is enough! We have lost one centre we don't need to lose another and be pushed into the community who don't understand Mental Health needs and politicians who think people with Bipolar and Schizophrenia are fit for full time work.

This same centre invited prospective MPs to a Question Time session before the
general election. I attended this along with many others; they did not answer my question on Discrimination! They(she) skirted around it talking about employers who have a duty to be fair. Their fairness is shown to me in not being shortlisted for interview in the last 14 years!

Under the New Equality Act it is illegal to discriminate against people with Mental Health issues!!!!!!

Pamella D Main MS

- Mental health sufferers are ***** bricks about the proposed changes to DLA, JSA and housing benefit. We live an extremely insecure life anyway, not knowing when the authorities will turn up to section us with police support and handcuffs for six months. This can happen several times a year to some people, for no apparent reason. Also we have countless appointments to attend with stupid pompous shrinks and have to make our homes open to nosy community psychiatric nurses often two or three times a week.

Now the governmet has given us the present of not knowing whether we will be able to pay the rent, possibly losing £500 of benefit a month and repeated assessments to see if we are fit to work. I have already seen mental health sufferers aimlessly walking the streets, desperate for company because of the cuts in drop in centres and the ethos of 'going back to work'. How the hell can we go back to work when we face such insecurity. Who would employ us? Don't you think we are grieving enough at our loss of employability? Now we face the indignity of losing our basic standard of living and even our homes. DLA enabled me to make some kind of recovery and hold my head up. Now the governmet are going hammer and tongs to undo any of the good that has been done.

We are not 'all in this together'. Some of us are more vulnerable than others. Go after companies like Boots who moved their headquarters to Switzerland to avoid tax; not the weakest in society who suffer unbelievable hardship and prejudice already.

Ann

Sensory Support

- The Sensory Support Team plays an invaluable role in providing the essential emotional and practical support to enable blind and partially sighted people at a time of crisis to regain confidence and the ability to return to becoming active members of the community once more. To consider depriving blind and partially sighted of this service would most certainly condemn a large number of Norfolk residents to a life of restriction, depression and isolation which could otherwise be avoided by retaining the service.

From an economic aspect, to withdraw the service would be a false economy as blind and partially sighted people would become more dependent on critical services. Furthermore, the proposed closure of the service is completely at odds
with the Government's Prevention Agenda. Norfolk has long since been known to provide a first class sensory service to Blind and partially sighted people and this service should be maintained. After decimating its sensory service provision, Cambridgeshire realised the error of the decision, turning full circle to rebuild a service, and whilst in Suffolk a Sensory Service remains still Norfolk's service provision is highly regarded and the envy of many. It would be a tragedy for current and future blind and partially sighted people should they no longer be able to rely upon a service which can restore their sense of well-being and self esteem by learning the vital practical skills of getting out and about safely, caring for themselves in their own homes with meal preparation and home management, and with the opportunity to learn other methods of accessing information—all of the everyday tasks that sighted people take for granted.

Pat Crawford

Personalisation and personal budgets

Encountering more and more difficulties with mobility and even coarse manual handling, last weekend, I contacted Norfolk Social Services Department to see, first hand, what their approach to personalisation is and if there is a slight chance I would be eligible for a personal budget. I was led, on the Norfolk County Council website to a web form for inquiries (in general as well as Adult Social Care self-referrals) so I completed it. On the form I explained I had looked at the eligibility criteria and felt I was on the verge between 'moderate' and 'substantial' and that, as a retired social worker and a current service user activist, I had some knowledge of the processes. I asked for a social work assessment, having in mind the possibility of some signposting should I be ineligible.

This morning I received a phone call.

"Good morning, this is Norfolk Care Connect."

No explanation of who or what Norfolk Care Connect is—and I certainly didn't 'connect' it with my self-referral to Adult Social Care. The person on the phone then began to ask information about my personal details. Foolishly, I suppose were all a bit unguarded at times like this, I stated to give some—a check on my address, then my date of birth [...] I stopped.

"Can you tell me who you are please."

"Norfolk Care Connect"

"And what do you do."

"We're the front end of Norfolk Social Care."

"Ah [...]" I connected. "So you're a separate organisation commissioned by Norfolk Country Council to work with Adult Social Care."

"No, we are a part of Norfolk Social Care—we've just been renamed. I need to take your details"

By this time she'd taken on a tight lipped tone of voice. Barging on and pushy with it, she asked me what my problems are. Foolishly again, I had given her a detailed list before pulling
Written Evidence submitted by the Norfolk Coalition for Disabled People (IL 82)

myself up and realising what I was doing, I said I objected to giving detailed private information over the phone to an unqualified stranger. I told her I had completed a personal health plan as part of my work NCODP and NHS Norfolk which would have all the detailed information they needed and I could either print it out and post it to them or, if she could give me an e mail address, let Adult Social Care have a copy over the internet.

She spelt it out for me: “norfolkcareconnect@norfolk.gov.uk”

“Surely that's an address for general inquiries, isn't it— I don't want to send my private information there.”

“That's alright, there's only me on duty here this morning and I'll get it.”

Brushing that aside, she tightened her pushy belt and barged on:

“How do your problems affect you?”

Again, I started to go into details about my mobility difficulties then realised once again that this process over the phone is both dysfunctional and unacceptable. I said so. She said she (an unqualified telephonist) has to have the information to make an initial assessment as to whether or not I might meet the eligibility criteria entitling me to have an assessment by a qualified social worker. I said goodbye and put the phone down.

There are social barriers for disabled people and social barriers!!!!!

Posted By Blogger to PPlog on 5/17/2011 11:43:00 AM

The government decisions being referred to are:

The Budget

Many of the policy announcements in the budget will increase the inequality experienced by disabled people. Regressive taxation affects poorer people disproportionately so measures such as the rise in VAT will increase the poverty experienced by many disabled people. Under equality laws, we believe the government should have assessed whether its budget proposals would increase or reduce inequality for disabled people. So does Teresa May, who warned the Chancellor of the Exchequer that cuts imposed in the June Emergency Budget may be in breach of the Equality Act 2010. This is because they would have a disproportionate effect on women, pensioners, ethnic minorities and disabled people.

Furthermore, she said, "If there are no processes in place to show that equality issues have been taken into account in relation to particular decisions there is a real risk of successful legal challenges."


Other proposed measures in the budget, including changes to housing benefit, will affect the income of disabled people which will put their ability to pay higher rents and the tenancies at risk.

The newly announced proposals to cut the Supporting People budget by up to 40% will have a significant impact on the most vulnerable disabled people.
Independent Living Fund

The Independent Living Fund (ILF)—which provides financial support to disabled people with high support needs to support the cost of their personal assistance, and is separate from social care funding—is essentially closed for business. Disabled people in work have been prioritised in the short term.

The potential problems these decisions give rise to are significant. As the ILF’s own equality impact assessment of the decisions notes:

Giving priority to people who are in paid employment of at least 16 hours a week has the potential to adversely affect people in terms of race, gender and age. Disabled people who are from ethnic minority communities, women and young are less likely to be in paid employment. People with learning disabilities are also less likely to be in paid employment.

By giving priority to people who are in paid employment ILF will no longer normally accept applications from people in receipt of Income Support and similar benefits. Therefore the change is also likely to adversely affect people who are at a socio-economic disadvantage.

The costs of meeting the social care needs of disabled people who previously could have applied for the ILF will instead fall to local authorities or will not be met.

It’s not efficiencies. It’s not bloated public spending or welfare dependency. It’s disabled people not being supported to meet the most basic elements of day-to-day life—getting out of bed, making a cup of tea, or going to the supermarket—being active and equal citizens.

Disability Living Allowance

The Poverty, Worklessness and Welfare Dependency report is good on noting the inbuilt disadvantage that many groups of people face. For example, it notes that disabled people:

- Are more likely to live in poverty (29% of families live in poverty when at least one family member is disabled, compared with
- 20% of families with no disabled people) (p8)
- Are more likely to live in persistent poverty compared to non-disabled people (11% compared to 5%) (p18)
- Are less likely to be in work (over half of disabled people do not work) (p9)
- Are less likely to have formal qualifications (24% of disabled people have no formal qualification) (p12)

But the report then doesn’t note the factors which lead to these institutional barriers. The effect is to create a suspicion that disabled people are not trying hard enough to gain a qualification or get a job.

It is worth noting that at no point does the report define what DLA is for—DLA helps with the additional costs of disability, primarily related to personal care and mobility. It is for people under 65, though you can continue to be in receipt of DLA over the age of 65 if you have it before you are 65. Attendance Allowance is the equivalent for people over 65. Both are non-means tested.
The Coalition Government are drawing exactly the wrong conclusion about DLA from its own report. For example,

For example, the report notes that "over one in five DLA claimants are in the top two income quintiles (when DLA is included as income and no account is taken of extra costs of disability)". DLA is designed precisely to take account of the extra costs of disability/impairment. Secondly, and taking the figures at face value, they tell us that over 20% of DLA claimants are in the top 40% of income distribution. That is, 80% of DLA claimants are in the bottom 60% of income, meaning that DLA is targeted exactly at those disabled people who live in relative poverty.

Incapacity Benefit and Employment

The Coalition Government is cutting spending on incapacity benefit (IB)/Employment and Support Allowance (ESA). These benefits are for sick and disabled people between 18 and 65 who because of ill health or impairments are unable to work. Currently 2.6 million people receive IB or ESA.

The previous government's similar effort to cut back incapacity benefit, led to disabled and seriously ill people being deemed fit for work. This included people with advanced Parkinson's Disease, Multiple Sclerosis, with severe mental illness and those awaiting open heart surgery.

The results of this are that disabled people will have their living standards cut, be forced into low paid and often inappropriate ‘Mac’ jobs or be excluded from claiming benefits because they are not ‘actively seeking work’.

Along with cuts to IB, massive cuts are being proposed to spending on social services. The latter provides most of the funding for the personal budgets that allow disabled and older people to live independently in the community. Less funds and a stricter criteria for receiving social care will mean increased hardship for a great many disabled people. The threshold for eligibility for personal budgets and access to services has been raised so high that many disabled people, especially people with mental health issues, have been excluded from receiving support when they need it.

Access to Work Fund

The cutting of the Access to Work Fund by 20% exposes the lie that the Coalition Government wants to assist disabled people to work. The changes transfer greater responsibility and costs for equipment and adaptations on to the employer. This makes it even less likely that employers will recruit disabled people as they will cost more than non-disabled employees. At a time of cuts to public services and recession for the private sector these changes are regressive and discriminatory.

Co-Production and Consultation
The democratic deficit and the con of consultation. None of the policy changes involved disabled People’s Organisations (DPOs) prior to announcement. There has been no meaningful upstream engagement. Any ‘consultation’ that has happened has been downstream and tokenistic. As a DPO involved in co-production we know the difference.

**Conclusion**

NCODP knows that some benefits are well-focused and support precisely those people who face institutional barriers to equality and independence. The ILF, DLA and Access to Work are key to disabled people moving out of ‘welfare dependency’, accessing training and gaining employment. They are not welfare benefits, they are to compensate for the extra cost of being disabled—being discriminated against by the barriers to accessing the world equally with fellow citizens.

**Actions**

- A full and independent National Equality Impact Assessment (EIA) is carried out on the cumulative effects on disabled people of the cuts and reforms nationally and locally.

- The Government suspends and takes no further action on the proposed changes in implementing cuts and welfare reform until the EIA is finished and they have actively consulted with Disabled Peoples Organisation’s (DPOs).

- These consultations need to be broad and in depth based on the principles and practices of co-production. They also need to be in accordance with the UNCRPD.

- Implement the UN Convention on the Rights of Persons with Disabilities (CRPD) particularly through ensuring legislation is in place that fully supports disabled people’s rights and by working in partnership with disabled people’s organisations (DPOs).

- Raise the status of disability within government—move the Office for Disability Initiatives (ODI) out of Department of Work and Pensions (DWP) into the Office of the Prime Minister or Dept. of Justice at the very least—and give disability to a Secretary of State.

- Ensure that public bodies implement the disability equality duty.
What steps, if any, should the coalition Government, the Scottish Government or other public agencies take better to meet the obligations in Article 19 and to secure the right to independent living for all disabled people in the UK?

The right to independent living, under all definitions is about people’s right to live life as they choose. The difference between isolation and independence is clearly enshrined in article 19 when it discusses the right to community life. Independent living is about far more than people having a home of their own. KeyRing believes that the spirit of Article 19 is about people having an ordinary life in their community, where everyone, including those with support needs, share their gifts and talents for mutual benefit. People’s community life may include accessing community services but their presence should not be restricted to this.

Whilst community access features in Fair Access to Care Resource Allocation guidelines, it does not receive the high profile which it deserves.

We believe that there is some work around messages to be undertaken:

In order to secure the right to independent living:

- a full and proper understanding of the scope of the term needs to be ensured.
- The importance and benefits of independent living (as fully defined) of this needs to be demonstrated and disseminated

If you consider changes to policies, practices or legislation in the UK are necessary, please explain.

In times of economic constraint support to access the community is often the first resource to be cut. For example, KeyRing is an organisation which supports people to live in the community, offering each other mutual support and providing access to a voluntary ‘good neighbour’. Whilst there is recognition of the long-term cost-savings and improved quality of life offered by the formation of strong links, Local Authorities are increasingly considering replacing our service for a few hours floating support to cover basic tenancy related support.

This means that KeyRing’s community connections/mutual support work is lost and people become isolated.

We believe that in order to improve things, it is necessary for Local Authorities:

- to think in a more strategic and long-term way (even in times such as this, a modest investment to save resources makes good fiscal sense and does not compromise people’s quality of life).
- have a truly outcomes based approach when commissioning services.

The Committee would particularly welcome evidence on the Big Society” (re Impact of funding on the right to independent living)
The “Big Society” is highly congruent with Article 19 and has the potential to offer a great deal to disabled people but only if they are seen as equal partners and are supported to play a full part. This particularly includes people with autistic spectrum disorders and learning disabilities who may struggle in a social setting. Many of our service users are people with low incomes and few academic qualifications. There is a danger within “Big Society” that community facilities will be run by the most able in the community, resulting (unintentionally) in poor consultation processes and therefore a lack of involvement from those who would benefit most. The result could be alienation of some groups; in order to mitigate this, “Big Society” initiatives must be properly resourced, community leaders must work to engage both those traditionally believed to be hard to reach and organisations such as KeyRing who have good access to these groups. At the moment, this is not happening and opportunities are consequently being lost with a possible contravention in Article 19 ensuing.

**What impact does funding have on the ability of the UK to secure the right to independent living protected by Article 19 of the UN Disability Rights Convention?**

The things that are measured are the things that get done! At present Local Authorities are focusing on cost savings and therefore this right will only be protected if decision makers understand the long-term value of independent living in terms of outcomes for individuals and resulting cost savings for Local Authorities. For example, where Local Authorities have accepted the Care Service Efficiency Delivery (CSED) case study on KeyRing, they recognise the value of commissioning a service which supports people to become known and valued in the community with the resulting cost savings this brings. This is a win-win situation as outcomes for individuals are improved, rights are upheld and savings are made.

KeyRing is a national organisation working in over 50 Local Authorities. We find a huge discrepancy between Local Authority understanding of the value of community life and until these benefits are championed and cost savings articulated at a strategic level, the right to independent living will continue to be put at risk.

**What steps should the Government take to meet its obligations under the Disability Rights Convention to involve disabled people in policy development and decision-making, including in budget decisions such as the Comprehensive Spending Review?**

It is not sufficient to consult with representative organisations unless a wide variety of service user views are obtained. People with learning disabilities will need support and training to be fully involved in decision making and this requires additional time to be built into consultation processes. Some easy read materials assume that people will not have the capacity to make informed comment on more complex issues (for example the Transparency in Outcomes easy read booklet in our opinion did not adequately cover the ideas in the main document). This assumption is highly damaging to consultation processes as it means that input from people with learning disabilities is at risk of being tokenistic.

It should be noted that during times of financial constraint organisations will be less able to run consultation exercises as they have little capacity for anything other than meeting contractual agreements. It would therefore be helpful if calls for information were underpinned by good quality easy read resources (and ideally a visual presentation of some description).
Are the current arrangements for involvement of disabled people in policy development and decision-making working?

The national arrangements appeared to be working well. However, these arrangements will have been damaged by the disbandment of the central Valuing People Now team, which included a person with a learning disability on their staff.

Our experience of Partnership Boards across the country is that the voices of people with learning disabilities are not heard uniformly. For example, two workers in London, working with two different Local Authorities both report systems which represent good practice (accessible paper-work, good use of sub groups etc.). However, one worker feels that important decisions made within her Local Authority do not represent the views of people with learning disabilities and that despite 'ticking the right boxes' people's involvement is largely tokenistic. Another worker reports that, using similar structures, her Local Authority really engages people with learning disabilities and involves them in important strategic decisions. It should be pointed out that the Local Authority used as an example where good practice led to inclusive decision-making has just reduced the funding of the Speaking Up group which fed into the Partnership Board.

With the onset of personalisation it is possible that the rights of the individual service user may be less well met and therefore need safeguarding. The reason we are concerned about this is that some individuals will only have a small amount of money to spend with service providers and may not, on their own be viewed as “high value customers”. This may mean that despite the intention of Personalisation to give people increased power, they may, unless supported to have a collective voice, receive poorer services.
1. Summary

This witness statement briefly describes how a local authority financial reassessment in which a previous decision regarding the service users contributions to her care package was over turned. The consequences have been to limit the independence of the service user undermined the financial stability and employment prospects of the whole family

2. The submitter

I am a Disabled person as a result of a car accident (1981) when I was 15. After graduating from university I worked for the Derbyshire Centre for Integrated Living for 3 years. I then moved into the field of community development at regional and national level. Since 1996 I have been a self employed consultant, researcher and trainer. In my own time I established and support a peer support group for people who self-direct their support packages. I am married with two children (11 years and 8 years)

3. Factual Information

3.1 In 1984 I received a personal injury claim following a civil court case. (The drivers insurance company admitted liability but by solicitors felt their offer was insufficient to meet my needs—the case ended with no increase in the offer). My compensation was invested in a number of Gov bonds in order to provide me with a modest income whilst at university.

3.2 I have always worked in order to ensure a modest income for our family, supplemented by income from my invested compensation. I have been unable to claim any benefits other than DLA. I use the capital when required to buy a mobility scooter, suitably adapted car etc.

3.3 Both my husband and I have had to find work which has provided flexibility and the ability to work reduced hours to accommodate my needs. We have worked primarily in the voluntary sector which has little long term job security, lower earning potential and very limited pension contributions.

3.4 In 2003 I contacted Doncaster social services for the first time to ask for support following the birth of my second child as my husband was offered a new job opportunity. Following a care assessment I was awarded 20 hours of support through a Direct Payment. A Financial Assessment Officer assessed my contribution as 'nil' as my capital is a result of my personal injury compensation. I have employed PA’s since and this has provided essential support which has enabled me and my husband to work and for our children to have full, active lives without being burdened by the need to provide me with care and support.

3.5 In Nov. 2010 I underwent a re-assessment of my support needs as a result of the move to Personal Budgets. I was awarded a slight increase in my package. I was visited by a Financial Assessment officer 6.1.11 who within 5 minutes overturned the previous decision regarding my contribution. I was told I was to pay £177 per week towards my care package. This took effect within 3 days with no consideration for my obligations as an employer to my two PA's.
3.6 We do not have sufficient weekly income to cover £177 and as a family would be unable to secure employment with high enough earnings to meet these additional costs.

3.7 DMBC’s position is that they only disregard personal injury claims that are held in Trust (this was not an option open to me at the time of my claim) and I must therefore treat my compensation as capital to pay for my support. This is based on guidance within the Charging for Residential Care Guidelines (CRAGS) which is within the Fairer Charging Policy. DMBC’s Fairer Charging Policy has not been updated since 2003.

3.8 I have been unable to appeal against this decision as it was made within the Welfare and Benefits department which only has a complaints procedure.

3.9 My complaint was dealt with internally. The finding was that I have no case to be heard as the CRAGS policy still stands. I have now submitted my case to the Local Government Ombudsman.

3.10 The consequence of this decision are:

- Both my PA’s have been made redundant.
- I have had to limit the amount of work I can undertake.
- My husband was made redundant in March from a voluntary sector infrastructure organisation due to loss of funding. Although a skilled professional he cannot now actively seek work as he now needs to provide the support and care I need.
- My children have had to undertake additional tasks around the home and to help me. For example, carrying washing, shopping for groceries, assisting me with buttons, jewellery etc.
- Emotionally and financially this is placing our family under considerable strain.
- Once my capital is used as a family we will be dependent on welfare benefits and social housing.

4. Recommendations

4.1 Local Authority Fairer Charging Policies urgently need reviewing in the light of Personalisation. Ultimately charging is discretionary but decisions are being made which are undermining individual care plans and the ability of disabled and older people to live independently and with dignity.

4.2 Charging policies also contradict and undermine other government strategies and legislation such as the 2008 carers strategy which supports carers right to work and the rights of children as described in the Children’s act 1989.

4.3 Independent living is regarded as a lifestyle choice rather than a right. Most disabled people, like myself, cannot afford the support they need so are forced to compromise and ‘make do’ thus limiting their ability to be active citizens contributing to society. The long
term consequences are of greatly increased costs to health and social care as individuals income drop and health deteriorates.
Scope welcomes this opportunity to submit written evidence to the Joint Committee on Human Rights, regarding the right to independent living of disabled people. We feel that this is an important and timely inquiry, and commend the Committee for investigating such an important issue. Our submission covers issues that the Committee has indicated that it wishes to examine as part of the inquiry.

1. ABOUT SCOPE

1.1 Scope is a leading disability charity that supports and works with disabled people and their families at every stage of their life. We believe disabled people should have the same opportunities as everyone else and we run campaigns with disabled people to make this happen. Scope operates in England and Wales and provides localised, individual care and support, residential, information and advice, employment and education services for disabled people and their families. As a charity with expertise in complex support needs and cerebral palsy we never set limits on potential.

2. INTRODUCTION

2.1 We believe that Government policy should identify the need to promote independent living as a key aim, placing clear primacy on enabling disabled people to lead full and independent lives. The UN Convention on the Rights of Disabled People (CPRD) commits the Government to take steps to make the right to independent living a reality. Article 19 recognises "the equal right of all disabled persons to live in the community, with choices equal to others," and sets out clear benchmarks against which the progress towards ensuring independent living for disabled people in the UK should be measured.

3. EXECUTIVE SUMMARY

3.1 Scope is concerned about the potential for regression in promoting independent living for disabled people as a direct result of recent proposals for reform. The Government should ensure that the impact on independent living is understood and addressed throughout the various reform processes. To protect and promote disabled people’s right to independent living, we would recommend taking action on the following:

- Implementing the UN Convention and ensuring that legislation is in place that fully supports disabled people’s right to independent living
- Supporting the existing means for delivery of independent living (such as direct payments and personal budgets) with the provision of appropriate information, advice and advocacy where needed
- Ensuring that adequate support is available to disabled people to cover the extra costs of disability, which represents a key factor in sustaining independent living

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• Ring-fencing budgets (such as social care) provided to local authorities to ensure that funding is used to secure independent living, and transforming the social care system to address the challenges to independent living from the current post-code lottery and lack of portable support packages

• Securing statutory duties as minimum guarantees for disabled people, and ensuring that regulatory reform (such as through the disbanding of the Audit Commission) does not result in fragmentation and local variations of support available

4. SCOPE’S RESPONSE

Below we have provided responses to the main areas of inquiry posed by the Committee.

4.2 Should the right to independent living continue to form the basis for Government policy on disability in the UK?

4.2.1 The promotion of disabled people’s right to independent living should indeed be at the core of the Government’s policy. This provides a framework through which the Government can address the barriers that prevent disabled people from participating fully in society. Independent living, as a goal, is crucial for challenging barriers to inclusion. It aims to enable disabled people to live their lives in the way they choose, being in control of all aspects of their lives (their care, support, and so forth).

4.2.2 Despite a policy emphasis on promoting independent living for disabled people, there are still many barriers to be overcome before it can become a concrete reality for disabled people. While the existing policies pre-date the UN Convention on the Rights of Disabled People which the UK has ratified, the Government should seek to ensure compliance with the full scope of its obligations under the provisions of the Convention. Article 19 of the Convention (‘Living independently and being included in the community’) sets clear benchmarks for what action the Government should take to guarantee independent living for all disabled people.

4.3 Do existing policy statements, including the Independent Living Strategy, represent a coherent policy towards the implementation of the obligations in Article 19 of the UN Disability Rights Convention? Could current policy be improved? If so, how?

4.3.1 Current policy frameworks, such as the Independent Living Strategy, place great emphasis on extending choice and control as the mechanisms for achieving independent living. The Strategy, published in March 2008, was placed at the core of the Government’s commitment to facilitate independent living. The future of the Strategy remains unclear, as the Coalition Government confirmed that it was looking into the best way forward for this. While we would agree that the Strategy has provided an important milestone in making progress towards independent living, this is not to deny its limitations, particularly in that it did not address independent living as a human rights issue.

4.3.2 The policy framework should reflect the full sense of its meaning under the UN Convention. The concept of independent living, as envisaged under the UN Convention, is a broad one in its aims. We believe that the Government should work within the framework of the Convention to promote independent living, and that the obligations set out in the Convention should serve as the path towards achieving this goal. Moreover, we would stress
the need to support policy with the necessary legislative change. Another weakness of the strategy was the lack of legislative underpinning for independent living. Recognition of the need for legislative reform to establish a basic enforceable right is crucial for sustaining progress towards ensuring independent living for all disabled people.

4.4. What steps, if any, should the coalition Government, the Scottish Government or other public agencies take better to meet the obligations in Article 19 and to secure the right to independent living for all disabled people in the UK?

4.4.1 The failure to adequately provide support structures undermines the overall policy goal of promoting independent living. As addressed below, there are currently limits on disabled people’s opportunities to exercise independent living due to a consistent lack of support, including support to overcome the barriers to independent living that arise from the additional costs disabled people face. The Government does not yet have a clear enough understanding of what the barriers to independent living are, so we do not believe it will be able to assess who faces the most significant barriers. To ensure that the adequate support is in place to achieve independent living, there is a need for better understanding of what these barriers look like, how they can be determined through assessment, and how these translate into extra costs for disabled people.

4.4.2 There is a substantial body of evidence that suggests that the extra costs of disability to individuals are substantial and significant. Establishing how these costs affect independent living has emerged as a potential weakness of the new Personal Independence Payment (PIP), replacing DLA, particularly regarding its planned assessment. A poorly targeted new benefit risks further undermining independent living for disabled people by failing to accurately identify these additional costs and compensate for them accordingly. While some of the overall extra costs that a disabled person incurs are driven by the severity of impairment, research by Scope and Demos has demonstrated that it is certainly inappropriate to base proposals for the reform of the DLA into the Personal Independence Payment (PIP) using severity of impairment as a single proxy. Considering that there is no correlation between costs incurred and functional need arising from impairment, this could result in disabled people who have been determined as having a low functional impact of their impairment but high disability costs missing out on much-needed support. The proposed PIP, with its objective test of functional impact, may not prove accurate in targeting the extra financial support to help to remove the barriers to independent living that disabled people face. While the new PIP cannot, on its own, offset all barriers to independent living, the approach to supporting independent living needs to reflect and contribute towards the extra costs of disability. Establishing a thorough and accurate assessment regime for the new PIP is crucial for helping those who experience high costs barriers to independence (but not necessarily impairment-related barriers) overcome them.

4.4.3 Moreover, there are still inadequate levels of social care support that disabled people receive. It has been widely recognised that there remains much scope for improving disabled


people’s access to independent living by removing the barriers posed by the social care system.\textsuperscript{357} The current commitment to radically reform social care highlights both a recognition of the need to re-think the framework upon which it is based and of the need to ensure sufficient funding so that disabled people will be able to access the particular support they need to live more independently. New social care legislation (when proposed by the Law Commission) and Dilnot Review on long-term funding for social care should be underpinned by the principles and goals of independent living. Among the immediate challenges, many disabled people are increasingly facing a prospect of having their support needs unmet as a result of increasing charges, and tighter eligibility for support. Local authorities are increasingly raising the threshold for eligibility for services as their budgets come under pressure,\textsuperscript{358} which will leave more and more disabled people without access to essential support to achieve independent living. Against this background, we believe that there is incontestably a need for ring fenced funding and support arrangements, designed to enable independent living. If ring-fenced, the extra £2 billion funding that the Government has committed for social care would go some way towards addressing these pressures, by acting as a bridge towards a sustainable long-term solution to the reform and funding of adult social care. The decision not to ring-fence and protect this funding, at a time when local authorities resources are tight, means that it could be diverted to other budgets.

4.4.4 Finally, funding limits and narrowing eligibility criteria, rather than criteria of independent living, still largely determine what, if any, support disabled people receive. Thus, access to independent living often becomes restricted once a certain level of resources has been reached. We are concerned that in a climate of reduced budgets, the lack of an entitlement to independent living will allow other factors to dominate. The danger is that this may lead to a situation in which financial pressures and competing demands on budgets result in a lack of priority for independent living. Worryingly, the message that seems to be emerging is that independent living being seen as too high a financial cost to implement. The approach of many local authorities is too narrowly focused on finding a lower cost alternative of support,\textsuperscript{359} with little consideration of the implications that this is likely to have for a disabled individual’s ability to achieve independent living. Moreover, insufficient funding to support independent living is coupled with an overall lack of recognition of the considerable economic benefits of this. We believe that a greater focus should be placed on independent living as a preventative agenda, highlighting that investment in independent living would result in long-term cost savings due to less pressure on health and social care and economic benefits of increased participation in employment and education. The Government should seek to shift the focus of the debate from costs towards expenditure on independent living.


\textsuperscript{358} Community Care, One in seven councils raises eligibility bar for adult care (1 April 2011), http://www.communitycare.co.uk/Articles/2011/04/01/116596/one-in-seven-councils-raises-eligibility-bar-for-adult-care.htm.

\textsuperscript{359} Such a case is that of Elaine MacDonald (http://www.bailii.org/ew/cases/EWCA/Civ/2010/1109.html) whose council withdrew her night time care and decided to provide her instead with incontinence pads. This case has worrying implications in relation to the balance between independent living options and limited resources justifications.

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living options as an investment that promotes better value for money and improved outcomes for disabled people.

4.5. What impact do funding, policy and budgetary decisions have on the ability of the UK to meet its obligation under Article 19 to protect the right of all persons to independent living?

- the impact of (restricted) funding on the right to independent living (e.g. emergency budget; Comprehensive Spending Review; 2011 budget)
- the decision to remove the mobility component of Disability Living Allowance for all people living in residential care implication
- changes to the Independent Living Fund
- the “Big Society”
- restrictions on local authority funding, social care budgets and benefits reassessments
- increased focus on localisation and its potential impact on care provision, and specifically, on portability of care and mobility for disabled people

How will recent policy and budgetary decisions impact on the ability of the UK to meet its obligation under Article 19 to protect the right of all persons to independent living?

4.5.1 Since it took office, the Government has introduced a significant number of policy changes and proposals, which are likely to have an impact on its ability to achieve independent living for all disabled people, to which it committed itself when ratifying the UN Convention. The extensive changes and cuts to welfare benefits announced in the 2010 Emergency Budget and the Comprehensive Spending Review, exacerbated by the reductions in other forms of support such as social care, threaten to move the Government further away from the realising its goal of ensuring independent living for all disabled people. Despite the Government’s stated commitment to support disabled people to lead independent and active lives, these measures risk having the opposite effect for a significant number of disabled people.

4.5.2 Many aspects of the proposed reforms have clear effects on disabled people, and could knock back progress made in promoting independent living for disabled people. Scope and Demos research in the run up to the spending review modelled the impact of cuts to specific benefits and indicated that disabled people were going to be directly and disproportionately affected. Even more worrying, the Government chose to pursue these reforms without an analysis the cumulative impact on disabled people, which has meant it had no understanding of the knock-on consequences that these will have. These unintended but not unpredictable consequences will place many disabled people at a risk to experience

360 Demos (2010), Destination Unknown, http://www.demos.co.uk/publications/destinationunknown disability
361 Ibid.
increasing financial hardship and social isolation. Since April, we have already seen some significant changes coming into force, including the uprating of benefits by the lower inflation rate of the Consumer Price Index, the time limitation of ESA and the move to full national reassessment of Incapacity Benefit claimants, the housing benefit caps and significant reductions in local government spending. The consistent picture that emerged from a follow-up study to our initial research has been that disabled people are already seeing the initial negative effects of some of the new Government reforms. As the changes begin to take full effect, this would not only leave many disabled people worse-off, but also significantly restrict their ability to maintain their independence.

4.5.3 Reduced support will push disabled people into greater levels of dependency, with many of them being affected by a loss of support from a combination of different sources. Some of the policy changes that the Government is pursuing will result in the various forms of support that were once relied on by disabled people to help them lead an independent life being reduced or even withdrawn altogether. The plans were outlined in more detail in the Welfare Reform Bill. According to this, the measure to remove the mobility component of DLA from people living in residential care homes will be delayed until 2013 (previously 2012), whilst the Government has committed to conduct a review into funding for mobility support. Despite the delay, which we welcome, there remain great concerns about the assumption of an overlap with local authority funding. The Government has claimed that the mobility needs of disabled individuals are provided for by their local authority-funded support. Removing the mobility component, or diluting the support it provides to meet mobility needs within the new PIP, would leave disabled people in residential care without the support they need to be independent. Given the reservations as to the evidence that underpins this proposal, we encourage the Committee to recommend that the Government should remove it and amend the Bill accordingly.

4.5.4 Importantly, in terms of changes to the support system, the Welfare Reform Bill foresees replacing the Disability Living Allowance (DLA) with a Personal Independence Payment (PIP). The 20% reduction in caseload and expenditure will have a wide-ranging impact beyond the immediate impact of withdrawing the benefit itself, as DLA has an important passporting function to additional support and assistance. It is yet unclear who under the system will be entitled to these other kinds of support, nor which level of PIP would entitle individual disabled people to which passported benefits. A potential consequence may be that under the proposals for the new PIP, the introduction of only two rates for the daily living component, compared to the three rates for the care component of DLA, may result in disabled people who are currently receiving the Independent Living Fund (ILF) no longer meeting the necessary threshold and therefore losing this, while the fund has closed permanently for all new applicants.

362 Forthcoming report.
364 Ibid
Written Evidence submitted by Scope (IL 85)

4.5.5 The abolition of the ILF, which is to be phased out by 2015 with no current indication of a replacement, when taken in combination with the proposed changes to reform DLA and the reduced local authority funding for social care, poses one of the most significant challenges to independent living. The way that the ILF works is that a disabled person must receive the highest rate of the care component of DLA and will always be expected to contribute half of their DLA towards the cost of their ILF support and the other portion of the cost is expected to be met by local authorities. As the ILF is separate to social care, it provides extra funding to top-up the support provided by a local authority. These links between ILF and other support are crucial, as it is the combination of ILF, social care and DLA in a joint package which helps many disabled people receive enough support to maintain their independence.

4.5.6 The loss of funding from the ILF, DLA and the unmet social care needs from both tightened eligibility and increasing restrictions as to the level of needs that provision can meet, will lead to many disabled people losing out on support they rely on to continue living independently in the community. The ILF was an acknowledgement of the need for additional funding over and above what local authorities can provide for. Many authorities already relied on the fund to cover a shortfall in available budget for care, however, should the ILF cease to exist, disabled people would be wholly reliant on local authorities to fund their care. Given the current economic climate, local authorities simply cannot fill the gap in funding that would be left by its removal in order to meet the needs of disabled people with complex needs who are currently enabled by the ILF to have an independent life. The Government has argued that funding would be transferred to local authorities. However, there are inherent problems and dangers with this approach, particularly as it would risk being subsumed within other budgets. The independent review of the ILF highlighted the lack of certainty and ‘difficulties of ensuring that this would reach people needing social care support’365. This will result in a situation where disabled people will have less and less support overall, putting their independence at risk.

4.5.7 Concerns about inadequate levels of support for independent living are further compounded by the changes in social care provision. As it stands, there is no means of ensuring consistency and portability of care support under the current system, with ordinary residence rules severely limiting independent living options for disabled people. The absence of an ability to move one’s support package from one authority to another and ensure an equivalent level of support remains a significant barrier to independent living for disabled people. This situation is exacerbated by the significant reduction in budgets. Councils are still able to interpret the eligibility criteria according to their level of resources, leading to a rationing of services, rather than true independent living for disabled people. Evidence suggests that three quarters of councils now meet critical or substantial care needs only,366 with many disabled people expecting to lose their care provision as a direct result of increasing eligibility criteria for support. Furthermore, alongside this, the pressures on local authority budgets and the wider economic climate have brought to light a more fundamental


366 Community Care, Councils to deny social care support to all but most needy (15 September 2010), http://www.communitycare.co.uk/Articles/2010/09/15/115321/councils-to-deny-social-care-support-to-all-but-most-needy.htm.
tension within the independent living agenda. The implementation of direct payments serves as a good illustration. Direct payments provide a framework for social care that promotes independent living, yet the challenges posed by reduced budgets imply, in practice, that a concept with choice and flexibility at its core is increasingly being squeezed into a system of rationing resources. The impact of direct payments as a means of supporting independent living may be lessened through their positioning in a wider context of tightened eligibility for services.

4.5.8 Furthermore, there are potential challenges from an increased focus on localism. The Government is actively pursuing an agenda of localism, encouraging more decentralisation and handing of more power to the local level. In the social care context, there is a danger that the pursuit of localism may come at a cost of fragmented provision and lack of effective scrutiny. With the termination of the Audit Commission, we are concerned that there will not be stringent and robust enough mechanisms in place to ensure a transparent evaluation of how the additional £2 billion of un-ring-fenced funding will be spent; particularly to guarantee it is spent on social care. As such, the lack of independent financial monitoring (until new arrangements come in place), will mean a reduced accountability of councils by local citizens and will leave many disabled people who need social care provision ineligible for services.

4.5.9 If delivered in such a way that independent living is the overall objective for disabled people, support could be the lever to unlock the potential of many disabled people. There are opportunities for disabled people within the Big Society and localism agendas, such as building skills and capabilities that would better equip them for the transition into paid work. Key to making this work is the need for the Government to provide the support for disabled people to engage and take advantage of the new powers and opportunities presented by the Big Society and localism agendas, and thus play a greater role in their communities. Equally, it would be important to ensure that there is an approach that is truly inclusive of their communities, and seeks to overcome the barriers to participation that disabled people usually face. This would risk, otherwise, groups whose voices are heard less such as disabled people becoming even more excluded.

4.6 What steps should the Government take to meet its obligations under the Disability Rights Convention to involve disabled people in policy development and decision-making, including in budget decisions such as the Comprehensive Spending Review?

Are the current arrangements for involvement of disabled people in policy development and decision-making working?

4.6.1 The UN Convention is unique in the importance it places on the involvement of disabled people in the development of strategies and policies. It is important that the policy making process is based on an understanding of the reality of disabled people’s lives and that disabled people are involved in determining the impact of any proposed change in policy could have. A lack of involvement of disabled people in decision making can compound other inequalities and hinder the extent to which policies address their needs. There is considerable evidence to suggest that disabled people are under-representing in participating
in public life and are not empowered to have their voices heard. Despite the emphasis on the importance of disabled people’s involvement in policy developments, there remain concerns that the views of disabled people are often not sought on issues which affect them and that there are not always clear mechanisms for involvement.

4.6.2 There are even greater barriers to involvement in budget decisions and the extent to which disabled people can shape and influence priorities. In the case of the emergency budget and the spending review, the speed of the proposed changes and decisions on potential areas of reform made it difficult to ensure appropriate level of input from disabled people. An opportunity was lost, therefore, to engage with and consult properly with disabled people and organisations representing them in putting forward proposals for budget deficit reduction. Given that the spending review resulted in fundamental policy changes, there was a clear need to understand how different policy changes would interact to strengthen or undermine disabled people’s right to independent living. Such involvement would have helped to better inform some of the core assumptions made in the budget and spending review. In working out the detail of these policies and to avoid an adverse impact on disabled people, the Government needs to ensure that disabled people can feed in evidence into the process going forward.

4.6.3 It is important to also consider the interaction between the UN Convention and equality legislation at the domestic level. An equally important tool is the Disability Equality Duty, which was, in part, designed to enable participation in decision making by placing the onus on public bodies to involve disabled people in their policy processes. An important aspect of the duty has been the requirement to involve disabled people as partners at all stages and at all levels in the policy process, which has had a great impact in helping to achieve greater equality for disabled people. We are concerned that in its proposals for the new specific duties under the single equality duty, the Government has scrapped the specific duties around engagement and involvement in order to lighten the regulatory ‘burden’. By removing the current arrangements that exist to promote disabled people’s participation in policy development process and decision-making, this leaves no other alternatives as to how such participation might be achieved in the future.

4.7 What steps should Government take to ensure that disabled people’s views are taken into account when drafting their reports to the UN under the UNCRPD?

As part of the national monitoring mechanism, what steps should the EHRC, NIHRC and SHRC take to ensure that the Convention is implemented effectively?

4.7.1 Involvement of disabled people in monitoring the progress made in implementing the Convention is vital. The Convention is unique in setting forward a monitoring mechanism that puts such involvement at its core. The Government must make every effort to ensure that the monitoring and reporting process is driven by engagement with disabled people, and that this is accessible and open to all. It should also support the inclusion of ‘harder to reach’ or ‘seldom heard’ groups of disabled people whose experiences might not be captured.

Recognising the barriers to participation that they face as well as taking steps to overcome them is crucial, otherwise the danger is that the Government report will fail to capture the full range of disabled people’s experiences in the UK.

4.7.2 Another important aspect is the need to develop a clear set of indicators reflecting the standards that the Convention calls for, in order to measure progress made in the implementation process. This should be an ongoing process, to identify trends over time and gaps in compliance with the Convention. Finally, the implementation of the CRPD should be underpinned by a comprehensive action plan for taking forward the UN Committee’s concluding observations, which tie up the reporting process.

Thank you for taking the time to read Scope’s written evidence. If the Committee requires any further evidence or information, please do not hesitate to request it from us. Scope would welcome the opportunity to give oral evidence to the Committee to expand further on issues affecting the right to independent living of disabled people.

April 2011
1. About Guide Dogs

1.1 Guide Dogs provides a range of mobility and other rehabilitation services and campaigns to increase the independence, well-being and dignity of blind and partially sighted people throughout the UK. Services are delivered through district teams working with other local voluntary and statutory agencies to identify individuals whose mobility would be enhanced by the provision of a guide dog or other mobility services. Guide Dogs currently provides guide dogs to over 4,500 blind and partially sighted people.

1.2 Additional mobility services are offered to those who apply for a guide dog and who need some initial mobility training prior to taking on a dog or to those for whom a guide dog is not really a suitable aid to independence. This includes both teaching people how to use a cane and sighted guide training for family members so they can lead their loved ones safely and confidently both indoors and out.

1.3 We also campaign passionately to break down barriers – both physical and legal – to enable blind and partially sighted people to get around on their own.

2. Executive summary

2.1 Guide Dogs believes that the right to independent living should form the basis for the Government’s policy for disabled people. By supporting disabled people to live independently under their terms, their need for expensive care and support is reduced or will only arise much later on in life. It is vital that the Government recognises the importance of the provision of training and equipment to facilitate this. There is a sense that particularly in the social care arena that the emphasis is on keeping people free from harm rather than enabling them to become active participants in community life. Social care looks increasingly like a fourth “emergency service” rather than an enabler to independent living and citizenship.

2.2 Guide Dogs believes that while there are some policies which on the surface would appear to support the right to independent living but they do not necessarily translate to actual change on the ground. There are also further actions that the Government could take to secure the right to independent living for disabled people, which are not necessarily expensive step changes in policy, but could be as simple as taking into account the views and needs of blind and partially sighted people in a more effective manner.

2.3 A number of recent budgetary and policy decisions have the potential to adversely affect the independence and mobility of blind and partially sighted people. In particular, the proposed reforms to Disability Living Allowance have caused great concern amongst the disabled community. The lack of clarity when introducing the proposals and the speed in which they have been introduced has not served to calm the situation.

2.4 Despite the fact that the participation and consultation of disabled people in policy development and the decision-making process can support initiatives such as the ‘Big Society’, it appears that often it is not happening in an effective way. Blind and partially
sighted people either do not feel involved in these processes at all, often due to the lack of accessible information, or for those who do get involved, feel that their views are not taken into account.

2.5 During debates in recent years about increasing the amount of time that terror suspects (numbering in their hundred) could be held without trial to as much as 56 days there was a public outcry. Our research suggests that as many as 180,000 blind and partially sighted people never or hardly ever go out, effectively living under house arrest. The situation suggests that independent living for all disabled people is not yet within reach, let alone within our grasp.

2.6 With regard to the Government’s reports to the UN on the Convention for the Rights of People with Disabilities, it is vital that disabled people are continually involved in the production of these reports and that an accurate and representative portrait of the situation is conveyed to the UN, so that policy changes can be made at a strategic level. With regards to the monitoring and implementation in the UK by the appropriate bodies, it is vital that achievable action points are set and that these bodies are made accountable for achieving them, so that disabled people can benefit from any significant policy changes.

3. The right to independent living

3.1 Guide Dogs believes that the right to independent living should continue to form the basis for Government policy on disability in the UK. For Guide Dogs, the right to independence and mobility is a fundamental human right and enabling people to assert that right is key to what we do through the provision of guide dogs and other mobility services.

3.2 Guide Dogs does appreciate, however, that there is a dilemma that arises from different, sometimes competing interpretations of what independent living means. Whilst we would agree that ‘Independent Living’ does not (necessarily) mean “doing things for yourself, or living on your own”—we would argue that for many this is precisely what it means. When speaking to guide dog owners and other blind and partially sighted people, they often define independent living in those terms. In order to support that aim, they often make reference to the importance of acquiring to the skills and tools they need to achieve that independence.

3.3 Guide Dogs is aware that all too often the lack of access to specialist support such as independent living skills training means that people with failing sight can fall into premature dependency, unable to perform everyday tasks unaided, possibly leading to unnecessary admission to residential care. Guide Dogs is also aware that in these current strained economic times, that the provision of these skills and tools can be seen as unnecessarily expensive and not always considered as a priority. This is why it is vital to promote the concept of the right to independent living and why the Government should still take it as a basis for their policy on disability.

3.4 Our survey “Functionality and the needs of blind and partially sighted adults in the UK” published in 2007 catalogued the self-reported outcomes achieved by blind and partially sighted people—pretty much all of whom were registered, and so by definition had been brought to the attention of statutory services. We discovered that nearly a quarter of the people we interviewed were not experiencing minimum acceptable levels of independent living. There is however no official definition of “minimum outcomes” for independent living.
which makes it harder for Government to benchmark the success of its efforts in this policy area.

3.5 In conclusion, Guide Dogs believes that the Government should continue to support the right to independent living and demonstrate this through their policies, as it can improve the lives of disabled people, both now and in the future. The long-term view must also be considered as part of this policy, as if there are more disabled people able to live independently due to being provided with the skills and equipment they need, the less likely they are to need complex and expensive help later on in life.

4. Existing policy to support independent living

4.1 At the moment, Guide Dogs supports the ambitions of the Government when looking at independent living for disabled people. The principle of extending choice and control for disabled people has the potential to empowering disabled people and significantly improve the quality of their lives. Unfortunately, as was recognised in the Independent Living Strategy 2008, “for many disabled people, that vision [of independent living] can seem very removed from their lives”368 and that there is still a gap between the intentions of national policy and the everyday experiences of disabled people seeking to live independently in the UK.

4.2 One specific issue is that there is no legislative strength behind the Independent Living Strategy and as a result, no enforceable rights. This is the same issue for the UN Convention on the Rights of People with Disabilities, as that too falls down when it comes to enforcement. If the Government wishes to strengthen the right to independent living for disabled people, there needs to be some teeth to these policies and some underpinning legislation.

4.3 The recent decision by the Government to amend the public sector duties in the Equality Act 2010 was of concern, particularly when announcements described the current duty as “an inefficient burden that would simply have created more red tape”369. The duties in the Equality Act were considered to be a positive step forward by many in the disability community and comments of that nature do not inspire them to believe that the Government is committed to the rights of disabled people and their right to independent living.

4.4 There is more that could be done by the Government to secure the right to independent living for disabled people in the UK and this submission will just list a few of the actions that could be taken to achieve this. There is a need to consider the impacts of multiple policy changes on the ability of disabled people to live independently. For example, a blind and partially sighted person may experience difficulties if a council-funded taxi card scheme is abolished and that buses in the local area do not have audio-visual announcements (alerting them when to disembark or how much further they have to go) and are therefore not inclusive.

368 Independent Living—A cross-government strategy about independent living for disabled people, Office of Disability Issues, 2008

369 Time to get ready for new equality duty, Minister tells public sector, DWP press release, January 21 2011
4.5 It is important that a positive attitude towards the disability community is fostered by Government. This would have been particularly helpful during the recent discussions around welfare reform, where comments by ministers and then extrapolation by the media led to the feeling that those claiming disability benefits were ‘scroungers’ or making fraudulent claims. This attitude is not conducive to creating a Government and society that is accepting of disabled people and their needs.

4.6 In order to facilitate greater levels of independence, disabled people could also be supported to be more empowered to act for themselves. This can be done through the allocation of individual budgets, as is currently being tried by the Government, but also through facilitating the consultation, participation and involvement of disabled people in policy development and the decision-making process. Although Guide Dogs’ thoughts on this are largely covered by section 6, it is worth highlighting here that by involving disabled people more about decisions in their own lives, be it the care and support they receive, or the design of the area they live in, they should then be able to indicate what is needed to support their ability to live independently.

4.7 In conclusion, there is more that the Government can do to secure the right to independent living for disabled people. The changes can be made through changes in attitudes and are not necessarily expensive shifts in policy though it is naïve to assume that the improvements required can all be funded through “efficiency savings”. We believe that savings will be realised in the longer-term but investment in supporting independent living is required before that can happen. We are also keen to see improved well-being and quality of life being given as much attention as continual drivers to reduce the cost envelope. The involvement of disabled people in decision-making and policy development is invaluable to further supporting the right to independent living and ascertaining from disabled people themselves what is needed to support them to achieve that.

5. Impact of recent policy and budgetary decisions on independent living

5.1 It is fair to say that a number of policy and budgetary decisions made recently have had an impact on the ability of disabled people to live independently. That is not to say that the current system is perfect and Guide Dogs would support reforms that ensured everyone in need of support would be able to benefit from it, as this would support more people to live independently. However, the current Government’s plans to cut spending have raised concerns that the welfare of disabled people and their ability to live independently may be compromised as a result.

5.2 When discussing the potential impacts of recent policy decisions, one that has been most frequently cited to Guide Dogs by our clients is the planned cuts to Disability Living Allowance. As one of our clients explained:

“We are told that the ethos behind it is to look at the system as it has not been looked at since DLA was introduced in the 90’s but I am very sceptical as all we hear from the Government is that they want to reduce the benefit bill. I am not convinced that this change is for the benefit of disabled people.”

Guide dogs is concerned that the impact of sight loss and the needs of blind and partially sighted people are not always fully understood. Sigh loss affects the ability to receive and use
information, to get out and about and travel independently, to act effectively as an informed consumer and generally to participate in society. Disability Living Allowance can therefore have a real benefit on the mobility and independence of blind and partially sighted people. Without it, more people will become isolated.

5.3 The proposed changes to Disability Living Allowance have been particularly of concern to blind and partially sighted people and this has not been helped by the lack of clarity in the plans. The proposed decision to remove the mobility component of Disability Living Allowance for all claimants in residential care caused a great deal of concern to many disabled people, particularly as it assumed that those in residential care were either unable to go out or that these costs were borne by local authorities. Although the recent Budget statement confirmed that this would not be removed was welcome, the proposal is still a possibility as it has now been moved into the general plans to reform welfare. This lack of clarity can also be seen in the concerns raised by disabled people that the original plans for welfare reform would penalise those who used mobility aids, as it meant they were more able to get around and consequently would need less benefit. This caused huge concern for guide dog owners, who expressed their concern to Guide Dogs that they would receive fewer benefits because they used a guide dog, leading to some querying whether they should in fact give up their dog. Although this was subsequently clarified by Minister for Disabled People Maria Miller MP in a recent Westminster Hall debate, who explained that guide dog owners would not be penalised, the lack of specific clarity about how the proposals will affect claimants combined with the insistence that the level of spending on welfare will be reduced has caused concern amongst the blind and partially sighted people that they may lose out on benefits that support them to live independently.

5.4 Another concern for the proposed reforms to Disability Living Allowance is the speed in which they have been introduced. The Welfare Reform Bill was introduced to Parliament the day after the consultation closed, which provoked suspicion amongst disabled people that the responses to the consultation had not been adequately considered before the Bill was introduced.

5.5 With regard to other new policies, the current proposals to develop the ‘Big Society’ could also have an impact on independent living for blind and partially sighted people. The encouragement of people to participate more fully in society is commendable and certainly something that Guide Dogs supports, not only through the provision of the guide dog service, which empowers people to be more independent and consequently more able to participate in society, but also through other work we are carrying out such as our Sighted Guiding Service, which will train volunteers to act as guides for blind and partially sighted people and enabling them to start becoming more mobile. However, it is important that the ‘Big Society’ is not used to plug gaps created by cuts in statutory services and that a postcode lottery does not develop where there are shortages of volunteers who are available to run ‘Big Society’ projects.

5.6 There is a danger that blind and partially sighted people are simply viewed as potential beneficiaries of “Big Society” initiatives rather than as participants in them. One plea that we frequently hear is that the kind of support that is available to help disabled people to secure and maintain employment (through the Access to Work scheme) should be available to

370 Commons Hansard, 23 March 2011, Column 332WH
those wanting to engage in voluntary work. Indeed, such experience may enhance the employment chances of a group of people who experience disproportionately high levels of unemployment. Sadly opportunities for blind and partially sighted people to get involved are fewer than they are for their sighted peers.

5.7 In terms of other recent policy and budgetary decisions that have been made, the cuts to local authority expenditure may have an adverse effect on the independence of blind and partially sighted people. One way that this could particularly affect them is the removal of funds for the social care of those whose levels of need are not deemed to fall into the “critical” or “substantial” bands under eligibility criteria. Indeed, there is evidence that more local authorities have further tightened their criteria in recent months. It is important to note that even for those with lesser needs, the removal or reduction of the social care they do receive can make it much harder for them to live independently.

5.8 Another potential impact of local authority spending cuts is the impact on public transport. The provision of accessible public transport can be a lifeline for disabled people and support them to be more mobile and to live more independently. In some areas, local authorities have decided to make cuts to local public transport services and also to concessionary fares. For those who can claim concessionary fares and also have access to public transport, these cuts could leave them isolated and unable to travel as and when they need. Guide Dogs recently supported the Campaign for Better Transport’s open letter to the Prime Minister raising these concerns.

5.9 Another recent policy decision that could impact the independent living of disabled people is the current Government’s promotion of localism. One of the key factors that can aid disabled people in being mobile and independent is the knowledge that they can expect consistent standards across the UK in aspects such as street design, accessible environments and even eligibility for social care. The concept of localism means that a postcode lottery is likely to develop and some areas may be avoided by disabled people, as the local environment may be inaccessible or the criteria to receive care and support may exclude them in one area, but include them in others. As well as providing consistency for disabled people and increasing their levels of confidence in going out and about, the development of national standards is a more efficient tactic than allowing many different local authorities to all go away and come up with their own standards and policies. In this current time of economic prudence, it seems more efficient for one set of standards to be developed, so that local authorities are aware of what makes an area accessible and how disabled people should be supported appropriately.

5.10 In conclusion, it can be seen that a number of recent policy and budgetary decisions could have a detrimental effect on the independence and mobility of blind and partially sighted people. It is therefore crucial that both local and national Government take into account the potential impacts of these decisions and do their best to ensure that disabled people are not adversely affected. This can be done through a number of ways, in particular ensuring the participation and consultation of disabled people in policy development and decision-making, which is covered in the next section.

6. Participation and consultation of disabled people in policy development and decision-making
6.1 The need to ensure that disabled people are appropriately consulted and enabled to participate in policy development and decision-making is vital. This is particularly relevant at the moment, with the Government’s plans for extensive reform and wide-ranging legislative change to a number of areas. When this is combined with the Government encouraging for people to participate more fully in the ‘Big Society’, it demonstrates the clear need to facilitate better participation and consultation of disabled people in policy development and decision-making.

6.2 Although the Government is keen to make progress on the policy areas touched on, it is important that disabled people are appropriately informed and involved if these changes are likely to affect them. The speed of some of the current planned reforms has made it difficult to ensure disabled people have been consulted and have participated in the policy development process.

6.3 Guide Dogs are aware of the need to consult and involve our clients in our work and we do so through our District Client Representatives (DCRs). This is a group of guide dog owners who represent the views of our clients to each District Team, supporting them on matters relating to guide dog ownership. They are directly elected by guide dog owners. Through this, the voice of clients is expressed and influences how Guide Dogs plans and delivers its services. The DCRs are involved in a wide range of activities, ranging from practical advice on policy and access issues, to supporting Guide Dogs’ campaigning activities, as well as representing guide dog owners directly and indirectly by supporting clients as a whole.

6.4 With regards to whether the current arrangements for ensuring that disabled people are adequately consulted and able to participate in policy development and decision-making, for blind and partially sighted people at least, it seems there is still a long way to go. Our DCRs have fed back to us that they do not always feel appropriately consulted in changes proposed by national or local Government and as a result they have been unable to participate fully in decision-making processes. It is worth noting that our client representatives are more aware of these issues and consequently more likely to proactively seek out opportunities to influence and participate. If this group feels disenfranchised from the decision-making process, then it is likely that other blind and partially sighted people will have similar, if worse experiences.

6.5 There can often be a number of obstacles faced by blind and partially sighted people when it comes to getting involved in policy development and the decision-making process, which can be resolved relatively easily. Documentation can be difficult to obtain in an accessible format (i.e. Braille, large print), which makes it difficult for blind and partially sighted people to access the information they need to become more involved. If meetings are held to facilitate the decision-making process, it is important to ensure that they are not only held at accessible venues, but that the venues themselves are easily accessible by public transport.

6.6 Another key issue related to us through our DCRs and through other blind and partially sighted people who involve themselves in these processes is the actual impact their views have on the final outcome. The following comments from one of our representatives is sadly typical of this:
"No I don’t feel that I am influencing any decisions even though I do sit on consultation groups, the bottom line is always cost, or as in one instance locally aesthetics outweighed an acknowledged need."

It is vital not to confuse consultation with involvement and to see it as a tick-box exercise. Steps must be taken to ensure that the opinions of all those who are consulted are fully taken into account. If blind and partially sighted people feel that their opinions are not being noted, they are less likely to volunteer and to participated in such exercises.

6.7 In conclusion, it can be seen that despite the need to ensure better and more effective participation and consultation of disabled people in policy making and the decision-making process. It is vital that the appropriate steps are taken to ensure that firstly they are fully able to participate, particularly in terms of providing them with accessible information. It is then important that having sought the participation and consultation of these groups, that their views are appropriately taken into account and subsequently feed into the policy development and decision-making processes.

7. Monitoring the effective implementation of the Convention

7.1 It is vital to ensure that disabled people’s views are appropriately taken into account by the Government when drafting their reports to the UN under the Convention on the Rights of Persons with Disabilities. This means the real involvement of disabled people to determine the appropriate outcomes and performance indicators.

7.2 In order to facilitate this involvement, many of the comments in the previous section can be applied to this, such as ensuring disabled people are aware of the processes, that they are fully enabled to participate through the provision of accessible information, and that their views are appropriately taken into account.

7.3 In order to ensure that this involvement has a real impact on the lives of disabled people in the UK, it is important to collate findings and research from across the country. This must involve looking at the everyday experiences of disabled people and highlighting where policies are either not working correctly or are not being appropriately implemented. These real-life experiences must be used as a basis to effect policy changes at a strategic level. In order to ensure that the report captures a fully representative picture of the situation for disabled people in the UK, there must be an appropriate range of experiences, both geographical and of different disabilities.

7.4 In terms of ensuring effective implementation and monitoring of the Convention, it is important that action points are set for the appropriate bodies in the UK to implement. As it is crucial that these action points are acted upon in order to make the needed changes, these bodies must be made accountable for ensuring that they are achieved. Therefore, it is also vital that these action points strike a balance between being realistic and achievable, whilst also implementing needed changes for the lives of disabled people in the UK. What is clear is that many blind and partially sighted people are not achieving the sort of independent living that the UN Convention suggest that they have a right to. The Government should acknowledge this in its reporting.

7.5 In conclusion, the appropriate participation and consultation of disabled people is vital for the drafting of reports to the UN on the Convention, ensuring that the reports paint an accurate and representative portrait of the situation in the UK. In order to ensure effective
implementation and monitoring for the appropriate UK bodies, it is important that action points are appropriately set and are given sufficient weight that these bodies are not only able to achieve them, but also that they commit to achieve them.
About us

1. The Spinal Injuries Association (SIA) is the leading national user-led organisation supporting the interests of approximately 40,000 people in the UK who have sustained Spinal Cord Injury and their families. SIA has a membership of over 5,000 SCI people.

2. As a user led organisation the following memorandum has been based on the experiences of our members, who are increasingly contacting us regarding the effects that Government policies and budget cuts are having on their ability to live independently.

The impact of funding on the right to Independent Living

DLA Mobility component in residential care

3. SIA would like to express their complete rejection of Government’s intention to remove the Mobility component of DLA and PIPs from disabled people in residential care. Mobility is absolutely crucial to a disabled person’s independence. Those who live in care homes will be even less able to exercise this basic human right.

4. Newly injured Spinal Cord Injured people are increasingly being discharged straight from hospital into a Care or Nursing home as an interim arrangement while they wait for suitable care packages, housing or property adaptations to be arranged. These can be drawn out processes and may leave such people in care homes for extended periods.

5. It is of vital importance that newly injured Spinal Cord Injured people start to reintegrate into mainstream society as soon as possible to avoid becoming hospital dependent and institutionalised. Removal of the mobility component, or indeed any of DLA or PIP, could severely restrict their ability to leave their institution, adapt and become independent.

6. With the considerable cuts being faced by Local Authorities across the country SIA anticipates that many more disabled people will be housed in Nursing and Care homes in the foreseeable future as savings are plundered from social services budgets. Removing such an individual’s means for mobility will dramatically reverse the independence agenda for those disabled people most in need, in many cases irreparably.

7. The Government states that it is committed to supporting disabled people to exercise choice and control over their lives. This is a commendable intention, but one that will be jeopardized by limiting access for those who rely on the mobility component of Disability Living Allowance for the independence they currently enjoy and is their right.

The Independent Living Fund (ILF)

8. The ILF is a vital source of funding which supplements the care packages of disabled people and allows them to live an independent life with support which extends beyond activities such as bathing or having a meal cooked for them. Without ILF it is likely that a disabled person could not afford to do anything more than manage their condition.
9. With the closure of the ILF to new claimants and, in all probability, existing claimants from 2015, Local Authorities will be required to make up the shortfall in funds which the ILF has traditionally provided. This money will have to come from stretched budgets that are already under enormous pressure. If the ILF is amalgamated into the overall Community Care budget SIA believes that the awards for care packages will inevitably be driven down considerably.

10. With severe cuts to Local Authority budgets, SIA fears that many will only be able to provide minimal funding to those with high care needs. Spinal Cord Injured people without access to ILF will be without the extra support to enable them to take an active part in mainstream society. This situation will be more acute for the newly injured who require more support to reacclimatise themselves to life with a disability.

11. SIA calls on the Government to reopen the ILF with immediate affect to all those who meet the eligibility criteria for accessing funding and to work with users of ILF and their representative organisations to ensure ILF works at maximum efficiency for its users, it is accountable and it delivers value for money for UK tax payers.

Continuing Healthcare

12. Continuing Healthcare (CH) is increasingly becoming a concern as local health budgets are squeezed, resulting in reduced care packages for those who receive it. Despite the fact that Spinal Cord Injury is a stable condition which neither improves nor has a medical cure, there are numerous examples of care packages being dramatically reduced after reassessments. The case of Pamela Coughlan established that a tetraplegic who has an injury of the C5 vertebrae or higher has needs which “far exceed” the threshold for CH provision. However, even Spinal Cord Injured people with considerably greater healthcare needs than this are seeing their care packages severely reduced.

13. This pressure on budgets leads to an ad-hoc, post code lottery service as different trusts limit their budgets to different extents and the National Service Framework is interpreted differently to meet the needs of budgets rather than people.

The Big Society

14. SIA believes that the notion of ‘The Big Society’ will do little to negate the impact of budget cuts on disabled peoples’ ability to live independently.

15. Services which are run by volunteers are inherently inflexible as they are dictated by the times the staff are available—for instance a shopping trip may occur at a particular time each week. Flexibility is absolutely essential to the idea of Independent Living—the power to do whatever you want whenever you wish.

16. There is no indication where this army of volunteers will come from, but it is likely that the majority will be those of retirement age. It is questionable as to whether these volunteers will be willing to give up late evening and early morning time to support disabled individuals, yet such support is vital if disabled people are to truly live independently.

17. An individual has more control over a service that they pay for as they are paying customers. It is considerably harder to complain to a volunteer who is giving up their time of
their own free will, and this will impact the suitability of services that disabled people reliant on volunteers will receive.

**Conclusion**

18. SIA believes that if the UK Government continues to cut funding on the benefits and services which support disabled people it will not be able to fulfil its obligations under the UNCRPD.

19. SIA also does not believe that the Government has looked at their reforms holistically and by reducing the support costs to disabled people across the board they will severely disenfranchise disabled people and prevent them from living the independent lives which should be their right.

20. Indeed, such cost cutting reforms may actually burden the tax payer with additional costs elsewhere. For instance, inadequate care packages, which result from a drive to cut budgets across numerous different areas, are likely to result in increased hospitalisation episodes due to poorer standards of care management, with conditions such as pressure ulcers and urinary tract infections becoming more prevalent. As a result of seeking savings from a social service budget, the cost will inevitably transfer to an NHS budget, but at a higher rate as the treatment of such conditions is considerable. Not only will the cost to the tax payer increase by hundreds of millions of pounds, the cost to the individual will be even greater, resulting in poorer health, loss of independence and reduced capabilities, in many cases for life.

21. SIA calls on the UK Government to continually assess the implications of any current and future budget cuts which may impact upon disabled people’s rights as they are laid out in the UN convention.
This is a consolidated response to the Joint Committee on Human Rights consultation about disabled people and independent living.

INDI (Infrastructure Network for Disability Information) South East is a regional infrastructure network for disability related organisations. We have over 300 members and support them by providing resources, sharing information, spreading knowledge and bringing skills together. We have a dedicated website, an ebulletin service and run networking events.

INDI South East is submitting this response on behalf of disability related voluntary and community sector organisations. The following four key questions have been addressed in the consultation.

1. Could the government do more to give disabled people the same rights as everyone else to live independently? If so, what could they do to make this happen?

Recommendation:

The government could re-examine cuts in social welfare benefits which directly impend on the opportunity for some disabled people to live independently. The right to live independently is preferential to being dependent on others.

2. How can the government involve disabled people in planning services and deciding how to save money?

Recommendation:

The government could invite disabled people to attend planning sessions. Also, government consultations should be more accessible to disabled people i.e. in different formats and communicated more effectively through widespread marketing.

3. How well are disabled people involved in planning and making decisions?

Recommendation:

The main problems highlighted in the involvement of disabled people in planning and making decisions revolved around their views ‘not being heard’. The government could publicise more opportunities for disabled people to engage in decision making other than consultations which have proved to be unrepresentative and ineffective.

4. How can the government ensure that it includes ideas from disabled people in its reports?

Recommendation:
Written Evidence submitted by INDI (Infrastructure Network for Disability Information)
South East (IL 88)

The government needs to discuss their ideas and reforms with disabled people. This would mean contacting disabled people directly and proactively through various social and community services.

In closing, here is a parting comment from one of the consultation respondents:

“As a recently disabled person at the age of 82 years, it has been an amazing learning process. I have been extremely surprised by various attitudes by some people and also would say that there appears to be a lack of kindness and humanity towards disabled people, by the 'so called' norm.”

INDI South East endeavour to report feedback from consultations to disability related voluntary and community sector organisations and to individuals that have taken the time to respond to our consultation enquiries. Thereby, we would be most grateful if you could provide us with published feedback to this consultation when it becomes available.
This is a report by Andover and District Mencap following the request from Mencap and the Joint Committee on Human Rights to provide evidence and stories of people with disabilities and issues surrounding housing.

We have taken a two part approach. Firstly, this document will detail our experience as an organisation that has supported people with learning disabilities in the Andover area for 40 years. We run a support worker service and have over 40 people who are currently supported in independent living situations. As you can appreciate we do have some experience with both the good and bad in terms of achieving good outcomes over the years. This is due to be submitted to Mencap by April 1st 2011.

Secondly, we will aim to have some individual experiences available from our members, which due to time will be submitted directly to the Joint Committee for Human Rights to meet the deadline of 29th April 2011. (We shall also forward this material to Mencap).

Over the last 40 years we have supported many people to achieve their goal of living independently within our community. As you can imagine that has involved many scenarios over the years but we have chosen to put a few together from the last few years, which give a flavour to some of the problems that we have encountered.

In 2004 we decided we would like to buy a house to become a home to 4 of our members and identified a house on a fairly new build of large family houses in Weyhill Road called Denning Mead. The property we intended to purchase was on 3 levels and offered excellent accommodation for the 4 young members who had indicated they had a wish to move out. Unfortunately, whilst the lady who owned the property was nothing but helpful, a local estate agent who lived on the site, had found out about our intention to purchase the accommodation and formed a ‘NIMBY’ group on the estate, with the express purpose of preventing Andover Mencap from purchasing the property.

We were accused of running a business on the estate that was not allowed, however, our investigations especially at Companies House, revealed that many people living there were running business’s from their homes and all we intended to do was be landlords and develop support to our members.

Much pressure was put upon the seller and a campaign of disinformation about people with learning disabilities and concerns about having them as neighbours on the estate ensued. There was even a suggested offer to buy out the seller in order to keep us out and thereby keep up property prices.

In due course the lady selling the house asked if we would pull out as she felt she could no longer take the pressure from this group. We could really use the phrase ‘do not trust estate agents’ and in this case it would be absolutely true. The residents seemed to feel that four young people living on the estate with 24 hours care would somehow pose a threat to their way of life and cause serious devaluation to their asset. No amount of information from us could prevent this behaviour, so for the benefit of the seller and our members, we decided to shift our attention elsewhere.
Written Evidence submitted by Andover and District Mencap (IL 89)

Having failed to purchase a property in Denning Mead we searched elsewhere and the parents of one of our clients had a large 4 bedroomed bungalow with wheelchair adaptations on the market as they were looking to downsize. This proved to be a successful process for us and we now had an appropriate property in Blendon Drive to proceed with our efforts to house our 4 members.

The process of housing these individuals however failed. This was because although the members wanted to move and live independently, after 18 months they all had problems with getting firstly assessments and then care plans. In addition social services changed the goalposts in terms of how they were looking to support people in independent living.

When we started out on the project, we were told that groups of 4 people with provision for 24 hour support was the model to which we should work, by the time we were 2 -3 years down the line, this seemed to have changed and when combined with the problems with securing care plans basically lead to the failure of the project.

Subsequently we commercially let the property on a 6 month rolling lease, in order to secure some income whilst we looked at members who were looking to live independently and whether care plans could be put in place for them to be able to move in.

This process started in 2004, last year 2010 we finally got 2 ladies who are now living in the bungalow, and a third has just recently joined in 2011. Whilst we are very pleased that after 6 years the project is finally moving forward, it was Andover Mencap as a charity who wound up taking on board the risk in terms of buying a building for the benefit of our members, and were left holding the baby when the care process fell to bits.

The building was also empty for a period of over 6 months whilst much talk and ‘planning’ was flying around between ADM and prospective clients and social services, which was not really helpful to the charity at all as at least when we could let it, some income came in, however empty it was of no help at all to our members or the charity and therefore once again we were left with the risk.

Charitable organisations are often well placed to assist their members with moving into independent living environments, but statutory agencies really need to work in a joined up manner in order to help third sector organisations to make the best use of their resources and to avoid them funding anything which could be considered to be a statutory function and therefore against the rules laid down by the Charity Commission.

We also have experiences of some of our members who would be considered to have moderate learning disabilities and consequently have proven to be extremely vulnerable whilst living independently.

Two gentlemen in their 30’s, shared a property in a quiet residential area. They caused some concern to the local neighbours, some of whom really did not understand the difference between learning disability and mental illness, but additionally did not help themselves by getting drunk and coming home late at night being noisy and having arguments. Ultimately their shared living broke down and the two gentlemen moved to other accommodation.

Another of our more able clients was living independently and alone and had lots of ‘friends’, who mainly associated with him to spend his money, squat in his home, drink and take drugs. The neighbours were really upset about the situation as they were feeling unsafe in their
own homes. Our Chair organised a meeting to try and work out some of the problems and to actively involve the neighbourhood. Eventually with the help of statutory agencies the man was evicted and went to another town. Sadly he ended up in prison but it does demonstrate that although those with moderate learning disabilities are more capable, they are also at most risk within the wider community of being taken advantage of and abused.

We do have lots of success stories, people who are living independently, with friends or alone, who are living lives and are happy. One such case is three ladies with severe and complex learning disabilities one of whom came from her mother’s home, but two came from institutional backgrounds. These ladies are now living with 24 hour support in their own home and are accessing the community and other social activity as much as possible. They have good support workers who ensure that they have good lives. This is how it should be.

However the process to achieve this took several years (which was in large part due to the Health Authority in this instance taking two and half years to decide and organise funding) and much inter-agency working including at least 5 funding streams, which was facilitated by Andover Mencap acting as the ‘oil’ in the proceedings. This is where the third sector can really have an impact and make a real difference to the people they support.

As stated earlier, we shall be submitting individual evidence from our members, we hope that it can be of some help. Things are not always hopeless, but are often made very stressful, complicated and difficult. The harder it is to achieve a positive outcome, the more likely it is that the situation of housing people with learning disabilities will become crisis managed, often involving either elderly parent/s and additional expense in dealing with their personal situation or a breakdown in the physical or mental health of the parent/carer.

Two things would be very helpful.

1. A streamlining of the process and nationwide practice and criteria are put in place.

2. Independent advice and/or advocates are available throughout the process. Ultimately it is clear that both people with learning disabilities and their parents/carers need help and support to get through this process successfully.

This has been compiled by the Campaigning Group within Andover and District Mencap.
Shout out is an independent self advocacy group for adults with a learning disability in Medway, Kent.

Shout out members want to tell you some things that they think make it difficult for people to get their right to independent living.

People with a learning disability need more choice of better housing.

So people can get out and about, people want their housing to be near shops and transport links.

People need good support to live independently.

Jobcentres need to make it easier for people to get jobs. This means a positive attitude and information in a way that people can understand.

“Things are supposed be changing but people are experiencing no difference in their own lives.”

“Carers training should include understanding Human Rights— that should help change attitudes”

“About benefits—the cost of everything is going up quickly but benefits are being cut”.

“People need money to go out and about to be independent”.
1. The right to independent living

1.1. Could the Government do more to give disabled people the same rights as everyone else to live independently?

- Yes, for people with learning difficulties
  - Lack of information about what is available for independent living—what choices are available - lack of a central point quality information which allows us to make informal choice

- Complexity— direct pay—personalisation agenda.
  - Once a placement has been chosen (care home)—Pay for all those services; find them, book them. Learning disability someone else is making those choices.

- After independent living training
  - Pressure was overwhelming on him to stay at home.
  - Pressure to do what costs the least
  - Independence not a problem
  - Fight for him to go into independent living

- A core question for me is who is policing these choices?
  - Old system one choice to make which is surrounded around the care home—Who used to offer the full package consistency
  - Now the system is so complex that toe nails booked to come at intervals that meet with the budget rather individual—

- Policing on behalf of people with learning difficulties:
  - Mental capacity act 2005—a lot of professionals still not aware of the legislation therefore are nor practicing it—there for many people with learning difficulties are still not being involved in the most basic decisions that affect them
  - Toe nails, bathing, who cares for him & when

- Advocacy services
  - Lack of resources for advocacy to support with people with learning disabilities, 'What happens when parents die or are not capable to be advocates?'

1.2. What could they do to make this happen?
• Disabled people inspectorate
  ▶ Someone who has the authority (independent) to go in and examine
  independent living home to ensure that they are complying with current
  legislation need of individuals are being met

• Care manager in independent living setting should oversee strategies that surround
  the individual this currently isn’t happening particularly in regards to:
  ▶ Care plans are met
  ▶ Statutory review complied with and followed through (action plans)
  ▶ Timely responses problems

• Finance of Independent Living establishments:
  ▶ Should be transparency in financial arrangements of care settings
  ▶ Should regularly show Investments made and profits produced
  ▶ Should be open about salaries paid
  ▶ Should provide a breakdown of all costs and payments made
  ▶ Provide clients with detailed accounts? Which includes what is left

1.3. Do you think the Government need to change any laws or the way they do things?

• Firming policing of care settings—individuals and family members should have more
  power
  ▶ Consultation is great—it allows people however no law exists have to listen
    (shape services)
  ▶ Recommendations considered reasons presented why wasn’t listen—decisions
    made.

• Firming guidance on representation
  ▶ Who consulted (disability)
  ▶ How many
  ▶ Back ground
  ▶ People should be accountable for the decision they make

1.4. If so what needs to change?

• Social workers should be proactive.

2. Lack of money
The Government need to save money. The Joint Committee would like to hear how people have been affected by:

2.1. Change to benefits

- Review a whole range of benefits—general feeling is going increase the current issues already highlighted
  - Not sure how this is going to effect
  - Lack of clarity of what is going happen once the cuts in benefits hit
  - Welfare reform bill means we won't know until it hits
- Carers allowance—£54.00 is not enough
  - Saving billions to Government just not comparable
  - Then not all carers are entitled to it - pensioners
- Learning difficulties
  - Are more reliant on carers because they cannot ask they are not able to develop social networks
  - Cuts will only mean independent living compo Risk increases of social inclusion

2.2. Cuts in funding

- Lack of funding for taxis
  - Take away his freedom—and only option so socialize and leave the setting, reduce independence
  - No more night class
  - Ensen will only be met
- Safeguarding—volunteering—safe recruiting has been promised

2.3. Changes in services

- Cuts in funding means that new forums, better policing, accountability won't happen
  - Standards will drop further protection
  - Worsen not stay the same
  - People's lives are centred on funding and services.

2.4. The way the local councils decide whether you can get a service or not

- Funding guides assessments
2.5. The Joint Committee would like to know if you think these things are making being independent more or less difficult

- More difficult

3. Getting involved and saying what you think

3.1. The UN Convention about rights for disabled people says Governments must involve disabled people in decisions that affect them. How can the Government involve disabled people in planning services and deciding how to save money?

- Disable forums as discussed
- Meaningful Involvement
  - The right numbers
  - The people who matter most effected
  - Responsibility for the decision

3.2. How well are disabled people involved in planning and making decisions?

- Involved, not on a meaningful level—often based on ability—perceived lack
  - Not of any group solely made of people with learning disabilities
- Fight to be involved
- Language used difficult to understand, plain English
- Government could learn from the con. Doc
- Lack of responsibility
- Independent living forum should be established that acts locally but links nationally
  - Informs bodies such as Human Right Commission, Care Quality Commission.
  - Central/local Government
  - Equality & Human Rights Commission

4. Sticking to the UN Convention

In summer 2011 the Government has to say how well it is sticking to the UN 4.1. Convention about rights for disabled people. How can it make sure it includes ideas from disabled people in its reports?
Written Evidence submitted by David Howarth (IL 92)

- Talk to them/us please!
- In a way we can respond
- Feedback to use once we have been involved
- Set up forums
- Local national.

14 April 2011
1. **Personal Background:**

1.1 I am a disabled person with mobility, sensory impairment and a heart condition. I am a former Executive Council Member of both RNm and The National Federation of the Blind UK; a former Vice Chairman of JCMBoPSUK, an adviser to various government departments on disability issues. Currently, I am the elected Chairman of The Tunbridge Wells Disability Access Group, a Founder Member of The Kent Reference Panel, which advise Kent County Council and 60SE on disability issues. I also act as a Disability Tribunal Advocate. I have recently been seconded to The RNm "Cut's Watch" Team.

1.2 I am willing to be questioned by the Committee on my submission if they so desire.

2. **Historical background:**

2.1 I believe that it is relevant to set out briefly the historical background to the situation which exists today and will result from the Coalition Government cuts and proposed changes to disability allowances and benefits.

2.2 As far as the vast majority of disabled people were concerned The Disability Discrimination Act 1995 (DDA), turned out to be nothing more than a paper tiger, it set out various requirements designed to improve awareness of disabled peoples needs and requirements by "making reasonable adjustments for the majority", rather than meeting the needs of all groups of disabled people. It was further hampered by being secondary legislation and was, for the most part, ignored by public authorities and departments of government. Its greatest virtue was making people “aware of disabled people and their needs”. Only after enactment of The Human Rights Act 1998 (HRA) was there any significant change. HRA was primary legislation and Articles 8 Independent Living and Article 9 Freedom of Association gave disabled people the legal punch to make changes actually happen.

2.3 Those of us involved were able to persuade the then Prime Minister Tony Blair to adopt UN Convention, which we tend to refer to as The Social Model of Disability (SMD) and at the same time introduce a raft of legislation and targets; including Direct Payment Act 2000, The DDA Regulations 2000 relating to Rail, Bus, Coach and Taxi’s; various government departmental advice and guidance booklets, a good example being The Department for Transport’s “Inclusive Mobility” and perhaps the most significant, The Equality Standards in Local Government Targets 2000. The targets required, at the lowest compliance level "adoption of the SMD (UN Convention)”. The reality was ‘that few understood its implications and those that did, could not afford its introduction.

2.3.1 Blair also set a final compliance target' for independent access to all goods, services, facilities, modes of transport and the workplace; together with the necessary support for all disabled people to have a level playingfield with non disabled people, at 2025. That target date remains in place, but **without the will and funding** win not be attainable. We were assured at the time, that this would be embodied within the proposed Disability Strategy 2009.
2.4 The DDA 2005, as we all know introduced The Disability Equality Duty (DED) and the requirement under the Regulations for listed public authorities to undertake Disability Equality Impact Assessments (DEIA) on all policies, practices, procedures and service provision. Both the courts and the tribunal services tended to find in favour of the claimant if the respondent failed to undertake a DEIA, irrespective of the rights and wrongs of the case. Such decisions and outcomes changed the public authority mindset towards disabled people. One of the most significant outcomes of those regulations were the sections dealing with “t Treating disabled people less favourably” and the “disproportional clause” which allowed for higher levels of treatment, medication and support to be given to disabled or chronically sick people to improve health, wellbeing, quality of life and above all, enable and empower them to have degrees of independent living and freedom of association. The problem was that other legislation affected by these changes was not updated, perhaps because the DDA remained secondary legislation consequently, in planning, for example, without guidance and legislative updating, disabled people found, as in the Torpey Case, that they could not alter existing property to meet their changed needs. In 2007, The Audit Commission ruled “that an agent, contractor or service provider of a listed public authority must comply with the DED of the listed public authority”. That ruling effectively brought those private companies and charities, hitherto exempted, within the scope of the DED, much to the annoyance of the government of the day.

2.5 For some reason, the growing cost of all this legislation and targets were not seen by successive administrations and were referred to as “unforeseen consequences”. In truth, no new adequate funding ever accompanied the introduction of new disability legislation, regulations or targets; consequently it was, and is, impossible to meet compliance. With the enactment of The Equalities Act 2010 and the introduction of The Public Authorities Equality Duty in April 2011, government attempted to put right what they saw as a “fundamental error” by downgrading the requirements and linking disabled peoples needs with those of the elderly. At a stroke they had undermined the objectives of The UN Convention and all the legislation to improve the rights of disabled people. They had set the stage for the next phase, to cut the funding of support for disabled people.

2.6 In order to obtain compliance with Article 19 of the Convention we need to have a Disabled Persons' Independent Living & Freedom of Association Bill. Only then will this issue be taken seriously.

3. Independent Living:

3.1 The first question should be “Should the right to independent living & freedom of association form the basis of government disability policy in the UK?” I believe, as disabled person, that the two rights go hand in hand, without one you cannot gain the other. Without the right to control your affairs, destiny and independence, a disabled person, even one with a mental health impairment, is a prisoner. To be able to meet and associate with others are fundamental human rights as set out in HRA 1998. What we need is legislation designed to bring that about (see para 2.6).

3.2 “Do the existing policy statements, including the Independent Living Strategy represent a coherent policy towards the implementation of the obligations under Article 19?” As you would expect from me, I believe, in the light of my comments in Section 2, that the statement needs to be improved, by the inclusion, after the words “appropriate measures to”, should be included “all necessary support, irrespective of cost to facilitate etc”.
3.2.1 It all comes down to money in the end. There are many reasons why this is the case, I have endeavoured to give some examples. Of the 10 million disabled people in the UK, only 3.2 million are in receipt of DLA. That is a measure of how good the DLA system is. Around only half of that figure get social care support or Direct Payment due to the tough means testing criteria adopted by local government and a desire on the part of Social Workers to block, wherever they can, the introduction or adoption of Direct Payment by disabled people. This is an "attitude" issue, they want us compliant, not in control of our own affairs. Likewise, charities often unwittingly, put the needs of the charity before those of their clients and are often compliant and acquiesce to the commissioning authority in order to retain favour and grant funding. Some even fail to inform disabled people of their rights in order to ensure that they remain compliant to their services, rather than applying for Direct Payment, which would enable them to have a degree of control and independence over their affairs. Starving the NHS and Local Government of funding to enable them to undertake legal requirements under existing disability legislation and regulations makes a total mockery of the UN Convention. It becomes for those of us struggling to gain independence and live our lives with little or no prospect of full support or proper funding of our special needs, as a "shambolic statement".

3.2.2 Many disabled people would like the opportunity to work, but due to the combination of physical barriers and lack of costly support they cannot. I refer you to correspondence between myself, Sarah Deacon & James Underwood at HM Treasury dated 14 February 2011 and subsequent replies in Annex 1 also Annex 2 letter to Rt Hon Vince Cable MP.

3.3 "What steps should be taken?" Central Government should:

- abandon changes to DLA and consider increasing the value of DLA by 20% and making sure that the mobility allowance access to housing, funding of alterations and adaption to make a disabled persons property independently accessible and fit for their needs

- new NHS/Community Health Boards should have a disabled person on each Board to ensure that disabled people’s rights are respected and complied with. There is no guarantee that this will happen. In fact evidence from the NHS Primary Care Service Trusts which replace the old PCT’s indicates that due to cost disabled people’s rights may well be ignored. Some GP Consortia are considering putting a limit on each practice as to the numbers of disabled people and chronically sick patients they have, this is to ensure that the Consortia gains the special premium for staying within budget. Is it any wonder that OP’s are in conflict one with another over these plans.

- The proposed alternative to DLA to be known as a Personal Independence Payment (PIP) is to introduce a change in assessment from medical condition and copeability (DLA) to mere copeability. It is the view of disabled people that this will encourage many to not attempt to cope, in order to maintain their levels of allowance or to gain an increase. Annex 3 Response to DLA Reform Team. Sets out some of the concerns.

3.4 From the comments that I have already made, clearly very costly changes must be made to policies, practices and legislation if the aims and objectives of the existing Strategy are to comply with Article 19. The problem has been that because legislation has not “compelled” changes, they have and are being put off, especially in the light of the very
difficult economic restrictions being imposed. Disabled people have to beg and plead for changes, to avoid upsetting public opinion (see Annex 2 Vince Cable letter relating to funding of lifts). If we were to enforce our rights, that would put the public against us. Those of us that are tasked with representing disabled people are mindful of the line we tread. Likewise, politicians both at central and local level are aware of our difficulty and use it against us to oppose costly change.

3.4.1 With the growing numbers of disabled ex service personnel, to whom we as a people owe a duty of care and support, we must all think again. I have always said that you cannot force the British people to do anything that they do not want to do. Policies such as DWP Welfare to Work, whilst they do have merit, are not appropriate at this time of high unemployment, especially in the youth market. In Annex 2, the comments in the Vince Cable letter by local Kent businessmen illustrate the problem rather well. We need to work together in harmony, not seek conflicts with employers and trade unions to reduce welfare dependency. We need them on our side, not against us.

3.4.2 We may need to think outside the box and restrict unilaterally if necessary the migration of EU Workers. If they do not have accommodation, then we do not admit them. We should make it a requirement for fluent ability in understanding and speaking the English language. We know that the public would back such a plan. The gaps they leave would soon be filled by local workers. We may need to consider that people on unemployment benefit should take voluntary work to earn that benefit and a special bonus premium for doing such work, that would do much to restore the work ethic. Such measures would take up some of the slack and leave room for employers to consider taking on disabled people and investing in their training. This will take many years to achieve and will not happen within the time frame announced by this government in its proposals relating to Incapacity Benefit, DLA and other Welfare Reforms.

3.4.3 When it comes to wider rights for disabled people, if the pressure on the public is reduced, they will support reasonable requests for change. The only alternative is to introduce an Independent Living & Freedom of Association Bill to hasten change and compliance with the Convention.

4. Impact of funding on the right to Independent Living:

4.1 The simple answer to the first question posed in this section, is it is vital! Without funding totally the support needs of all disabled people, they cannot function, let alone act independently. To date, DLA funding has only been a contribution towards those costs, made up with various other allowances ranging from Incapacity Benefit; Severe Disability Allowance; Income Support; Housing Benefit; Direct Payment; Tax Credits and Social Care Support. In addition depending on the nature of the disability The Blue Badge Parking Scheme; Free Tax Disc (Higher Rate DLA Mob) and the Disabled Persons’ Concessionary Fare Bus Pass and Rail Fare Concession. Gaining this funding support is complex, bureaucratic and often means tested, which deters many disabled people. It does not take account of special needs.

4.1.1 To give you an example of the problem, in 2007 I represented a disabled person who had aspergers syndrome, a mental health impairment. All his working life he had worked and at the time of the case was employed as an assistant manager on a grain farm in Kent. The farmer knew he had a mental health impairment, but sold his farm to a landholding company, they did not know he was disabled. Atos the benefits medical service required him to
undergo a reassessment for his DLA, but insisted that he do so “during the working day”. He applied for time off, and lost his job as a result. The effect on him was devastating and affected his health and wellbeing. As a direct result of my intervention on his behalf and others, Atos are now required to undertake such assessments for working disabled people, out of working hours or at weekends at their home address. This person had been supported by a mentoring scheme known as “Paula’s Plan” after the psychiatrist that piloted the 24/7 mentoring/problem solving scheme. As a result of the Tribunal Case, all mental health impaired claimants now get the lower rate of DLA Mobility Allowance, and those on this Plan get the higher rate of care component of DLA. Professor Gillian Baird stated that Paula’s Plan saves the NHS £10000 per patient per year in consultant, other clinical and nursing and support worker time, reduced medication (drugs) and general restrictive intervention. For the many individuals now on such schemes, they have degrees of independence and freedom of association. It has made a difference to the quality of their lives. The funding via DLA meets the cost of that support, remove it and the house of cards that is their life falls apart. In the case of the person I represented, we were not able to get him reinstated in his old job, but he now manages an apple orchard. As a highly qualified agricultural worker he has lost his place, in this very “closed shop industry”. DWP were criticised by the Chair of the Independent Tribunal Service for their actions.

4.1.2 DLA does not always cover all the costs faced by disabled people, for example, insurance costs are often higher, setting aside funding for maintenance contracts for equipment, saving up to purchase new or replacement equipment. Under the new proposals a person who is admitted to hospital could lose their Mobility or Support Allowances whilst they remain in hospital, yet they still have to pay for a personal assistant, Motability Contracts for a car or powered wheelchair. The announced changes take no account of the complex web of service contracts that disabled people enter into in order to provide for their independent living. Cut anyone of their funding streams for whatever reason and they go into debt. Disabled people also find it impossible to get bank loans, if they want a loan they are compelled to use high interest sources, which no right minded person would consider, sadly they have no option. That situation, as Mr Carey, Mrs Mountford and Mr Perry (see para 4.3.1) has been one of the major barriers to total independence for disabled people.

4.1.3 In answer to the second question in this section. My concerns are that in the light of George Osborne’s comments and those of the DWP, mental health impaired claimants are at great risk of being marginalised and excluded from the help they need by all the cuts. As I have suggested in Annex 1 that could resulting risk to life. There are serious concerns by disabled people regarding the proposed new assessment criteria, which is not based on medical diagnosis, but on the ability of the person to cope, for example if you are given a wheelchair you can get around; false limbs enable you to walk, no emphasis on sensory impairments, especially the visually impaired—how do they cope day to day.

4.1.4 Here are some examples of local government cuts in Kent:

- only minimum period of national concessionary fares. Previously, KCC paid for the period 0900 hrs to 0930 hours. There are concerns expressed by both disabled people and the elderly about getting to GP and hospital clinics on time, without incurring high costs, see Annex 4 taxi fare charges. Those charges are reflected across the county, one of my members a Mr John Brown, resident in Rusthall Tunbridge Wells was compelled to pay £110 return (no waiting time added) to take
him for a 0900 hours appointment at Maidstone Hospital, in the same week he made a further out-patient trip to the same hospital. In one week he incurred a debt of £220.00. There was no hospital transport available, to accommodate his wheelchair and carer

- £10 rail voucher towards the cost of Disabled Persons’ Rail Card withdrawn by TWBC

- cuts to be made to subsidised bus services, mainly serving rural parts of the county local bus operator replaced accessible buses with non accessible buses on guaranteed accessible routes

- maintenance of tactile delineators cut, this places visually impaired people at risk, especially on what are segregated cycle tracks

- Direct Payment and Social Care support to be cut by 50% over the next four years

- attempts to overcharge claimants for Social Care Support, or refuse them Direct Payment when there was evidence of just entitlement

- reorganisation of NHS services and cuts will result in rehabilitation staff and services being cut along with many specialist services for disabled people. Local charities will not be able to cope or have the funding resources to fill the gaps left in general support service provision

- central government funding for on-going improvements to independent access on railways and other facilities cut

Since 1 April 2011, all severely blind people have been granted the higher mobility allowance of DLA, according to statements from DWP confirmed by RNIB, they will lose this allowance in 2014 with the introduction of the PIP. That will bring about a legal challenge involving the concept of non retrospection in English Law, which could trigger a constitutional crisis for government and would be seen as treating blind people less favourably, in contravention of The Equalities Act 2010.

4.1.5 I quote directly from my response to Sarah Deacon (Annex 1)

“Withdrawal of mobility allowance from disabled people in residential care—did you know, they use that allowance to purchase powered wheelchairs and as a contribution towards mini buses. If it is withdrawn, the government breach Articles 8 and 9 The Human Rights Act 1998 (HRA) (Independent Living & Freedom of Association). It indicates just how poor is the awareness and understanding of the complexities of funding and supporting disabled people. That decision makes them prisoners—which if implemented, will result in action by The EU; The Court of Human Rights; The United Nations for a violation of human rights and a direct breach of The UN Social Model of Disability to which the UK has been a signatory since 2009. That will result in unwelcome financial penalties being imposed on the UK”

Currently adult social services when assessing residential care costs, for a claimant, do take full account of the fact that a disabled person is getting DLA Mobility Care Component (See the Blue Book). The comments from James Underwood (Annex 1)
illustrate just how poorly informed the Treasury are. **Mr Jason Semple, the Manager of “Seven Springs” Cheshire Home, Pembridge Road, Tunbridge Wells, Kent TN24NB Tel: 01892 531138**; a charity run residential home, within my Group area, has many severely disabled residents, who fit the above comment. By arrangement he would welcome a visit by the Committee Members who would have an opportunity to hear first hand from the residents just how they feel about the proposed government changes to their allowances and benefits, as well as the affect that the worry and stress is having on their health and wellbeing.

4.2 The Welfare Reform Bill, which impacts directly on the lives of all disabled people and will result in them being treated less favourably, discriminated against and put under pressure. The idea that they can all work is ridiculous, for the majority, being able to have degrees of independent living and freedom of association is the most that can be hoped for. It is clear from the response from HM Treasury that officials have no real concept of disabled people’s lives.

4.3 The DWP Consultation on DLA Reform, in which the government suggests that we do not understand the allowance—let me assure you—we do, “**it is designed to be a contribution towards the additional costs of our disability**”. The day to day costs of our support, social care etc should be met in full by Direct Payment and other allowances. Failure by the government to appreciate this distinction is indicative of their desire to undermine compliance with Article 19 of the Convention by all means at their disposal. Reassessing those between the ages of 16 & 65 will cause massive trauma to those most vulnerable, as will the proposal for delaying payment of DLA at a time when disabled people most need support. It is criminal and a contravention of our human rights!

4.3.1 **Disabled People prepared to talk with Committee Members:**

Mrs Francoise Mountford, […], a disabled person, who is in a wheelchair and is a member of CILK/IAM would be willing to discuss the impacts with your Members. She has been an adviser with GLAD and has European expertise on disability issues.

Mr George Carey, […]. Both Mr Carey and his wife are disabled, they are compelled to live in inappropriate housing association property. His complex medical condition makes his case and the way he has been treated by medical, social services and other local support staff of considerable interest in relation to Article 19 and the government’s funding changes, which directly affect them both. He is an example of what can happen when things go wrong in the system and how he is being made a prisoner by the system.

Mr Christopher Perry, […]. He has a mental health impairment but lives independently, with support, he undertakes voluntary work and is Co Chair of The Kent District Group Partnership—which represents groups of disabled people, especially those with a mental health impairment. He is a good example of what can be achieved with proper levels of support, but is worried that his reassessment for DLA and other allowances may cause his support to be cut. His Social Care support has been cut and he is required to pay a higher amount from his DLA Care Component.

5. **Participation & Consultation:**
5.1 Broadly speaking at all levels of government there is a willingness to consult now. Many have done so only because they must, as a result of the legal requirement of the DEIA within the OED, or The Equality Standards in Local Government Targets.

5.2 At a local level, this has been achieved via local town forums, access groups and similar bodies, although now there is growing conflict between meeting the needs of disabled people and meeting the growing demands of the elderly. This is a situation that should not be allowed to happen, but it does regularly and the pensioners win because they are often less costly or because of their voting power. At a county level, here in Kent we do have the small brains trust of The Kent Reference Panel (KRP) which advises KCC and GOSE, when called upon. Needless to say this body has been in demand by other agencies of government and local bodies such as The Kent Link which is now the county watchdog for the NHS and County Primary Care Service and Community Care Service.

5.3 Do they listen—yes.

Do they act on our suggestions or advice—rarely because it involves cost. Sadly the only way we get things done, is to put individuals on the spot or compel them under threat of legal action, then they listen and act. This is often a matter of “attitude” or “perception”, they see us a headache which will not go away. To give you an example: For 13 years my Access Group has been trying to get two lifts installed, together with other accessible facilities in our local Adult Education Centre and Library/Museum/Art Gallery with its computer areas. We have the money, which is ringfenced, a costed plan and plans produced by architects. But in spite of protracted consultation by my predecessor and I we still do not have a start date. Without the lifts these two key buildings exclude disabled and elderly people. Outreach programmes run for local schools result in disabled children being excluded. When I asked the E&HRC Disability Enforcement Unit to act, they refused, on the grounds that it would not be a landmark case and advised us to go to County Court. To date they have failed to provide the promised Case Law upon which a local case could be mounted. This is not unusual practice. Disabled people view the E&HRC as a “waste of time”. To quote one of my members, “If the E&HRC was more proactive and enforced all cases, by now we would have greater independent access to facilities, transport and the workplace”. If however, without funding public authorities cannot fulfil their obligations to disabled people. Although in our case, the money is available, we just need the green light.

5.3.1 Another barrier is lack of access to the internet. Many elderly people and disabled people cannot afford to pay internet rental costs. Many have not learned to use a computer. In the case of visually impaired people, like myself, I have a 30 year old “talking” word processor, to upgrade, would be costly due to software and hardware costs, retraining etc. without funding that becomes a major problem, especially when local charities see a 70 year old blind man as a waste of funding. Ageist it may be, but seen as a choice between young and old, the option to fund is clear and totally understandable. The problem is that government departments and other bodies, both central and local, assume that everyone is on the internet, can use computers and email. If you cannot, then they tend to ignore you. From my research in Kent I estimate that within the UK 20 million people have yet to be trained and the vast majority are disabled or aged over 60 years. If they are excluded intentionally or unintentionally then you breach the UN Convention, not to mention national legislation. It should be made an offence to exclude anyone, by any means, with a
minimum fine of £1000, for major companies and public bodies, that minimum fine should be set at £10000. Only then will this type of exclusion stop.

5.4 When I was a nationally elected disability representative, I often found resentment from politicians and twice from Tony Blair, when I pointed out to them, that my elected constituency was the UK, whereas theirs was a mere local area. Disabled people find it very hard to be accepted in work and politics, they do not present a good image. This may be changing a little, but I will never see a disabled person become Prime Minister, but it may happen, one day.

6. **Monitoring and effective implementation:**

I can only speak from my experience of the E&HRC. Clearly they do what they can under the constraints. But from a disability point of view, we would like to see a much more aggressive, proactive stance, which resulted in pressure being applied across England & Wales. If necessary given the powers to enforce changes. Using their single landmark cases they will be able to indicate a "kind of compliance with the Convention". The practical reality is somewhat different.

6.1 In Scotland, there is an entirely different approach, with plenty of funding, up to now. This has resulted in all buses being independently accessible, rail stations being accessible and much more, including the use of pictograms for people with learning difficulties. But if you were to say to me what is the reason behind this, I would have to say that it stems entirely from the way people treat you. The Scottish people today respect each other and do all they can to help each other, accept perhaps when clan or religion are involved. They remind me of the way it was in England in the 1950's, they give up their seats to ladies, a disabled person, "**must sit in the area set aside for them**", even if the bus is full and the person was happy to stand! In England we are losing the caring spirit. We can learn much from the Scots.

6.2 We need to establish a series of indicators and these need to be filled in by each county area in England, Wales, Scotland and Northern Ireland.

The list should include:

**Local Government at a County, Borough, Rural District, Unitary Authority & Parish Council:**

- **Highways**—what percentage of footways have been made independently accessible, with appropriate tactile delineators—indicate. final compliance date
- **Highways**—what percentage of traffic signal controlled crossings have audible and tactile delineators—indicate final compliance date
- **Highways**—indicate percentage of tactile/audible signage—indicate final compliance date
- **Local Transport Authority**—are all bus stops equipped with bus boarders, audible real time information boards and raised footways—indicate total compliance date
• **Local Transport Authority**—indicate percentage of independently accessible buses now operating on all routes within your area—indicate final compliance date (2017). How many are equipped with both kneeler and ramps for easy access by wheelchairs—indicate when this will be achieved

• **Licensing Authority**—indicate the total number of independently accessible licensed hackney carriages available in your area—indicate final compliance date

• **Planning**—indicate the number of independently accessible houses available in your area

• **Planning**—do you have a policy on all workplaces being independently accessible? If so what percentage are accessible? Are all refurbishment subject to independent access criteria? When do you anticipate total compliance (2025)

• **Adult Social Services**—what percentage of the total number of resident disabled people including elderly people with disabilities are in receipt of Direct Payment? When will total compliance be met for all disabled residents?

• **Adult Social Services**—what percentage of resident disabled people, including elderly people with disabilities receive direct social care support in their homes? How many are in residential care? How many residential care homes are in your area?

• What additional support to you give to disabled people, indicate:

• **Library Service**—talking books, computers with specialist software for use by disabled people

• **Leisure Services**—sports complex, social activities, Other Services—please specify

• **Local Education Service**—indicate the numbers of special schools within your area, the numbers of children currently attending special schools, the numbers in normal primary education with SEN support and in Secondary Education with SEN support with SEN additional support

• **Local Education Service**—are all establishments run by you or by Trust's independently accessible Indicate the number not accessible as a percentage of the total establishments. Indicate final compliance date

• **Local Police Authority**—provide policy on human rights and dealing with disabled prisoners within custody suites, interviewing of prisoners with mental health impairments.

• **Local NHS Acute Trusts**—examine disability equality policies as they affect, patients, employees and working practice

• **Local Primary Care Service Trusts** (in place since 1/4/11)—examine disability equality policy as it affects patients, employees and working practice
• **DWP—Employment** of disabled people in full time employment. Disabled people in part time employment. **Support:**—indicate the total numbers on DLA in each category and the percentage figure on m, SDA, Income Support as a percentage of the total number of Disabled People registered in the UK (10 million)

• **CBI—total numbers of disabled people now employed by their members**

• **Trade Unions**—how many disabled members do they have? What are their policies towards disabled trade union members and their rights? This would cause debate, especially in the current downturn.

**Note:**

The Local Government Association; Department for Health; ACPO/Home Office; DWP & CBI could assist to collecting information from its respective members

6.3 These would be some of the indicators which would give an idea of just how well the UK is performing area by area. It would then be possible to publish a league table of best performance. This would be a way of local people pushing for improved services in their areas.

In conclusion, my members have instructed me to say that they welcome the involvement of The Parliamentary Select Committee taking an interest and seeking evidence on disabled people’s rights to Independent living and freedom of association. They feel that the only way to achieve the aims of the Convention is by introducing a Bill within the life of this parliament. This Bill would then compel all government departments, local government, agencies and other bodies to respect disabled people’s right to independent lives and freedom to associate.
There was a general feeling from the group of too little too late—why are the government concerned with asking the views of people with disabilities now?—When decisions have been made and policies are already being implemented.

Re Lack of money:
- Cuts in funding

There is no uniformity across the Local Authorities

The funding that an individual receives needs to be based on individual circumstances—rather than a blanker approach to all.
- The way local councils decide whether you can get a service or not

There needs to be a consistency between Local Authorities—there are many differences between local councils

Re Getting involved and saying what you think
- How can the government involve disabled people in planning services and deciding how to save money?

Remunerate people properly, pay people the statutory rate for mileage.

Local MP’s should consult with local people with disabilities.

Experiences from the group were that often MPs hold surgeries in inaccessible buildings and at times that make it impossible for people with disabilities to attend. Individuals also reported that they receive no information about how to engage with their MP or with other government bodies.

Re sticking to the UN Convention
- How can it make sure it includes ideas from disabled people in its reports?

There needs to be more publicity that the comments from people with disabilities would be welcome.

There needs to be more advertising in public places e.g. libraries, GP surgeries, Post Offices—rather than relying on people visiting the website to find out about consultations.

April 2011
In response to the enquiry into the implementation of Independent Living for Disabled people.

I cared for my daughter who has mental and physical handicaps for 33 years and I only decided to let her go into residential care approx 18 yrs ago. My husband had died 2 yrs earlier of pancreatic cancer and I felt should I become ill or inform my daughter could be placed just anywhere in residential care. She lives in 24 hr care with a charitable trust called ‘AVOCET’ and is quite well cared for.

Over the years my husband and myself have had to fight very hard for financial help, day care etc. and it would seem that now the government are planning to remove the mobility component of the disability allowance for people in residential care for more than 28 days.

This mobility component allows such people as my daughter to use wheelchair taxis for social outings, doctors visits and dental appointments, etc. robbing them of £50.00 per week!!

I feel that this will rob people such as my daughter from the only freedom they can experience and their homes can become virtually a prison cell especially when the weather is bad.

20 April 2011
Summary

This submission relates largely to the Inquiry's term of reference about the right to independent living. I make the submission as an individual who has lived with substantial physical impairments for the past 30 years during which time I have managed my work, domestic and social life by using personal assistants (PA's) and self directed care. For many years I have received direct payments from my local authority on the basis that I require 7 sleep-overs and 21 hours personal care per week.

My submission focuses solely on a discrete point which is the inequities inherent in the Fair Access to Care Services (FACS) guidance and other regulations that relate to the finances of disabled people.

"Independent living is about disabled people having the same level of choice, control and freedom in their daily lives as any other person."

Your webpage quotes this definition of independent living which I fully endorse. As the situation stands now, disabled people (particularly those in work) do not share a level playing field with others as regards choice, control and freedom over their finances or the luxury to save for their futures. This has a direct impact on life choices.

Evidence

I have long been involved in the disability movement including campaigns to realise the prospect of independent living for as many disabled people as want it. This included taking part in campaigns and negotiations to get legislation allowing direct payments on to the statute books and to discount earnings from local authority means tests linked to care packages. I therefore hope that the right to independent living will continue to form the basis for Government policy on disability in the UK. In ratifying the UN Convention on the Rights of Disabled People the UK Government enhanced earlier commitments to independent living because Article 19 of the Convention sets out in detail State Party obligations required to underpin real independent living and the Convention (building on the European Convention on Human Rights) in general emphasises the significance of autonomy for disabled people. But currently, financial autonomy is not an option for disabled people like me who receive direct payments or other care packages funded by local authorities. A level playing field will only materialise if current policies on charging for care are amended.

My story—I am 50 years old and live with a significant physical impairment which means I need, at the very least, assistance with almost all aspects of personal care including bathing, washing clothes, dressing, bladder and bowel management and cooking. The direct payment I get is enough to employ the PA’s I need and I appreciate the autonomy and flexibility direct payments allow as regards who I employ and the times I need them to be here. Sometimes my care needs increase, for example if I have to stay on bed rest due to pressure sores which happens occasionally and I’m advised is likely to happen more as I get older and my skin becomes thinner. My direct payment does not cover the need to buy in additional PA support at these times and although my local authority assure me they can increase the payment at times like these the assessment, negotiation and form filling this entails and time
this all takes is not something I can easily handle whilst ill and therefore I tend to self fund PA’s or rely on family. There are other ways in which I supplement my direct payment which are explained below.

I have been in work for the past 25 years mostly full time, although I have recently reduced my week to 4 days. I am a lawyer and earn a good salary which is discounted for the purposes of the care package means test. For entirely logical and understandable reasons connected with fostering financial independence and the aging demographic, recent Governments have encouraged, through various means including tax breaks, people to save for their futures and particularly retirement. As I understand it, the aim is that this will lessen the burden on the state and ensure people don’t experience too much of a fall in income on retirement. The FACS guidance and related regulations provide that if I build up savings over a certain limit which is currently £23,250 the additional amount ‘may’ be used in full to pay for my care package. Over the years I could easily have saved more than this but have refrained from doing so because I object to the inequity that means there is a disincentive for disabled people in my situation are from planning a secure future through financial autonomy. I know from talking to disabled friends in similar circumstances that they feel the same way—obviously this impacts more on people who work and are in a position to save some of their salary on a regular basis.

There are significant additional costs linked to living with a physical impairment like mine which are not covered by direct payments and which are only likely to increase as I grow older. (Some of these may be discounted for the purposes of care package means tests, for example additional heating, water rates, taxis etc but in my past experience as an adviser to disabled people you require razor sharp financial and negotiating skills and a hefty dose of confidence to get them discounted.) Those that are highly unlikely to be discounted in a means test are holiday costs which will always be more than average because in many countries abroad budget option hotels are unlikely to have wheelchair access and unfortunately for me camping is out of the question(!) and PA flights and food have to be paid for as do accessible taxis and high insurance premiums. I could give many more examples such as additional PA costs, equipment (wheelchairs etc) costs and repairs, home improvements, assistance with gardening etc. At the moment I use my salary to pay these costs but a savings pot of £23,250 will not account for these for many years once I retire and whenever I think about that fact, including now, I am frankly very frightened about my future.

Another glaring inequity related to regulations governing care charges and people in work is that, although earnings are exempt from means test calculations, redundancy payments

371 Local authorities differ in how they implement this rule though in the current climate the expectation is that most will require disabled people to use savings over the limit to pay the full cost of their care package—mine already does so.

372 So that disabled people receiving care packages who can and want to are not penalised financially for getting a job.
and pension income are not. These regulations, which appear to be relatively unknown, have
directly impacted my life choices over the last 5 years as I have twice been in a position to
apply for voluntary early release (akin to redundancy), along with the entire workforce, but
did not do so because my financial settlement would take me over the £23,250 savings limit.
This has prevented me from choosing to leave my job to enjoy a career break and retrain as
a teacher which is something I want to do. Colleagues who accepted voluntary early release
have been in a position to choose new directions in life such as career breaks, retraining,
building up their own businesses or move abroad but none of these choices have been open
to me. I feel bound by the regulations to carry on working and earning until retirement age
which is something I do not relish and may not be physically able to manage when I’m older.
These regulations stipulating that redundancy payments and pension income are taken into
account as savings and income for care package means tests seem additionally unfair to me
because they are ‘benefits’ directly related to work.

Thank you for reading my submission. I hope you understand that the FACS guidance and
related regulations about disabled people with care packages and restrictions on their
savings and income are limiting how we can choose to live our lives and save for the future
in ways that do not limit others. They militate against autonomy and a level playing field
and undermine the principle of independent living.

***

I would like to support the above submission. I am a 54-year-old disabled person, I have
spinal muscular atrophy which means I have very little movement, using an electric
wheelchair for mobility. I need assistance with transferring from bed to wheelchair, from
wheelchair to toilet and regular physical adjusting in my chair for comfort. I need to be
washed, dressed and I have recently become unable to feed myself.

I have relied on support from social services for help with all these functions and have been
a recipient of direct payments since the late 80s. I have worked since 1975 (apart from one
period of unemployment lasting 10 months and a three year period spent doing a degree). I
am lucky that I have been able to work, but as I approach retirement age I am becoming a bit
particularly aware of the anomalies within the formula by which disabled people are required
to make a financial contribution towards care packages. The key issues that need to be
tackled are:

- **disabled people, are not allowed to have an income of more than Income Support
  +25% unless they are in employment. This means that pensions and other forms of
  income, which on retirement, will be essential to maintain a reasonable standard of
  living, cannot be used in the way they are intended. Instead, having a pension will
  simply mean the person will be cut off, either partially or fully, from the source of
  essential support. The likelihood is that a person’s retirement pension will be less
  than their earnings, but assuming it is higher than Income Support +25%, the
  pension will mean the loss of the income necessary to sustain the basics of life.**

- **It must be understood that a pension is deferred wages and the same applies to
  savings and capital.**

- **For many people, savings form a key part of their retirement plan. The present
  system allows savings of £23,250. This is not a big retirement nest egg, but any**
money held over that amount means that an individual will no longer be entitled to a state supported care package.

- I will reiterate that even when in receipt of a care package the likelihood is that the individual is going to have to meet hefty expenses in order to have a holiday and do other "normal" activities.

**Suggested way forward**

Disabled people must be allowed financial autonomy. Currently, we are barred from having any substantial income, savings or other resources with which to sustain ourselves. This means sustaining ourselves in the way that able-bodied people do and sustaining ourselves in terms of our disabilities, given that care packages often need supplementing.

It needs to be understood that there is little point in allowing disabled people to earn wages and to benefit from social services support, but not allowing them to use those wages to support themselves in retirement.

A solution that the enquiry may like to consider, which I feel sure would suit some disabled people, is to work on a deferred basis, in terms of contributions. This would work particularly well with regard to capital and savings. The disabled person could commit to give an amount, up to the entire value of care package received from their estate, when they die. In the meantime, they are free to function as they wish and exercise their full human rights and freedoms.
You have asked for people to let you have their views on whether and how much disabled persons can exercise their right to live independently in the community 'with the same choice, control and freedom as anyone else'.

My own personal experience relates only [so far ??] to being severely deaf and having to rely on powerful hearing-aids, and induction hearing loops being there and working properly at public places which I have to, or wish to, visit. The need for all places which set out to serve the public [shops, libraries, hospitals, railway stations, meeting halls, etc, etc] to provide such hearing loops wherever necessary is set out in the Equality Act 2010, and in the Disability Discrimination Acts of 1995 and 2005 which it succeeds and incorporates. However, I have found that relatively few of these places actually have such loops satisfactorily installed, and maintained, and working properly, and with the staff aware of them and how they should be used. This experience of mine is confirmed by an investigation which the Royal National Institute for the Deaf recently carried out which found that loops were not satisfactorily present in over 85% of the places they visited, which included major supermarkets, high street chains, libraries, etc.

The absence of loops present and working properly at all such places prevents persons disabled through severe deafness from 'exercising their right to live independently in the community with the same choice, control and freedom as anyone else'.

However, when this absence is pointed out at an 'offending' location, usually nothing is done to remedy the situation, and it just carries on as before. [The NHS, in my area at least, does seem to be a welcome exception, and is trying to improve the position regarding loops at necessary points in its premises]. I have come to the conclusion that this lamentable overall position is due to the fact that the relevant legislation does not provide any real incentive to comply with it. The Equalities Act, as its predecessors did, only provides as the route for redress a civil action to be brought by a 'wronged' user-complainant. I suggest that this actually happening is very rare indeed, not only because of the considerable possible financial cost to a complainant of bringing such an action, but also because disabled persons usually have enough problems, be they physical, 'spiritual' and financial, etc, to contend with already, to have the drive and energy to undertake such an action. The 'offender' therefore knows that it can pretty safely do nothing and just carry on as before.

I feel that at the very least the legislation should signpost and enable the way for a person who has been 'disabled' by the lack of the proper equipment etc, being in place at a location [in my case hearing loops, but for others perhaps entrance ramps, easily openable doors, accessible controls, etc] to report the fact to a suitable authority, such as for instance the local Trading Standards Office, or Borough Surveyor, etc, who would then take action as appropriate, using the tools of fines, and threats of withdrawn licences and registrations, etc.

Of course, the most effective remedy would be if failing to meet the requirements of the Disability legislation were made a criminal offence, with the penalties being sufficiently large fines, and the possibility of prison sentences for the offending owners, chief executives and managers, etc. I bet that would bring compliance rates sharply up nearer to 100% !!
In sum, the legislation intended to protect and 'enable' disabled people does not have the necessary teeth for it to work.

18 April 2011
Could the government do more to give disabled people the same rights as everyone else to live independently?"

I am writing to address the above question. I am writing as the father of a young man with quadriplegic cerebral palsy, and my focus is on the right to live independently in the community of those disabled people who have high and complex support needs.

Such people could be at the greatest risk of not being able to live independently. Increasing pressure on local authority budgets means they are likely to struggle to find the money to support independent living support plans, for example those which comprise high cost provisions. Local authorities’ mainstream funding may be focussed on basic care needs. At a strategic level there needs to be a specific and complementary source of ring fenced independent living funding for disabled people who have the highest and most complex needs. This needs to be combined with consistency of standards for this group, integrated with the wider strategy and policy framework, and with effective partnership working to achieve the best outcomes.

Enablement of access to independent living for this group of “higher needs” disabled people merits careful consideration in order to ensure they have real choice and the same rights as everyone else to live independently.

28 April 2011
1. Key points:

a. The right to independent living is fundamental to disabled people’s participation as active citizens and the lack of it limits the contribution we can make to society.

b. Funding has a significant impact on independent living and the apprehension around funding at present renders disabled people vulnerable to fear and distress.

c. Involving disabled people in the design and delivery of services is vital to ensure that we can access services that enable us to live as active citizens.

Introduction

2. I am responding to the call for evidence on protecting the rights of disabled people to independent living as an individual disabled person who uses a wheelchair and uses personal assistants for most basic tasks in life. I have been living independently since 1982 but, as I have a progressive impairment, my support needs have changed substantially during that time.

3. Currently, I run a management consultancy, chair a national disability charity, am a member of an advisory body to Government (a ‘quango’) and chair a public sector body’s disability advisory group.

4. My response is based on my experience and is purely personal. It is informed by my work with disability organisations, government agencies and disabled peoples organisations but does not represent any of their views. As it is based on my experience, I have not named any of the organisations I refer to. I am not proposing to respond to all the questions in the call for evidence. The questions I shall address are:

Should the right to independent living continue to form the basis for government policy on disability in the UK?

How will recent policy and budgetary decisions impact on the ability of the UK to meet its obligation under Article 19 to protect the right of all persons to independent living?

What steps should the Government take to meet its obligations under the Disability Rights Convention to involve disabled people in policy development and decision-making, including in budget decisions such as the Comprehensive Spending Review?

Are the current arrangements for involvement of disabled people in policy development and decision-making working?

Evidence

Should the right to independent living continue to form the basis for Government policy on disability in the UK?
5. Without a right to independent living, as a disabled person I will not have the opportunity to play an active part as a citizen of the UK. In order to take part in normal day-to-day activities such as work or civic duties, I need choice and control over what I do, how I do it and when I do it. For instance, if I cannot choose to get up at a different time in the morning in order to catch a different train into London to take part in a work or civic activity, I will be excluded from the world that I have chosen to operate in. Although it may not mean that I cannot work altogether, it would limit the level of choice that I have, and thus my ability to participate at the level I currently do, amongst other things reducing my worth, as a working person, to the exchequer. Therefore, I believe it is vital that the right to independent living forms the basis for Government policy on disability.

6. As a result of the decision to remove the mobility component of Disability Living Allowance from people living in residential care, one of the organisations with which I am involved is having to make difficult decisions about what to spend voluntary funding on. I have a strong belief that disabled people should be allowed to operate freely in society without having to rely on the charity of others, which may be given out of pity, and may also be withheld at any point. This renders disabled people's lives very precarious. As a decision-maker in the organisation, I am concerned that I may either have to compromise my beliefs or hang those we work with out to dry, and if such a choice is forced on us it would mean that I could no longer work in the organisation. Although this could be true of a non-disabled person as well, as a disabled person I feel a responsibility towards other disabled people that has a significant impact on my life choices.

7. A Disabled People's Organisation to which I have made a work proposal has had to delay its decision to undertake the work for six months because its own funding, from its local authority, has only been extended for six months, leaving it in uncertainty about its longer term future. This makes its situation very precarious but also has a negative impact on my own income stream. For those of us who work extensively in this arena, the uncertainty that Disabled People's Organisations are experiencing has a knock-on effect on our ability to sell our services and potentially, therefore, our ability to support ourselves.

8. It does not appear that the system impacts of reducing or withdrawing funding from disabled people are being considered. The example at point 7 is an instance of this. As an additional instance, if Disability Living Allowance is reduced or withdrawn, it may affect the ability to buy more accessible or specialist equipment for daily living activities (ranging in my case from an electric can opener to a ceiling hoist). This in turn can create a greater demand for personal assistance hours (e.g. to open cans) or injury to me or my personal assistants through using inappropriate equipment, resulting in cost to the NHS and possible ongoing cost to the benefit system depending on the seriousness of injury.

9. Finally, the uncertainty and apprehension that I feel about my future, not least because of the potential for a reduction in my Disability Living Allowance payments following the new assessment and the uncertain effect of spending cuts on my own local authority’s ability to continue supporting people like me and the community, is extremely stressful and wearing. As someone who has experienced depression in the past because of the physical barriers associated with inaccessible housing, I am concerned that my mental well-being may be affected by the present situation. Managing a team of personal assistants brings with it the
responsibilities of an employer, and it requires a certain amount of mental toughness and optimism to fulfil this role properly. Therefore, if my mental well-being is affected, I am concerned that my ability to manage my own living arrangements will be similarly affected.

**What steps should the Government take to meet its obligations under the Disability Rights Convention to involve disabled people in policy development and decision-making, including in budget decisions such as the Comprehensive Spending Review?**

**Are the current arrangements for involvement of disabled people in policy development and decision-making working?**

10. It is of great regret that the Government has chosen to water down the Public Sector Duty such that there is no longer a requirement actively to involve disabled people. This would have been an appropriate response to the Disability Rights Convention requirement. For many reasons, not least that involving disabled people in decision-making was a new thing both for public authorities and for disabled people themselves when it was introduced in 2006, many authorities had been only gradually getting to grips with the best ways to involve. However, examples of best practice were beginning to be established and, had this requirement been left in place, my experience of involvement both as an expert and as an individual 'punter' suggests that it would have been an increasingly positive experience for both parties and would have improved outcomes all round.

11. There are some positive examples of coproduction between disabled people and various agencies, such as the Right To Control. I am concerned that these will remain at the margins, linked only to things that uniquely concern disabled people, despite the rhetoric of the Big Society. Much of the guidance on coproduction starts with the delivery of services, but for disabled people the design of those services is almost more important than their delivery. Services that are not designed specifically with disabled people’s access needs in mind are almost certain to be inaccessible for me and, once again, such inaccessibility reduces my choice and control, as I may have to rely on specialist services instead or do without and accept the consequent reduction in life quality.

**Recommendations for the Committee to consider**

12. The right to independent living should be enshrined in primary legislation.

13. Full system impacts of withdrawing funding from (or changing eligibility levels for funding for) disabled people should be taken into account. Local authorities should be directed to work with other agencies such as the NHS to understand the benefits of enabling independent living.

14. The Government should re-introduce the requirement to involve disabled people in public sector activities and seek to encourage public bodies to learn from each other to coproduce successfully.

27 April 2011
We understand you are calling for evidence about how the cuts are affecting people with learning disabilities and organisations.

This evidence supports both these calls

At Speakup Self Advocacy the cuts are certainly affecting the organisation, we are the strongest self advocacy organisation within the Yorkshire and Humber Region often supporting other groups throughout the region and running the Yorkshire and Humber Regional forum for people with learning disabilities [...] and to say that we are limping along is an understatement. All the staff here have taken large pay cuts and the people with learning disabilities who are salaried has gone from 11 to 4 with only three on permitted work [...] there used to be 19.

As an organisation we are a better position than most [...] in that our council locally is still supporting us well and we are in a position to trade some of our resources because we make information friendly and accessible [...] However, many of the training and resource budgets have dried up and so trade through our social enterprises at the minute is almost nonexistent and funding pots through grants are completely overwhelmed.

We have done everything that the Big Society agenda is saying that the organisation should do. We have diversified, we are marketing, we are looking for funding daily and we are using lots and lots of volunteers. On a day to day the organisation thrives, it’s teeming with volunteers who are self advocates with learning disabilities who are fully involved in a work based environment running the advocacy and accessible information service and actively involved in all our ongoing projects.

However, the financial projections are very poor and unless these improve substantially the group will soon not be in this thriving position.

We have moved premises to cut overheads and cut our spending generally, sadly through loss of employment and pay cuts from £42,000 spend each month to between £22,500 and £30,000 each month and we have continued to look at the future optimistically and restructured accordingly. However, from July onwards some months we have only half this financial monthly projection so it is doubtful how long we can go on without retreating back to back to 1990’s levels of expenditure. This will mean very few people employed and a very limited service being offered locally.

We cannot understand why the government has allowed groups such as ourselves to face failure in this way [...] we are 23 years old and have gone from strength to strength always delivering targets and looking at different ways of improving services. We have developed business as far as we are able and often supported other organisations to work on a similar model.

However, we are not business marketing people, we are teachers and experienced supporters and our self advocates are expert’s by experience.
Unless the government offers more grant income to deliver the big society agenda many organisations such as ourselves will falter and ultimately fail. Leaving services wide open for large organisations to come in with a reduced second class service offering things like generic advocacy that doesn’t work within the personalisation agenda for people with learning disabilities and other vulnerable adults. (We see this in retail don’t we, with the giant supermarkets dominating the market with smaller traders swept aside [...] does the government really want this for its health and social care services).

We have supported our council deliver three beacons and we know we deliver an excellent services see our websites www.letsgetitright.org.uk www.speakup.org.uk www.imapersontoo.org.uk and www.works4me.org.uk and you will see all that we offer which is fantastic? What’s gone wrong?? Certainly we were not responsible for the banking crisis.
INTRODUCTION

1. Disability Action is a pioneering Northern Ireland charity working with and for people with disabilities. We work with our members to provide information, training, transport awareness programmes and representation for people regardless of their disability; whether that is physical, mental, sensory, hidden or learning disability.

GENERAL COMMENTARY

2. The impact of 30 years of conflict in Northern Ireland has resulted in a long-term and continuing lack of political prioritisation of such non-conflict issues as disability.

3. In this jurisdiction provision is differently organised from Great Britain. For example health and social care are combined and delivered by five Health and Social Care Boards which in Disability Action’s view is to the disadvantage of disabled people requiring community services as the majority of resources are directed towards acute services.

4. Similarly social housing is delivered by the Northern Ireland Housing Executive, employment services directly by the Department for Employment and Learning, the equivalent of the Department of Work and Pensions and education currently through five Education and Library Boards.

5. Additionally the fact that the public sector constitutes a much larger part of the Northern Ireland economy than other jurisdictions and therefore disabled people here are likely to be harder hit by the recession than their counterparts in England, Scotland and Wales.

6. As a result of social economic disadvantage and the conflict, there are higher levels of disability in Northern Ireland than in other jurisdictions.

The Right to Independent Living

Q1 Should the right to Independent Living continue to form the basis for government policy on disability in the United Kingdom

7. Yes, the policy increases independence, personal choice, control and the potential to participate in all aspects of society.

8. In Disability Action’s view there is no coherent policy on disability in Northern Ireland. Each government department delivers a series of policy objectives in a silo-like fashion. In June 2004 following a major conference (organised by Disability Action and two government departments) to mark the European Year of Disabled People 2003, the Office of the First Minister and Deputy First Minister, the department responsible for equality issues initiated a Promoting Social Inclusion Working Group on Disability.

9. This group comprised officials from all central government departments and representatives from disability organisations its remit was to identify the barriers to employment, education, transport, housing, access to information and lifelong learning—many of the elements required to live independently.
10. A survey commissioned to accompany the working group—the Northern Ireland Survey of Activity Limitations and Disability produced its first report in 2006/07. Findings were as follows:

- 18% of people living in private households reported having a disability
- Prevalence rates for adults was 21%
- Prevalence rates for children was 6%

No further reports of analysis of this important survey have been produced and it is Disability Action’s understanding that the survey of those living in communal establishments has not been completed.

11. The PSI working group took five years to produce 80 recommendations. These were presented to the First and Deputy First Minister on 3 December 2009 and to date there has been no response from the Northern Ireland Executive.

**Q2** Do existing policy statements, including the Independent Living Strategy represent a coherent policy towards the implementation of the obligations in Article 19. Could current policy be improved? If so, how?

12. Disability Action believes that the concept of independent living is not yet well understood in Northern Ireland

- There remains a lack of application of the social model of disability.
- There is confusion regarding the difference between living independently and independent living.
- As separate Disability Rights Commission existed in other jurisdictions until 2007 there was sufficient time for disability legislation and case law to bed in.

13. In Northern Ireland no overarching, coherent disability policy exists, current policy could be improved through the introduction of a programme of culture change for not only policy makers, commissioners and providers but disabled people to increase their participation in discussions about their lives. Such change must be incremental beginning with a focus on awareness raising for disabled people and policy makers. In addition the lack of a coherent disability policy points to the need for co-ordination at the highest level.

**Q3** What steps, if any should the Coalition Government, the Scottish Government or other public agencies take better to meet obligation of Article 19 and to secure the right to Independent Living for all disabled people in the United Kingdom?

14. They should recognise the need to take a grassroots approach working from childhood with disabled people to embed a belief that they have the right to the same choices and control as non-disabled people. There should be real involvement of disabled people in the planning monitoring and evaluation of services. Finally agencies and authorities need to demonstrate a commitment to deliver the policy of independent living from the highest level.
Q4 If you consider changes to policies, practices or legislation in the United Kingdom are necessary, please explain.

15. The Coalition Government needs to fully analyse and appreciate the effects on disabled people of their policy decisions in areas such as Welfare Reform, the local funding of social care and any planned budgetary changes which will limit the full implementation of Article 19.

Impact on Funding on right to Independent Living Evidence on

Q5

- Removal mobility component of Disability Living Allowance for people in residential care
- Changes to Independent Living Fund
- Big Society
- Restriction on local authority funding, social care budgets and benefits reassessment
- Increased focus on localisation and its potential impact on care and especially on portability of care and mobility for disabled people
- What impact does funding have on ability of UK to secure right protected by Article 19
- How will recent policy and budgetary decisions impact on UK’s ability to meet Article 19 obligations

16. The impact of the following on the right to independent living is clear

- Removal of mobility component of the DLA to those living in Residential Care

Statistics show that just over 10% (182,423)\(^{373}\) of Northern Ireland’s population is in receipt of DLA. In the last decade the proportion of the working age population in receipt of DLA has risen from 8% to 9% and is twice the rate of Great Britain. The predominant suggestion is that there are large numbers of people who make fraudulent claims—the reason for the high numbers on this benefit. However, research evidence would suggest that “part of the explanation for higher DLA recipiency in Northern Ireland lies in its worse levels of ill-health”.\(^{374}\)

Disability Action believes that the Government has fundamentally misunderstood how people living in care homes use the mobility component of DLA.

\(^{373}\) DLA Summary of Statistics, Nov 2009, DSD www.dsdni.gov.uk/dla_publication_feb_2010.xls

\(^{374}\) Disability Living Allowance Recipients NI www.poverty.org.uk/i15a/index.shtml
The Government believes that this cut in benefit will save £135 million a year by 2014/15, but what will be the cost to those people whose lives will be affected?

Will they and their families have to hand back their cars, will family members have to pay the transport costs to get to and from a hospital or care home, will people living in care homes be expected to stay in them for the rest of their lives without being able to participate in or make any contribution to society?

- Changes to the Independent Living Fund

As at December 2010 there were 856 users of the Independent Living Fund in Northern Ireland. The fear engendered by government statements in June 2010 was significant among users. Although in December 2010, Minister Millar’s statements protecting existing recipients and structures was welcome, the future remains uncertain and for new applicants impossible. The Independent Living Fund is a central plank in the Independent Living Strategy it deserves adequate protection.

**Participation and Consultation**

**Q6 What steps should Government take to meet its obligation under UNCRPD to involve disabled people in policy development and decision making, including in budget decisions such as CSR**

17. Not only are there greater numbers of disabled people in Northern Ireland, the attitude of disabled people here is distinctly different. There has been no organic growth of a movement of disabled people here. Disability Action has attempted on at least […]

18. This lack of development is likely to be a result of disabled people seeking to survive on the margins of their local communities in the midst of 30 years of “The Troubles”. However what is required is that the Northern Ireland Executive must recognise the need to resource a series of capacity building programmes at levels and ages to enable Northern Ireland’s disabled citizens to “catch up” with their British peers.

19. People in Northern Ireland have very limited access to information on their rights and on the services available to them therefore Disability Action believes that the next support to be put in place by Government is broad access to relevant information with associated advocacy services.

20. People cannot participate unless they have the information, knowledge and experience necessary to form their opinions. In order to empower disabled people to effectively participate in consultations the Northern Ireland Executive must immediately, efficiently and effectively build their capacity.

**Q7 Are current arrangements for involvement of disabled people in policy, development and decision making working.**

**Monitoring the effective implementation of UNCRPD**

21. No, current arrangements are not working. In the main service user involvement is not supported by the range of training, transport, accessibility and other issues required to ensure effective and meaningful participation.
22. Increasingly policy consultation is delivered using e-technology, yet Government seems to ignore the fact of low use of the internet by disabled people. Government targets for use of the internet by disabled people in 2005 was 70%, in 2011 it remains at a high of 35%, proof of the technology exclusion of disabled people.

23. Arrangements particularly in relation to the involvement of disabled people in the monitoring of the Convention are exceptionally weak. In Northern Ireland, in the year the United Kingdom has to present its first report to the Convention Committee, arrangements for the real and active involvement of disabled people in monitoring the implementation of the Convention (as per Article 33 (c)) are practically non-existent.

Q8 What steps should Government take to ensure that disabled people’s views are taken into account when drafting their report to UN?

24. Disability Action is disappointed that the draft initial report currently out to consultation is unrelenting positive, making no attempt to present a realistic picture of life for disabled people in the United Kingdom at this time.

25. Steps to ensure that disabled people’s views are taken into account when drafting the UN Reports should have included

Capacity building programmes

- In Northern Ireland the development and funding of an organisation for disabled people similar to the Participation Network (set up by central government to respond to the UN Convention on the Rights of the Child)

- In Northern Ireland changes to disability discrimination legislation to ensure that disabled people’s rights in Northern Ireland have parity with their peers in Great Britain (currently not the case)

- Reinforcement of the practices associated with Section 75 of the Northern Ireland Act 1998 to ensure a more robust approach by public authorities to screening and impact assessment in relation to disability.

Q9 As part of the national monitoring mechanism what steps should EHRC, NIHRC and SHRC take to ensure that the Convention is implemented effectively?

26. In Northern Ireland the Equality Commission and the Human Rights Commissions act jointly as the monitoring mechanism. Disability Action believes that until both Commissions agree effective strategies to involve disabled people the Convention will not be implemented effectively.

CONCLUSION

27. Disability Action believes the work of Thomas Hammerberg in his latest publication for the Council of Europe “Human Rights in Europe” states the issues and the solutions.

28. Disabled people in Northern Ireland have been disappointed by a number of lost opportunities to gain their rights one of the most recent being the failure to achieve a Bill of
Rights for Northern Ireland. In addition, the difficulty remains of getting policy makers to recognise disability / independent living as a human rights issue.

29. If the Joint Committee requires any further information, Disability Action is happy to provide a longer written submission on any area required.
INTRODUCTION

1. Disability Action is a pioneering Northern Ireland charity working with and for people with disabilities. We work with our members to provide information, training, transport awareness programmes and representation for people regardless of their disability; whether that is physical, mental, sensory, hidden or learning disability.

2. Disability Action would like to thank the Joint Committee on Human Rights for the opportunity to comment further on this important inquiry.

The Right to Independent Living

Q1 Do you believe that the UK Government and each of your devolved Government shares your understanding of what independent living means for disabled people?

3. Disability Action does not believe that there is a shared understanding. In order to have a starting point for understanding of independent living there has to be a mutual acceptance that there is a ‘right’ to independent living. Awareness of the UNCRPD remains low especially amongst policy makers and persons with disabilities as demonstrated by the near absence of reference to it in policy papers coming out for consultation and the relative weakness of the disability rights campaign. Research for the Equality Commission for Northern Ireland by Disability Action 375 found that in that disabled people, campaigning groups and departmental representatives believed that it was essential that awareness raising is prioritised as an area of action by government to ensure the implementation of the UNCRPD.

4. In Northern Ireland, the report ‘Promoting Social Inclusion Working Group on Disability’ (PSI) Report 376 regarded independent living as a goal through which every disabled person should be supported to empower themselves to become active, independent citizens with the freedom to make choices that affect their lives and avail of services that are individual centered and accessible. The PSI Report recommended that the Northern Ireland Executive should undertake a review of Independent Living to identify practical and innovative ways to enable disabled people to live their lives the way they want to and place Independent Living at the centre of its focus on Disability Issues. 377 To date, no such review has been released although the OFMdFM is currently working on a strategy.


376 OFMdFM (2009) Annex to the report of the Promoting Social Inclusion working group on Disability

377 Annex to the report of the Promoting Social Inclusion working group on Disability, Recommendation 48, 2009
5. Disability Action would also refer the Joint Committee to Paragraph 12 of our written submission.


**Q2 Other witnesses have commented that there is a gap between independent living policy and the actual experiences of disabled people. Are there similar gaps in Northern Ireland?**

7. Independent living is a complex area with a number of factors including housing and living arrangements, participation, personal mobility, access to information, support services and access to social and community services on an equal basis to others and the responsiveness and effectiveness of these services and policies. The right to advocacy under Article 12 UNCRPD for which there is no national strategy is also relevant. As reported above there is currently no coherent policy in relation to independent living in Northern Ireland.

8. The most comprehensive research on the experiences of disabled people was the 2010 ONS survey in Great Britain[^378] which found that independent living is fundamental to achieving disability equality, enabling people with disabilities to fulfil the roles and responsibilities of citizenship. As is common, this ‘national survey’ did not include Northern Ireland.

9. Within Northern Ireland, some research has been carried out into aspects of independent living[^379] however there is little comprehensive information as much of the Northern Ireland Survey Limitations and Disability 2007 instigated to accompany work of the PSI working group remains unpublished and the expected survey from of those living in communal establishments remains uncompleted.

**Q3 You have commented that the impact of the Government’s proposal to reform the benefit system, together with cuts to local authority funding could lead to a breach of Article 19 of the UN Convention on the Rights of Persons with Disabilities. Can you explain your conclusion—and is there a particular proposal which you think will violate the Convention? Can any of you give us a concrete example of the cumulative impact of recent policy changes on the lives of disabled people?**

10. As commented above at paragraph 7, independent living is a complex area and many UNCRPD articles affect the provisions of Article 19. Article 19, in part, allows for progressive realisation and it likely that any restrictions due to the UK economy will enviably result on the State’s ability to fully implement the UNCRPD. In some instances a reduction in provision may lead to a regression in the level of the rights already enjoyed.

[^378]: ONS (2010) Opinion Survey
[^379]: For example; the work undertaken by IMTAC on transport in Northern Ireland. See http://www.imtac.org.uk/publications.php
11. Through ratification of Article 19, State Parties recognized the equal right of all persons with disabilities to live in the community. It is important to note that the article explicitly states ‘all persons with disabilities’ without qualification of any kind. In living in the community, persons with disabilities should have ‘choices equal to others’—this provides a standard by which both the nature and the extent of policies and programmes which are required can be determined for any given State Party.

12. State Parties are obliged to take ‘effective and appropriate measures’ (which will include a range of policies and programmes) to ‘facilitate’ (not ‘ensure’) full enjoyment of this right. Distinct from the facilitation of enjoyment of this right, there is also an obligation on States Parties to facilitate ‘their full inclusion and participation in the community’. What is required of States Parties in fulfilment of this right and the nature of the obligation of ‘full inclusion’ are elaborated upon further in a non-exhaustive list of things which States Parties must ‘ensure’. This list provides a check list against which policies and programmes can be measured as sufficient for the fulfilment of the obligations of this right. States Parties must ensure that Persons with disabilities:

- Have the opportunity to choose their place of residence;
- Have the opportunity to choose where and with whom they live (on an equal basis with others); and
- Are not obliged to live in a particular living arrangement;
- Have access to a range of in-home, residential and community support services.

14. In a clear ‘end implies the means’ explicating phrase, Article 19 (b) stresses that support services must include ‘personal assistance necessary to support living in the community and inclusion, and to prevent isolation or segregation from the community’.

15. Article 19 (c) requires that community services and facilities aimed at the general population be available to persons with disabilities ‘on an equal basis’ and that they be ‘responsive to their needs’. This clearly requires policies and programmes across the range of community services and facilities to ensure that they are so available.

16. Disability Action previous written submission to the Joint Committee used the example of the proposed removal of the mobility component of the DLA to those living in Residential Care. One of the elements in Article 19 and central to the UNCRPD is to increase participation and reduce isolation. Policy makers must ask the question would the removal of mobility component of DLA for people in residential care reduce the ability of these disabled people to participate and contribute to society. Would it reduce the rights currently enjoyed by these persons with disabilities? The question should be, is this regression a violation of their rights? This is a complex question due to the interplay of a number of civil and political rights which must be realised without delay and progressive rights on Article 19. This question may only be answered by further clarification from the UNCRPD committee or by a body of legal precedents.

Q4 It has been suggested that the impact of funding cuts and changes to benefits will have a disproportionate impact in Northern Ireland. Have you seen any evidence that the impact on people in Northern Ireland or Wales will be particularly acute?
17. The effects of £600 million reduction in Northern Ireland funding is only beginning to impact and Disability Action is part of the Hardest Hit campaign which brings together disabled people, carers and organisations and groups who represent them to monitor the effects on people with low incomes which include a disproportionally high level of disabled people and to campaign to reduce the effect of these cuts.

18. There is evidence that Northern Ireland relies heavily on the public sector due in part to the legacy of the ‘troubles’ and consequently the reduction in public spending will have greater impact. There is also evidence that the population relies more heavily on benefits than other areas. An example given in the previous written submission (paragraph 16) is that statistics show that just over 10% (182,423)\(^{380}\) of Northern Ireland’s population is in receipt of DLA. In the last decade the proportion of the working age population in receipt of DLA has risen from 8% to 9% and is twice the rate of Great Britain. Research evidence would suggest that “part of the explanation for higher DLA recipiency in Northern Ireland lies in its worse levels of ill-health”.\(^ {381}\)

19. Disability Action has noted several impacts of funding cuts to date, uncertainty and delays in the funding of voluntary groups has led to the postponement of services and work planning and the withdrawal of services, for example, the family fund is closed for applications until October 2011.\(^ {382}\) Other services have closed following a withdrawal of funding, for example, the Northern Ireland Music Therapy Trust.\(^ {383}\) However as reported previously, there is no quantitative research currently available in Northern Ireland to clarify the position.

20. The absence of and the inaccessibility of statistics and information and of a broad local research base on disability makes any fact based argument difficult and is a potential barrier to the engagement of disabled people with the monitoring framework under Article 33(3) UNCRPD.

Q5 The National Implementation Mechanism in Northern Ireland—the ECNI and the NIHRC—has told us that it is important that equality legislation is reformed, but they do not consider that the Equality Act goes far enough. Do you agree that it is important that the legislative framework in Northern Ireland needs to change and if so how?

21. Disability Action would agree with the National Implementation Mechanism of the importance of Northern Ireland achieving parity with the rest of the UK in relation to equality legislation as long as any proposed framework in Northern Ireland covers issues such as religious sectarianism which have greater affects in Northern Ireland than elsewhere.


\(^{381}\) Disability Living Allowance Recipients NI www.poverty.org.uk/i15a/index.shtml


This may require changes in GB legislation if a single act is envisaged. Lessons learnt from the implementation of the Equality Act in GB should be incorporated into NI legislation and the principle of full participation in the drafting process should be adhered to.

**Q6 What role does the Equality Act 2010—in particular the public equality duties in the Act—play in the protection of the right to independent living?**

Outside the formal duties in the Equality Act 2010, do you think it is possible for public authorities to assess the impact of proposed changes to policy on independent living before they take effect? Do you think that there are any examples of good practice in Northern Ireland?

22. As the Equality Act does not apply to Northern Ireland Disability Action leave any comment on its effects to respondents with direct experience.

23. In general terms there are well established management practices to analyse the predicted affects of change. It is essential that the service users, especially people with disabilities fully participate in this process.

24. A good example in Northern Ireland was the participation and consultation during the formulation of the Autism Act 2011.

**Q7 The UK Government has told us that although difficult choices are being made to tackle the deficit, they intend to ensure disabled people with the most difficulties are effectively supported to live an independent life. They stress that independent living is “not just about the money”. Do you agree with the UK Government assessment that meeting obligations in the UN Convention is not just about money?**

25. It was never about the money alone. The UN Convention is about changing attitudes and practices; it is about awareness raising and the right to participate in society. It is about asking disabled people ‘first’ before policy formulation and change. It is about ensuring that the information people with disabilities want is available for them in order to fully participate in society. It is also about understanding that there will be extra costs and time required to ensure that some people with disabilities are able to fully participate and to include this in consultation budgets. It is about respect. These matters have been raised with the Implementation Mechanism in Northern Ireland (IMNI) in Northern Ireland through recent (as yet unpublished) 2011 research carried out by Disability Action for the ECNI. 384

**Q8 In the light of the proposals in the Comprehensive Spending Review, do you think that there are specific changes to Government Policy which could better meet the UK’s obligations in the UN Convention without increased funding?**

26. Disability Action’s research (see 3 above) asked disabled people and representative organisations what they believed was the most important change the state could make to ensure the full implementation of the UNCRPD. They believed that awareness raising to change attitudes to disabled people, through public campaigns, the media and schools was

the best way to achieve this. They stressed that disabled people must be involved in the
development of these campaigns and in their presentation. Many of their proposals would
involve minimal cost and relate more to a change of emphasis, notably in relation to the
teaching about Human Rights in schools in which it was proposed to highlight the UNCRPD
into the learning for work and life curriculum and the supply of a teaching pack. Some costs
would be involved for the envisaged national information campaign.

27. Another issue raised by the disabled people and representative organisations in the
Disability Action study was that access to robust information and statistics was essential to
allow them to both fully participate with government in the formulation of policy and in the
monitoring of the Convention. This change would require little cost but would involve a
review of procedures, a change in attitudes and greater coordination.

**Q9 Are there variation between different local authority areas in Northern
Ireland in terms of what levels and types of support disabled people can expect?
If so are there any proposals to address this in a Northern Ireland context?**

28. In this jurisdiction provision is differently organised from Great Britain. For example,
health and social care are combined and delivered by five Health and Social Care Boards
which in Disability Action’s view is to the disadvantage of disabled people requiring
community services as the majority of resources are directed towards acute services.

29. Similarly social housing is delivered by the Northern Ireland Housing Executive,
employment services directly by the Department for Employment and Learning, the
equivalent of the Department of Work and Pensions and education currently through five
Education and Library Boards.

30. Resources are allocated by a regional capitation formula to ensure the fair allocation of
the available resources for each geographical area for the allocation year. This is determined
by considering the resident population of the areas, its age and gender structure, along with
the relative need for each of the nine programmes of care.

31. Further adjustments are also made to each of the allocations based upon the rurality of
the areas and the economies of scale present within the structures within the areas being
considered.

32. The formula is updated annually with the latest demographic and expenditure data and is
produced at a number of geographic levels to fully inform planning and reviewing of
expenditure. Research to update the formula is carried out on a continuous and rolling basis
helping the formula reflect current thinking in the resource allocation community and
current socioeconomic circumstances prevalent within Northern Ireland. All research is
carried out under the direction of Capitation Formula Review Group (CFRG). The last
published review of the scheme was in 2008. The formula depends heavily on the
accuracies of the population figures which in relation to disability are variable in robustness.
NI Statistics and Research Agency half year estimates are currently used.

33. The Inequalities and Unfair Access Issues Emerging from the DHSSPS (2004) “Equality and Inequalities in Health and Social Care: A Statistical Overview” report\(^{386}\) commented on a lack of consistency across Northern Ireland in terms of the types and level of provision, which may indicate service inequities. The Northern Health and Social Services Board had the highest proportion of people in nursing home accommodation (46\%) as compared with 22\% in the Eastern Health and Social Services Board. The Eastern Board had the highest level of people in supported living arrangements (31\%) as compared with only 4\% in the Western Board and 3\% in the Southern Board. A report from the Audit commission (2009)\(^{387}\) on the resettlement of long-say patients from learning disability hospitals did not comment on the issue of inequalities of provision. It did however comment that Northern Ireland lags behind the rest of the UK in the speed of change from institutional care to independent living. in March 2009, 256 patients remained in long-stay hospitals in Northern Ireland despite the Department setting a target in 1997 that all patients in long-stay learning disability hospitals would be resettled by 2002. This target has been revised repeatedly and is now set for 2013. This process is the subject of a current High Court review in Belfast to challenge the delayed discharge of patients from Muckamore Abbey Hospital.

34. There is also strong anecdotal evidence that from support organisations that the levels and types of support disabled people can expect differs between the boards. However no collated data from these groups is available. The proportion of money allocated to each board is reflective of their population demographics however how the money is spent differs between the Boards within statutory guidelines. Populations in boards have different needs and this is reflected in the estimated needs shown in the Capitation Formula Review Group (CFRG) 2008 document.\(^{388}\) An in-depth across Board analysis of the composition of services and unmet needs is not publically available.

35. There are however examples of different services being offered by the Boards. While there is no policy in Northern Ireland for the personalisation of services or ‘Self Directed Support’, a small scale project (30 people) independently started in April 2011 in the Southern Trust. This project is entirely within the control of the Southern Trust and if successful will be promoted to the other Trusts.\(^{389}\)

36. As reported in paragraph 4 above the ‘Promoting Social Inclusion Working Group on Disability’ (PSI) Report\(^{390}\) recommended a review of Independent Living by the NI executive however a review has not been released.

Q10 Does disparity of provision and problems with portability of care have a particular impact across borders within the UK? If so, how do you think that this

\(^{386}\) [http://www.dhsspsni.gov.uk/learningdisability.pdf](http://www.dhsspsni.gov.uk/learningdisability.pdf)


\(^{388}\) Ibid


\(^{390}\) OFMdFM (2009) Annex to the report of the Promoting Social Inclusion working group on Disability
disparity impacts on the UK ability to meet its obligation under the UN Convention?

37. Care package are not transferrable between GB and Northern Ireland. On arrival in Northern Ireland the person would be reassessed and this may result in a different package being agreed. There may a substantial period of time between arrival and the care package being put in place.

38. No obligation in the UNCRPD to have an equal care package, but it does recognise (Article 19-a) the right for people with disabilities to choose their place of residence.

Q11 Do you think that the UK Government, local authorities and the devolved Government currently meet the obligations under Article 4(3) of the UN Convention to consult and involve disabled people in the formation of law and policy? If not, can you give us a specific example of a failure to meet these obligations?

39. Article 4(3) UNCRPD is extremely important to the UNCRPD in that requires close consultation in the development and implementation of policies to implement the convention. However Government consultation in Northern Ireland frequently is restricted to a statutory public consultation after policy has been formed. It is rare that policy goals, formulation, drafting, methods of delivery or monitoring is discussed with disabled people. This is especially notable in non ‘disability’ general policy affecting the population for example the environment.

40. Disability Action would also refer the Committee to Article 29 (b) which requires that States Parties actively promote an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs and encourage their participation. This is to be done without discrimination and ‘on an equal basis with others’.

41. Throughout Article 29 there is an emphasis not only on ‘full’ participation, but on ‘effective’ participation. The obligation to ensure the latter is clearly significant in assessing the adequacy of the range of policies and programmes which aim at delivering on its obligations. It is the active participation in the process of government and policy formation which is crucial in ensuring that the aims of the UNCRPD are achieved.

42. Research carried out in 2009 for the ECNI reported that out of the 21 public authorities assessed, 8 provided evidence they had consulted or involved disabled people in the production of their Disability Action Plans. However, 13 public authorities provided little evidence of meaningful consultation in terms of the activities undertaken, by reporting in detail on these activities and the outcomes of these activities.391 Disability Action is unaware of any research carried out into the number of policies on which disabled people have been consulted during the formulation period. The majority of policies are placed on statutory public consultation however few are directly forwarded to Disability Action for comment. The majority of customer facing policies are not consulted on.

43. It must also be commented that in Northern Ireland consultation (normally after final draft policy has been formed) takes place due to a statutory obligation under discrimination legislation and not as a consequence of the UNCRPD. Few departments or public authorities are currently making reference to the UNCRPD in their disability planning.

44. A specific example in relation to a failure to consult with disabled people in relation to Article 19 related policies is a difficult question to answer. As commented earlier much of the policies created as the result of interaction between bodies and little information is often available.

45. An example can be provided in relation to the policy on suicide prevention policy which illustrates a trend noted by Disability Action research on a number of occasions. In carrying out an impact assessment, public bodies examine the potential impact of policies on a number of groups such as women however frequently in the case of disabled people there is very little data available and it is therefore assumed that a general policy will suffice.

46. Suicide Prevention Strategy

In Northern Ireland the suicide rate has increased by an alarming 64% in the past decade.\(^{392}\) The primary policy is the Northern Ireland Suicide Prevention Strategy and Action Plan 2006-2011 which seeks to reduce the suicide rate in Northern Ireland.\(^{393}\)

An examination of the suicide prevention consultation report\(^{394}\) reveals, “When considering the equality implications of the Promoting Mental Health Strategy and Action Plan the Department considered data from the Health and Social Wellbeing Survey 2001, the Health Behaviour of School Children 1997/98, and Safety First: National Confidential Enquiry into Suicide and Homicide in People with Mental Illness. The Department has revisited the available information, and in particular specific information from the General Registers Office (GRO) relating to suicide. Data on all nine equality groups outlined in the Northern Ireland Act (1998) is not recorded. Information is only readily available for sex, age and marital status. However the full postcode is recorded which allows various geographical comparisons to be made”.\(^{395}\) The Department also considered research in sexual orientation.\(^{396}\)


\(^{394}\) DHSSPS Suicide consultation main report. See: [http://www.newcolin.com/uploads/7b7b01fe-58e2-4222-8385-7220f17ec7e8/Suicide%20Consultation.pdf](http://www.newcolin.com/uploads/7b7b01fe-58e2-4222-8385-7220f17ec7e8/Suicide%20Consultation.pdf)

\(^{395}\) Ibid, paragraph 2.6 at [http://www.newcolin.com/uploads/7b7b01fe-58e2-4222-8385-7220f17ec7e8/Suicide%20Consultation.pdf](http://www.newcolin.com/uploads/7b7b01fe-58e2-4222-8385-7220f17ec7e8/Suicide%20Consultation.pdf)

Following the consultation the department decided to use a dual approach using a population and targeted approach. The population approach seeks to tackle the issue of suicide in a wider generic context, with actions aimed at protecting the general population of Northern Ireland. The targeted approach seeks to tackle the issue by targeting actions at those within society who are most at risk of suicide, for example, young men and marginalised and disadvantaged groups which it states must be complementary.

The Department considered that the policy should impact positively on the health and emotional wellbeing of the general population and it commented that it considered that as the Strategy and Action Plan did not adversely impact on any of the nine equality groups and therefore a full Equality Impact Assessment was not required.

However the report recognises that the policy is most likely to have an impact on gender, age, religion, marital status and sexual orientation and that it will also impact on those from lower socio-economic groups. The report also recognizes that due to the limited equality data for deaths recorded by GRO, it is quite possible that there may be differential impact on other equality groups that have not been analyzed such as those with a disability, black and ethnic minority and those with/without dependants.

As stated despite this recognition a full impact assessment was not carried out and it appears that further investigation into the risk of suicide for disabled people and directed suicide prevention strategies for disabled people were not pursued. No changes were made in relation to the recording of disability by the GRO.

Q12 Are you satisfied that disabled people in Northern Ireland have been effectively involved in:

i. The preparation of the UK first periodic report to the UN; and

ii. In the work of the national implementation mechanism (i.e. in the work of the National Human Rights Commissions on the Convention).

47. The engagement with disabled people in the preparation of the UK first periodic report to the UN was poor. While a Disability Action representative was on the ODI working committee the primary opportunity to influence content was at the regional level. In Northern Ireland, primary research, including the extensive use of focus groups with disabled people and their organisations, was being undertaken by Disability Action for the IMNI (ECNI) at the time of the collation of data for the regional report by the state. Despite requests by the Disability Action research team there was little engagement with the research from the state. The state did hold a small series of discussion groups with disabled people and organisations at the end of this collation of reports from the departments.

48. Disability Action can only make comments on the Implementation Mechanism for Northern Ireland which consists of the ECNI and NIHRC. The IMNI has engaged with disabled people and their organisation through the commissioning of research and by direct engagement through seminars and a major conference. The ECNI are considering research submitted to them by Disability Action and it is intended to publish this, in a shortened format, for the information of interested parties.
CONCLUSION

49. Disability Action is happy to provide further information on any area if required by the Joint Committee.
1. The Public Interest Research Unit (PIRU) welcomes the opportunity to submit evidence to the above inquiry. PIRU is a small non-party political research and advocacy registered charity, which focuses upon discrimination law issues.

2. Our evidence is principally based upon research (covering the impact of the government spending cuts on employees with disabilities in the public sector) carried out by PIRU's chair between 2010 and 2011 in 22 local authorities, 8 colleges and universities, 4 museums, and two schools. Further details of this research are provided at appendix A to this submission (a conference paper presenting the findings of this research).

We have set out below some of the points (arising from the research) we would like to stress.

3. **Independent living**

Discrimination in the work place indicated in this research (including failures to make reasonable adjustments) is undermining the ability of employees with disabilities to live independently; especially when some of those who lose their jobs as the result of discrimination appear to suffer a substantial decline in health and find it hard to get back into work.

2. **Impact of the cuts on reasonable adjustments**

The government cuts appear, in some of the organisations, to have resulted in:

(a) Fewer reasonable adjustments being made, which appeared, in some instances, to have resulted in disabled employees being unable to do their job and thus being dismissed.

(b) It taking longer for reasonable adjustments to be agreed and made.

(c) Disabled employees having to fight harder to get reasonable adjustments.

(d) Disabled employees, as a result of fears arising from the threat to their jobs, being reluctant to request reasonable adjustments.

(e) The reasonable adjustments duty being breached more often; including as some employers failed to realise that particular adjustments would still, not withstanding a cut in budgets, have been reasonable in law.

3. **Impact of the cuts on the dismissal of disabled employees**

(a) In some organisations, redundancies appeared to be starting to have a disproportionate impact on those with disabilities and/ or health problems; and, in particular, on those with mental health conditions. It appeared that many disabled employees were going from being...
the hardest hit in the work place to (with cuts to disability benefits) the hardest hit out of work.

(b) Few redundancy procedures seen, from the interviewee organisations, appeared to have been impact assessed; raising speculative questions about the lawfulness of the redundancy process so far across the public sector.

(c) It appeared that some organisations, in making redundancies, may well have been acting in breach of the reasonable adjustments duty. For example, a disabled council employee, who had severe problems lifting, was only offered redeployment interviews for manual posts (for which heavy lifting was an essential requirement). Since he could not get close to doing these jobs, he was made redundant.

(d) It appeared (again in possible breach of the reasonable adjustments duty) that in some organisations, employees were made redundant because their organisation was unwilling to make reasonable adjustments to posts to which they might otherwise have been redeployed. It appeared, for example, that one interviewee was qualified to do an alternative post but was not able to take it up because the council was not prepared to transfer, to this new post, the reasonable adjustments (including time off for medical treatment) which were in place for her at risk post.

(f) It seemed possible in at least one council that capability and sickness absence procedures were being used to unlawfully to get rid of employees with disabilities or health problems, without needing to make redundancies. In the words of the interviewee, "they've been looking to weed out people that are easy to get out". An interviewee, from another council, said that employees with mental health problems are "being targeted for absence".

4. The future of disability equality in the public sector

The impression gained was that there was a quite strong public sector disability equality ethos across the interviewee organisations. However, it might be wondered whether - under the combined pressure of the cuts, an official nod towards side-stepping 'regulations', and the portrayal across the media of the disabled as fakes and fraudsters (the results of which appear to be spilling over into the work place) - the future of the public sector disability equality ethos might be in some doubt. Further, bearing in mind the positive role that the reasonable adjustments duty appeared to be having, it seems possible that any weakening of it, perhaps as a result of the euphemistically entitled Red Tape Challenge, could lead to a rapid decline in equalities practice and a spiralling increase in incidents which (but for the relaxation in the law) would have constituted unlawful discrimination.

July 2011
Changing Perspectives

Changing Perspectives is an organisation which works with disabled people to campaign for equality and inclusion. Simone Aspis (Director) oversaw People First’s campaign to ensure that people with learning difficulties were included in civil rights legislation (Disability Discrimination Act) and direct payments (Community Care [Direct Payments] Act). Since then we helped to set up the I Decide Campaign which campaigned for disabled people with learning difficulties rights to make their own decisions with support and for those lacking capacity to benefit from direct payments. (Mental Capacity Act)

Changing Perspectives have been commissioned by National Centre for Independent Living and People First to undertake pieces of work on what independent living means for disabled people with learning difficulties.

Focus of our submission

Changing Perspectives focus will be on how the Coalition Government’s housing policies are likely to impact upon disabled people’s rights to live independently. We are of the opinion that the Government’s housing policies will severely undermine disabled people’s rights to live independently, under UN Convention On The Rights of Persons with Disabilities Article 19. We anticipate many disabled people will be forced into institutionalised care in group living accommodation—a return to the long stay residential care / long-stay ‘asylums as a result of the Coalition Government’s housing reforms.

In this briefing we are going to highlight how the Government’s housing policy conflicts with their Article 19 duties, to support disabled peoples independence through the provision of housing.

Housing Benefit Regulations changes

Single Room allowance only payable for housing benefit claimants up to 35 years of age

Many disabled people under 35 years of age will be forced to live within institutionalised group homes unless they continue living with their parents. This is because most disabled people with learning difficulties are not in paid work and therefore will only be entitled to the shared accommodation allowance. And even when disabled people with learning difficulties are in paid work, many of them will stay in entry level jobs, without any prospect of promotion and increased wages throughout their lives. This will result in Disabled people being trapped in group living accommodation simply because they are claiming housing benefits. As a result many disabled young people under 35 years of age will not be able to live independently outside institutionalised group home accommodation.

Private Renting—Housing Benefits cap

Many private landlords advertise no DSS/Housing Benefit claimants please! This is perfectly legal and will reduce the choice of accommodation available for disabled people.
The Government wants to impose a housing benefit cap so that claimants will only receive an amount which covers 30% of the cheapest accommodation rent. The available ‘affordable’ accommodation will be in areas with social problems including high crime incidents and not be close to the disabled person’s family, friends, community they grow up in or near the services they use. Having family, friends and community we know not only enhances our quality of life but can aid our independence especially when social care is not forthcoming. For example a family member may help their daughter/son with paying the bills, going through the paperwork etc. If disabled people cannot afford to live near their social networks, then they are going to be forced into institutionalised group home accommodation.

With less social housing being available, increasingly disabled people will be forced to rely on the private sector for their accommodation. With no guarantee of a long term tenancy, many disabled people may find they cannot get their homes adapted with aid of a disability facilities grant. As a result many disabled people will end up living in “accessible” institutionalised group home accommodation.

Social Housing Changes

The Government is proposing big cuts in social housing grants. Many disabled people including those with learning difficulties live in social housing accommodation with secure tenancy and affordable rent. The Government wants social housing landlords to set their rent up to 80% of the market rent. This will result in social landlords being able to charge rents based on increased market rents as a result of landlord’s taking a financial advantage in absence of a sufficient supply of private rented accommodation. The Government’s proposals are going to have a real severe impact upon disabled people, who may never have the chance to own a home.

We understand the Government is allowing social landlords to give priority to the “deserving poor”, applicants who are in paid work—just like in the 1970s when social housing was only available for people who are in paid work and could provide references of “good character”. This was at a time where many disabled people with learning difficulties were living in long-stay hospitals if not with their parents. No doubt we will see a return to the “deserving poor” whereby disabled people with learning difficulties will not have access to social housing because of being unemployed. And for disabled people with learning difficulties in paid work, they are unlikely to afford the social housing rents which will be determined by private landlords taking a financial advantage even with housing benefit assistance because of the benefit caps.

Many disabled people will be priced out of social housing as well as private housing. This is likely to result in disabled people being forced into institutionalised group home accommodation as they will not be able to access disability facility grants or be able to afford either private or social housing rents with or without housing benefit assistance. Forcing disabled people either to live in group home accommodation or with their parents is clearly incompatible with Article 19.
1.1 On the 5th July 2011 Turning Point’s Director of Learning Disability, Adam Penwarden, gave evidence to the Joint Committee’s inquiry on the right of disabled people to independent living.

1.2. This submission is to follow up on a number of points raised during that evidence session.

Turning Point

1.3 Turning Point is a leading health and social care organisation. We work in over 200 locations, providing specialist and integrated services that meet the needs of individuals, families and communities across England and Wales.

1.4 We are a social enterprise and reinvest our surplus to provide the best services in the right locations for people with a range of complex needs including those with mental health conditions, substance misuse issues and people with a learning disability.

1.5 Turning Point has been delivering Learning Disability services for 20 years. Our provision in this sector includes day opportunities, floating support, supported living and residential care.

Our response

1.6 In my oral evidence given to the Committee I outlined why protecting the right to independent living is so important for people with a learning disability. I spoke about the impact cutting the mobility component of Disability Living Allowance (DLA) will have on the people Turning Point and others support and how the Government’s health and social care policy is affecting the lives of the people we support.

1.7 There were a number of points where I feel further detail may support the committee’s enquiry. This response therefore focuses on three key issues:

1. The arguments against the Government’s stance on scrapping the mobility component of the DLA as set out in the ‘Don’t Limit Mobility’ report.397

2. The importance of ensuring outcomes for people with a learning disability, whether living in residential care or supported living accommodation.

3. The potential impact of the Wychavon District Council v. EM case regarding the provision of supported living accommodation for people with capacity issues who receive housing benefit.

397 Don’t Limit Mobility was published in January 2011, supported by 27 social care organisations including the Turning Point, Learning Disability Coalition and the National Centre for Independent Living. The full report can be found here: http://www.southwiltsmencap.org.uk/SWM2/Docs2/Don’t%20limit%20mobility[1].pdf
1. The mobility component of DLA

1.8 As the Committee will be aware the 2010 Spending Review announced that from October 2012 the Government will no longer pay the mobility component of DLA to disabled people living in residential care, unless they are self-funders. The proposed change has been delayed until March 2013.

1.9 In response to the government’s arguments for this decision, 27 social care organisations and coalitions published the Don’t Limit Mobility Report refuting the government’s arguments for cutting the mobility component of DLA for people in residential care.

1.10 The conclusions of the report are that:

- The removal of the mobility component of the Disability Living Allowance, soon to become Personal Independence Payment (PIP) from people living in residential care, will directly undermine the government’s commitment to social justice and increasing independence for disabled people.

- The DLA mobility component provides absolutely vital support to many disabled people in residential care. It reduces individual’s dependence on their care provider and directly gives them the means needed to help meet the additional costs that they can face in getting out and about and living a community life.

1.11 I have included the report as an annex which sets out arguments and evidence against each of the central planks of the government’s thinking on this issue. As way of summary these are set out below:

(i) The Government has stated that the responsibility for mobility / transport costs should be met by the care home provider as they are obliged to support disabled people’s ‘independence’ as part of registering (as is outlined in legislation and guidance) and therefore there is no need to deliver support through the DLA/PIP mobility component.

(ii) DLA mobility is being misused and needs reforming

(iii) DLA mobility is being used to purchase wheelchairs when this cost should be met by the NHS Wheelchair Service

(iv) The change will align the rules for people living in residential care with people in hospital

(v) The Government has stated that many disabled people access transport provision through locally run schemes, such as dial-a-ride, which suggests an overlap in funding for transport / mobility provision where people are also receiving the mobility component of DLA.

(vi) Local authorities’ contracts with care homes should cover personal mobility needs

1.12 I did not want to repeat the whole report here but thought it was relevant to emphasise, following the question asked during the evidence session on the 4th July 2011 by Baroness Stowell, the evidence in the report against the financial argument for this decision, namely that DLA is paid twice.
1.13 The Government has stated that many disabled people access transport provision through locally run schemes, such as dial-a-ride, which suggests an overlap in funding for transport / mobility provision where people are also receiving the mobility component of DLA. The argument has also been made that “Local authorities’ contracts with care homes will cover services to meet a resident’s assessed needs. These will cover activities of daily living which may include providing access to doctors, dentists and local services such as libraries and banks. Local authorities should also take into account the resident’s emotional and social needs as part of the assessment.” Minister for Disabled People, Maria Miller MP, House of Commons (written answer, 16 November 2010)

1.14 In response to this argument the report states that many local authorities offer door-to-door transport schemes (like dial-a-ride) for people with restricted mobility. Some local authorities will charge for these services, and operate different eligibility criteria for membership. However the fundamental issues are that:

- DLA/PIP mobility gives absolute control. Residents can use DLA at a moment’s notice; schemes like dial-a-ride cannot replace this flexibility (e.g. London dial-a-ride scheme guidance states that “dial-a-ride may not be able to accommodate all of your requests, particularly if they are time specific”)
- Local authority run transport schemes are locally determined and vary enormously, both in availability and eligibility for membership.
- Many local authorities are cutting back on services like dial-a-ride due to costs.

1.15 The assumption that local authorities’ contracts with care homes should cover personal mobility needs is also not entirely accurate.

1.16 The formal arrangements between a local authority and care home may or may not specifically address the transport needs of the individual. Contracts tend to be costed against the eligible needs identified by the local authority through the community care assessment. In many cases, when an individual is being assessed by a local authority for a care package all of the benefits to which they are entitled are taken into account. Whatever the formal arrangement, in practice, the provision of 24-hour residential care has by custom and practice covered personal care, food and limited activities in the home. The problems are that:

- Contracts are costed against the needs identified by the local authority through the community care assessment. If personal mobility needs are not covered by this assessment then there will be no attached funding in the contract. In the majority of cases, therefore, local authorities do not currently pay any mobility or transport component meaning that the only means of funding for this is the mobility component of the DLA, e.g. £22 per week. If this funding is cut this will not be replaced.
- With increased pressures on local government, contracts are unlikely to include funding for anything beyond “activities of daily living”.
- If local authorities cannot make up this funding shortfall, which is likely given current financial pressures, the responsibility will fall to the care home provider and existing service contracts are already under enormous cost reduction pressures.
1.17 Therefore, if the DLA mobility component is scrapped for people living in residential care, it will not be replaced and individual's right to independent living will be severely limited.

2. Outcomes

1.18 In another set of questions the Committee asked whether independent living is being negatively impacted by the reduction in spending, following the Comprehensive Spending Review, and the cuts to frontline services that were unintended but being made as a consequence to this economic programme.

1.19 There has been great strides made in moving individuals out of large, long stay hospitals or residential homes to individual houses or flats. This is not because it is a cheaper way of providing services, but because it is, without a doubt, a better way of supporting people to live as independently as possible within their local communities.

1.20 Although funding goes a long way to support independent living by providing the range of community-based services needed, it is not all about the money. It is also important to ensure that the business model is right and that people are supported to achieve individual outcomes, regardless of the amount of money available.

1.21 To this end Turning Point has developed a bespoke outcome measuring tool for people with a learning disability called SPOT. Currently there is no national standard for outcome measuring in learning disability however with an increasing focus in health and social care to deliver measurable outcomes it is essential people with a learning disability are not forgotten.

1.22 Turning Point developed SPOT—our Support Planning and Outcomes Tool—which provides the people who we support with ONE plan that combines their personal needs as well as very clear outcomes, which staff support the individuals to work towards. This sounds simple but this tool is the first of its kind in this sector and is specifically designed for people who have medium to severe needs, many of whom will have come from settings where choice and outcomes were never discussed.

1.23 This tool is designed to help staff work with people in a person centred way, and to make sure that the people we support are able to pursue their aims in life – however big or small they might seem. It also helps Turning Point to know that what we do is genuinely useful to the people we support and that we are offering value for money and have the ability to prove this is the case.

1.24 SPOT is unique because it:

- Links support planning to specific outcomes for people
- Links outcomes for the people we support to the performance of staff and Turning Point as a whole
- Is measured on our client information system and so is easily reportable for commissioners to see.

1.25 What are the key elements of SPOT?
• A robust and meaningful plan is in place for everybody we support, and goals and objectives are agreed with individuals

• We use SPOT to provide evidence that the work we do is purposeful and that individuals are making progress against their goals.

• Each individual we support only has one plan in place, rather than a care plan and then a person centred plan, work plan, communication plan etc, etc (i.e. user friendly)

• The objectives identified for each person we support are reflected in the work plans of the people who support them. i.e staff performance is measured by their ability to support people to achieve outcomes.

1.26 Tools like this can ensure that whatever setting individuals live in, they can be supported to work towards specific goals which they are involved in setting, and continue to live as independently as they can for as long as they can.

3. The Wychavon decision

1.27 My final point is to refer the Committee back to the Wychavon case and the decision that followed. I attach an analysis in Appendix 1 of the case produced by Anthony Collins Solicitors for information.

1.28 In essence, a Housing Benefit Tribunal have concluded that people who lack mental capacity cannot enter into a legal agreement, and that in such instances Local Authorities have no obligation to pay Housing Benefit. The result of the judgement is that any organisation which has entered into a tenancy agreement with someone who in fact lacks the capacity to do so, could end up with having Housing Benefit payments withdrawn and, indeed, claims for repayment of Housing Benefit paid erroneously. The judgement is clearly wholly at odds with the general thrust of policy towards allowing greater independence for people with limited capacity.

1.29 My understanding is that an appeal has been made against this decision, and furthermore that the Department of Work and Pensions believe the judgement to be in error. However, if the decision is not overturned on appeal this will have a very negative effect on the ability of people with a learning disability to live independently.

1.30 We would wish to keep the committee informed of developments in this case in relation to their inquiry on independent living.

July 2011

Appendix 1: An analysis of the Wychavon case produced by Anthony Collins Solicitors for information

A disaster waiting to happen?

The case of Wychavon District Council v EM highlights the precarious position many providers of supported living accommodation can find themselves in if proper consideration has not been given to the capacity of the service user to enter into a tenancy.
Providers of accommodation for people with capacity issues who receive Housing Benefit can expect a significant rise in argument by Housing Benefit officers that there is no obligation to pay because there is no tenancy in respect of which rent is due.

The result of the judgement in the case is that Housing Benefit was withdrawn, in its entirety, from the service user. At nearly £700 per month this clearly going to be a bitter blow; more so when landlords were the service users parents who, with local authority encouragement, had built a special annex to their home for their daughter who was profoundly disabled and apparently not capable of understanding even the basic concept of tenancy.

It is not clear whether the decision has been appealed. It certainly should be given the serious consequences it might have and the fact that it goes against advice issued by the Official Solicitor and the views of many commentators.

We believe the decision could be flawed, it does not appear from the judgement that arguments were put forward either on the basis of the provisions of section 7 of the Mental Capacity Act 2005:

“If necessary goods or services are supplied to a person who lacks capacity to contract for the supply, he must pay a reasonable price for them.”

Nor does it appear that the common law doctrine of “necessitous intervention” which has a similar effect was raised.

The case raises serious issues which, it is hoped either the Court of Protection, or the Appellate Courts will deal with in due course. Until then the approach which should be taken is to ensure that a proper process for the formalisation of tenancy arrangements is followed. If the person concerned has insufficient capacity (and we appreciate this is a complex question in its own right which starts with the presumption of capacity) the options are as follows:

- To rely on a formal Enduring Power or Lasting Power of Attorney; this is unlikely to be available except in cases of acquired injury or progressive disease where such an instrument may have been signed, giving someone appropriate power to sign a tenancy.

- Obtaining a ‘best interests’ declaration from the Court of Protection; although we understand that the Court is reconsidering whether this is an appropriate approach to the issue and it may be that the Court will require a full Deputyship application (even if the application only leads to a limited declaration where the person has few assets).

- Getting a Deputy appointed by the Court of Protection to enter into the contract; if there is no existing Deputy this presents a problem due to the relatively complex process of making a full application which involves both time and cost which needs to be reflected in the planning process.

*June 2011*
I attach at Annexe A the answers to the Committee’s questions set out in your letter of 3 August, 2011.

Tim Cooper, the former Director of the Office for Disability Issues (ODI) has now left the Department for Work and Pensions. As the new Director of Independent Living and ODI, I would like to take this opportunity to illustrate the role the ODI has played in removing barriers to independent living by giving some specific examples of work led by Tim Cooper over the last couple of years (Annexe B).

My remit within DWP will cover all disability issues, including employment and benefits, reflecting a more joined up approach across Government. We have underlined our commitment to independent living in the description of the new Directorate.

Please let me know if you need more information.

29 September 2011

Annexe A – Answers to supplementary questions

1. Is the Government expecting an increase in the number of applications for Access to Work funding?

Access to Work supported 35,830 disabled people to keep and get employment in the 2010/11 financial year. Further in year figures are not yet available. The Department has not made any estimates of likely future demand.

2. Is the current budget adequate to meet this increased demand or will there need to be further restrictions placed on what is funded and who qualifies?

Liz Sayce published her report, Getting in, staying in and getting on, on 9 June 2011. The review includes Access to Work. The review was designed to ensure that Department for Work and Pensions’ specialist disability employment programmes provide the very best value for money and meet the needs of disabled people in finding and sustaining work and building fulfilling careers. The Sayce review recommends changes that will increase the number of people able to benefit from the programme. The review and consultation are about spending money differently, not cutting it. Budgets for specialist employment programmes are being protected.

3. Has the Government met the target of there being a user-led organisation (ULO), modelled on existing Centres for Independent Living (CIL’s), in every local authority area by 2010?

As there is no routine data collection on ULOs we are unable to say whether or not there is a ULO modelled on CILs in every local authority area. Department of Health funded the National Centre for Independent Living (NCIL) to undertake an audit in 2010 to identify
progress on having a ULO in every local authority area. Unfortunately, and despite substantive efforts by NCIL to derive more data (and additional time given by the Department for Health) there was a disappointingly low return of information from organisations. Government does work with user-led groups and key partners to support new groups. The Department of Health led invested over £1.745m between 2008 and 2010 to support 25 user-led organisations to become Action and Learning Sites. Department of Health and the Office of Disability Issues (ODI) provided a further £2.16m in 2009/10 to develop the capability and capacity of ULOs at local level.

4. What action is being taken to address the disadvantages that user-led organisations experience when competing for contracts with large organisations?

This Government aims to modernise our public services, making them open to a range of providers, including civil society organisations. A White Paper on the opening up of public services was published this July and more detail can be found at /www.openpublicservices.cabinetoffice.gov.uk/.

Setting up and running user-led organisations is, of course, a matter for disabled people rather than Government. We are aiming to build the sustainability and capability of Disabled Peoples User Led Organisations (DPULOs) specifically, through a programme funded by a £3m investment by ODI. The aim of this programme is to provide a range of practical and financial support which will create strong and self sustaining DPULOs, who will be in a better position to compete for contracts.

Annexe B—The Role of the ODI

The Office for Disability Issues (ODI) leads the government’s vision to remove barriers to create opportunities for disabled people to fulfil their potential and be fully participating members of society. ODI works collaboratively with government departments to make sure the needs of disabled people are reflected in their work and our own projects. We provide strategic advice and analysis; we share tools and develop skills among government staff. We achieve results through influence and guidance based on our acknowledged expertise. We do not have any formal powers of enforcement.

Case study: Leadership

Since the UK ratified the United Nations Convention on the Rights of Disabled People in 2009, ODI has been the champion for the Convention within government.

As the nominated focal point, ODI works with government departments to ensure policy makers understand how to incorporate the Convention in their work.

Example: This year, ODI has been preparing the Government’s report to the UN saying how the Convention is being implemented and progress to date. ODI worked with OGDs and the devolved administrations to pull the report together, and exercised a constructive challenge role so that the report meets the UN’s expectations and reflects what is happening across government.

The process gave ODI the opportunity to further raise the profile of Government commitment to the Convention and involve disabled people in challenging Government’s progress. ODI worked with a variety of disabled people’s organisations, including regular
Letter to the Lords Clerk of the Committee, from Jeremy Moore, Director, Independent Living and Office for Disability Issues, Department for Work and Pensions (IL 114)

meetings with a group chaired by UK Disabled People’s Council, and made the draft report available for public comment.

Case study: Building Skills and Knowledge across Government

ODI provides analysis of Government’s progress towards equality and builds the capability of departments to involve disabled people in social research and policy development.

Example: In August 2011, ODI published “Involving disabled people in social research”. (ISBN 978-1-84947-711-6). We also publish the “Life Opportunities Survey” which compares how disabled and non-disabled people participate in society in a number of areas. These include: work, education, social participation, transport and use of public services. The Office for National Statistics (ONS) runs the survey throughout the year across Great Britain. It interviews a random sample of households, with sectors of society chosen to reflect the general population.

Case study: Innovating

Example: The Right to Control is one of ODI’s most innovative projects. Co-produced from the start, this pioneering initiative aims to put disabled people firmly in control of their own lives and the support they receive through a legal right set out in the Welfare Reform Act 2009 by ODI. Right to Control is currently being tested in 7 areas, in partnership with local authorities, Jobcentre Plus, the Independent Living Fund and disabled people. ODI set up, funds and supports the project and has commissioned an evaluation which will report in 2013.
Baro
nenness Campbell of Surbiton asked whether there were any specific changes to Government policy that you thought should be made that would help the UK better to meet the UK’s obligations in the UN Convention without increased funding (Q 92). There was little time to answer this question so please feel free to provide any further detail in writing if you wish to do so.

I think a specific change the Government can make to its policy which would help the U.K.’s obligations to meet the UN Convention without any increase in funding would be to enact legislation which would enable disabled people to move their social care support from one authority to another which has often been a big stumbling issue. This would be of considerable help in improving the opportunities to live independently and would go some way in supporting the Government’s ability to meeting Article 19. Baroness’s Campbell Social Care Portability Bill would help implement this effectively.

In your written evidence you referred to the need for the Government to encourage more ‘co-production work’ with disabled people’s organisations. What do you mean by ‘co-production’ and what do you think the Government should be doing to involve those disabled people whose views are heard less often?

By co-production I mean disabled people working in equal partnership in designing, developing and implementing a piece of work. A good example of this was the Department of Health User Led Organisation (ULO) Project which worked towards supporting and capacity building of User Led Organisations around the country. Disabled people were involved with Government civil servants working alongside them designing the policies, design criterias and implementing the project. It was an extremely successful model. I think this kind of partnership working with disabled people and their organisation can also help us strategic partnerships in local areas in helping to design and deliver services. This kind of joint working is working very well in Hampshire with the Personalisation Experts Panel (PEP) where a group of users and carers working in a coproduction approach with Commissioners from Adult Social Care in the roll out of Personalisation and self-directed support and planning.

The Government could commission disabled people’s organisations to run awareness raising and capacity building sessions in order to make disabled people more aware of the UN Convention. The Government could use social media networks like Facebook and Twitter to try and spread the message about the importance of the UN Convention in the lives of disabled people.

You told us that disabled people should be involved in setting indicators to monitor progress on the UN Convention on the Rights of Persons with Disabilities. What are the outcomes and indicators that you think the Government should be using to measure progress on Article 19? Is there a sufficiently robust monitoring system in place to measure progress?
I think it is essential that there are some external independent indicators to monitor progress of the UN Convention in order to provide some benchmark guidelines. I do not think there is a sufficiently robust monitoring system in place to measure progress and I believe this is out of the remit of the Care Quality Commission. I think a monitoring group made up of representatives from the same appeal as organisations could draw up some appropriate indicators as they have the in depth, grassroots experience of independent living. It is not just a matter of a person living in one’s home and getting up and going to bed but it is their life, about the job, support in getting a job, living a meaningful life, forming friendships and social interaction and getting out and about being a true citizen. I think some disability organisations could quite easily draw together some effective indicators.

Some witnesses have told us that not enough is being done to make sure disabled people know what their rights are. What more could the Government be doing to raise awareness amongst disabled people of the rights protected under the UN Convention, including the right to independent living?

Again I think the government could use Disabled People’s Organisations to run awareness raising exercises and sessions to heighten the understanding for disabled people about their rights under the UN Convention. Disabled People’s organisations are well equipped to do this in terms of their knowledge of the UN Convention but usually it is a question of resources which prohibits them from doing more.

The government could be making much more use of Facebook and Twitter and other government department websites to bring more information to disabled people about the right to independent living.

3 August 2011
1. Introduction

The Disability Rights Partnership (National Centre for Independent Living, Radar and Disability Alliance) is grateful for the opportunity to provide additional evidence to the Joint Committee on Human Rights, and answer outstanding questions following our evidence on 24 May.

1.2 Through our evidence we have attempted to demonstrate:

(a) Areas where we believe gaps exist between the Independent Living right as provided by Article 19 of the UN Convention on the Rights of People with Disabilities (‘Disability Rights Convention’ or ‘Convention’) and disabled people’s lived experiences.

(b) Where the Government falls or may fall short of their obligation to realise the right to Independent Living.

(c) The impact of the shortcomings on disabled people.

And we have suggested what steps the Government can take to ensure progressive realisation of the right of independent living.

1.3 We believe it is vital to recognise that there are already tools to progressively realise the right to independent living; however these need to be utilised more, and better. These tools include—

— the Equality Act 2011, and in particular the public sector Equality Duty (s. 149).

— the Human Rights Act 1998, and in particular the s.6 prohibition on public authorities to act in a way which is incompatible with a Convention Right, and articles 3 (right to be free from inhuman and degrading treatment), 8 (right to respect for private and family life and your home) and 14 (right not to be discriminated against in the enjoyment of the Convention rights).

— the institutional framework (Equality and Human Rights Commission for Great Britain).

— the Independent Living Strategy.

1.4 The reform of social care law and funding provides opportunities to advance the realisation of disabled people’s right to independent living. Unless the legal framework and the funding is reformed to provide equitable solutions across the country, disabled people and carers will continue to experience restrictions on support and greater barriers to independent living.

2. Equality and Independent Living
Lord Lester asked if further information could be provided on our comments that the powers and duties of the Equality and Human Rights Commission, and commitments under the Equality Act, were being weakened.

2.1 Equality and non-discrimination are amongst the core principles underpinning the human rights framework and are vital to securing independent living.

2.2 Effective enforcement of equality rights is a necessary condition of the realisation of the right to independent living. Many disabled people are excluded from ordinary life because of barriers arising from the environment. These barriers include poorly designed buildings, discriminatory policies and procedures, negative stereotypes and people’s assumptions and attitudes.

2.3 The Equality Act 2010\(^{398}\) sets out to tackle these barriers and make appropriate adjustments, so that disabled people can exercise their human rights, fulfil their potential and contribute to society.

2.4 The Equality Act 2006 established the Equality and Human Rights Commission to protect and promote equality and human rights. In our previous evidence we expressed concern that the Equality Act was being weakened because provisions were not implemented properly, and that the Equality and Human Rights Commission’s role and ability to help deliver independent living was being undermined by the Government’s proposals.

2.5 In this additional evidence we highlight three areas: common parts, public sector Equality Duty and EHRC reform.

a. Common parts

2.6 Currently, landlords and management committees have a duty not to unreasonably refuse consent for physical alterations to premises—for example, an accessible bathroom/kitchen, removing steps/thresholds, installation of a stairlift. This does not mean that they have to pay for the alterations, only that they have to allow for physical alterations to be made. They can also provide for the alterations to be undone if a disabled tenant leaves, at no cost to the landlord. However this duty does not extend to ‘common parts’, i.e. those shared with other tenants, for example a car park, entrance, hall and lobby. In practice this means that a disabled tenant may be able to move around within the walls of their residence but they cannot get in or out of the building.

2.7 The Equality Act provides that the duty extends to ‘common parts’, and this was passed with cross-party support. There was also support from housing experts who welcomed the clarity.\(^{399}\) However the Government has not (yet) implemented this element of the duty. The benefits are evident—as well as liberating disabled and older people from their homes, there would be cost savings - the costs of funding common parts adjustments are estimated at up

\(^{398}\) Of course, this was also done by its preceding legislation (Disability Discrimination Acts),

\(^{399}\) http://webarchive.nationalarchives.gov.uk/+/http://www.dwp.gov.uk/docs/review-common-parts.pdf
to £27m, however the savings in formal care costs are estimated to be up to £40m (as
disabled people will not require residential care or other formal care support).

2.8 With an adjustment to common parts of their property, there are many positive effects
as evidenced in the Government’s impact assessment such as

— home care for some disabled people could be reduced by half.

— fewer people need to enter residential care (which is usually much more expensive
  than home care).

— the number of people admitted to hospital each year would be reduced as there are
  fewer falls, whilst people may be sent home earlier when their accommodation is
  more suitable. This would help reduce the ‘bed-blocking’ challenge/costs for the
  NHS.

— Informal carers could reduce the hours they spend caring.

— Other tenants or lessees may also benefit from the adjustments made, for example
  older people with mobility difficulties or parents with pushchairs.

2.9 We consider that delaying the implementation of the ‘common parts’ is a potential
breach of the right to independent living, and we hope that the JCHR will pick up this issue
in their report as one example for immediate government action.

b. Public sector Equality Duty

2.10 The Disability Rights Partnership strongly supports the public sector Equality Duty (s.
149 Equality Act). It requires public authorities to have due regard to the need to take steps
to advance equality of opportunities, eliminate discrimination and harassment and foster
good relations. The Equality Act further clarifies that the Equality Duty involves tackling
prejudice (as negative attitudes and low expectations towards disabled people can form the
greatest barrier for them to take control of their own lives) and encouraging participation in
public life or in any other activity in which participation by such persons is
disproportionately low. These elements capture some of the levers needed to realise
independent living for disabled people—and which are not provided in other legislation.

2.11 We believe that the public sector Equality Duty is a strong duty that, if used well, helps
public authorities to deliver equality and to avoid discrimination and harassment. The
Equality Duty is about better decision-making—it helps public bodies to identify potentially
negative effects and to take steps to mitigate those effects (within their resources).

400 Equality Act 2010 Impact Assessment, available at
Impact.pdf

401 Ibid

402 See, for example, Mansell J, Knapp M, Beadle-Brown J and Beecham, J (2007) Deinstitutionalisation and
Tizard Centre, University of Kent.
Importantly, public authorities can use the Equality Duty as a lever to require others to advance equality (for example, through attaching conditions to procurement, commissioning, licensing, grant allocation).

2.12 The question when designing any policy or practice is not only what the objective is, but also how the objective needs to be delivered. The following example shows the importance of the Equality Duty as an essential safeguard for disabled people.

**Example of how the Equality Duty protects independent living of disabled people**

Birmingham City Council decided that they would balance their overall budget by reducing spending on social care—a vital element of independent living. The council had consulted on their proposals, and there was an ‘Equality Impact Needs Assessment’ (EINA), available to members of the council’s Cabinet. Yet, the Cabinet approved the proposals solely on the basis of a ‘high level’ report on the impact of the change for those with substantial needs. Crucially, the Court found that the necessary refinement of this high level report with the findings of the consultation and the EINA never took place, and so the Judicial Review of the decision to raise the threshold to ‘critical only’ succeeded. Mr Justice Walker held that the decision of the Council had been unlawful.403

2.13 We are very concerned about the increasing need to challenge public bodies as councils seek to reduce expenditure of budget reductions with limited time to adequately assess options, and the costs associated with badly designed policies and practices and challenging these in the courts. There is also a risk of injustice as the cuts to legal aid will prevent many disabled people from pursuing legal cases in the first place.

2.14 In September 2011, the specific duties regulations came into force. The specific duties support the performance of public bodies in the carrying out of the public sector Equality Duty. We consider that the specific duties do not deliver that objective and therefore the Government has missed an opportunity to strongly encourage public bodies to involve disabled people and other interested groups, to gather evidence, to plan for action, or to report on progress. These are likely to be captured by the general Equality Duty however from our experience public bodies need to have these duties spelt out.

2.15 Of particular concern is that the Government’s guide on the public sector Equality Duty does not mention the need to involve disabled people or indeed to engage with any group.404 We believe that this is a deplorable omission, particularly in the light of caselaw,405 and the demonstrable success of involvement under the Disability Equality Duty406 and the Disability


405 Examples include R (W) v Birmingham City Council [2011] EWHC 1147 (Admin) and R (Lunt) v Liverpool City Council [2009] EWHC 2356 (Admin),

Rights Convention’s involvement and consultation obligations. We believe independent living can only be achieved in partnership with disabled people and ‘nothing about us without us’ has been used by disabled people and representative organisations to encapsulate this imperative.

2.16 We hope that the Joint Committee on Human Rights will urge the Government to provide leadership in the promotion and protection of the public sector Equality Duty and in particular how public bodies can advance equality for disabled people. The Government needs to work with disabled people and their organisations as well as public sector bodies to maximise the effectiveness of their work.

c. EHRC reform

2.17 The Government is currently reforming the Equality and Human Rights Commission (EHRC). Earlier this year they conducted a consultation, the outcome of which we are awaiting. At the same time, the Government was already putting in place some of the reforms still under consultation, for example the budget is being reduced and the helpline is being moved out of the EHRC.

2.18 In the context of the right to independent living, we are most concerned about slashing the budget of the EHRC by 69% which will harm their capacity to carry out their duties in relation to promoting and protecting human rights—including supporting local organisations that promote independent living, and to carry out investigations, for example their current human rights inquiry into home-based care and support for older people.

2.19 The independence of the EHRC is also put at risk as the proposal is to require the EHRC to obtain approval from the Secretary of State for their business plan. This may harm their ability to challenge the Government over any potential failure to meet human rights obligations. A better way to ensure transparency and accountability—as the Government is aiming to—would be to have a debate in Parliament about the strategic and business plan.

2.20 We hope that the Joint Commission on Human Rights will scrutinise any legislative measures, including budget-related steps, with a view on ensuring the EHRC can perform their duties effectively.

3. Welfare Reform Bill

Lord Morris of Handsworth asked for further details on where, in our judgment, the Welfare Reform Bill breached the UN Convention.

407 The funding of the Commission is being reduced from £70 million (in 2007) to a planned £22 million in 2015

408 For example, the EHRC report that sets out an approach to care and support from an equality and human rights perspective. EHRC (2009) From safety net to springboard. http://www.equalityhumanrights.com/key-projects/care-and-support/report-from-safety-net-to-springboard/

3.1 The Welfare Reform Bill is currently going through Parliament and received its Lords Second Reading on 13 September 2011.

3.2 Disability Alliance has issued a letter of claim to the Department for Work and Pensions. We believe that the Department has failed to have due regard to equality obligations—domestic and European—regarding Disability Living Allowance plans in particular (despite the DWP Equality Impact Assessment declaring that 100% of DLA recipients should be considered ‘disabled people’).

3.3 In this memorandum, we confine ourselves to Article 19. We believe that there are three significant threats to independent living—namely around DLA/PIP reform, ending DLA mobility support and the cap on housing benefit.

a. **DLA/PIP reform**

3.4 The Government is working to replace Disability Living Allowance (DLA) with a new benefit called the Personal Independence Payment (PIP) and they have stipulated that the reform will lead to reduced support for some disabled people who have lesser or reduced barriers to participation. However, DWP does not appear to have considered the impact on equality of opportunity reduced support will have on disabled people. Given the re-targeting of resources at disabled people with the ‘highest needs’ it is people receiving low rate care DLA payments that look most at risk of losing support. It is unlikely that this group will be entitled to or receiving care and support from their local authority as their needs are not considered severe enough. The consequences are likely to be: disabled people pushed into poverty and social exclusion with fewer independent living chances. Ability to live independently will be dramatically reduced as disabled people cannot access essential and basic support, which undermines the prevention agenda and will increase costs further down the line.

3.5 Recent research has suggested many disabled people may have to give up work, question the ability/value of going on living, and be unable to manage health or buy appropriate food as a result of reduced support. DWP has access to significant evidence of DLA use since its introduction in 1992 but has failed to demonstrate how reduced access to DLA/PIP would not affect disabled people’s ability to live independently.

b. **Ending DLA mobility support**

3.6 The proposal to end DLA mobility support for disabled people who live in state-funded care or attend residential schools is currently being reconsidered by the Department for Work and Pensions. This follows 39 disability organisations challenging the optimistic and un-evidenced assumption that disabled residents would have mobility needs met in different ways. However, the Bill would enable the Government to end access to support from April 2013 without DWP having analysed the impact on disabled people’s independent living.

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411 Part 4, clause 83 of the Welfare Reform Bill

opportunities. We demonstrated that many people would be cut off from their single line to independent living—i.e. choosing when and how they get around and where they go to. However DWP is carrying out their review behind closed doors and we are concerned that the Government is thus failing their duty to adequately involve and consult with disabled people. We welcome the Low Review as an alternative, transparent way of exploring how the mobility needs of disabled people in residential care and at residential schools can be met effectively. We urge the Government to take account of the findings of the review when it is published.

c. Cap on housing benefit

3.7 The Welfare Reform Bill also introduces a cap on housing benefit. This will mean that many families will need to move to another area with cheaper housing. However, disabled people often depend on support networks that they have grown around them and have fewer resources to build new ones. Furthermore, as long as portability of social care is not resolved, disabled people run the risk of losing their care whilst they wait for a new assessment to be carried out and having a new care package put in place. The exemption of DLA recipients—whilst welcomed in principle—does not protect those who will not receive the new PIP due to the 20% reduction target.

Welfare reform and independent living

3.8 In our view, the Government should better support independent living and exercise their role in delivering this right. This is not just a role for the Department of Work and Pensions, as for instance the HM Treasury has a responsibility to ensure joined-up government approach in spending and analysing the cumulative impact of the cuts on disabled people’s enjoyment of the right to independent living. There is also a role for other government departments to mitigate the impact of the welfare reform measures, for instance through better skills development (BIS), more support for local user-led organisations (DCLG and Cabinet Office) and better access to social care and support (DH).

4. Involvement and consultation

Do you think that the UK Government—and local authorities—currently meet the obligation under Article 4(3) of the UN Convention to consult and involve disabled people in the formation of law and policy? If not, can you give us a specific example of a failure to meet these obligations? Is there more Government could do to encourage good practice?

4.1 In the previous sections we have given several examples of the failure to consult and involve disabled people in the formation of law and policy—locally and nationally.

4.2 We would suggest that the Government could do more to promote the UN Disability Rights Convention and its practical application. Our members have told us that many bodies do not seem to be aware of the UN Disability Rights Convention or what human rights mean in practice. We believe that a greater awareness and understanding will help public bodies to meet their obligations better. The Department of Health, the British Institute of Human Rights and 5 NHS Trusts worked together to produce a framework to assist NHS
trusts to develop and apply human rights based approaches (HRBAs) in their organisations to improve service design and delivery.\textsuperscript{413} We believe this to be a model of good practice.

4.3 We also recommend that the Government should support greater use of the Equality Duty and in particular promote involvement as a tool to ensure better performance in delivering independent living and better quality, continuity, integration and cost effectiveness of care and support generally.

5. Big Society

\textit{How may the Big Society agenda make a positive contribution to the promotion of disabled people’s involvement?}

5.1 There is no clear definition of the ‘Big Society’ agenda, however we’ve interpreted it in the context of the setting the balance between ‘state responsibilities’ and ‘services by the voluntary sector’.

5.2 We want to be clear that we would not wish to see a ‘Big Society’ agenda that legitimises a return to ‘old times’ where disabled people have to rely on the charity of others to live independently and get around. In practice this means that disabled people have reduced choice and control over their lives and restricted opportunities to participate fully in society (socially and economically). Further, it places an additional burden on family carers as the cared-for cannot access paid support. A policy that relies on goodwill from others would be in contravention of the UN Disability Rights Convention that puts autonomy (self-determination) as one of its central principles.

5.3 The ‘Big Society’ agenda should not lead to increased inequities between disabled people, depending on where they live. We would also be concerned if the power to set budgets was in some way devolved to local communities without a proper system of checks and balances as in the above Birmingham case where elected councillors had not even been informed about the likely impact of cuts on disabled people.

5.4 There is a need for strong directions from central Government with clear and enforceable rights and entitlements for disabled people; to some extent these already exist under the Equality Act and the Human Rights Act. However, it will be essential that the reform of social care law and funding ensures that local authorities will give the appropriate weight to disabled people’s interests and meet their obligations under the Human Rights Act and the Disability Rights Convention, when they make decisions about spending and resources allocation. This would also help address the challenge of promoting localism versus the need to ensure enjoyment of universal rights.

5.5 We hope that the Joint Committee on Human Rights will consider how the Government can use social care reform as an opportunity to take a step closer to realisation of the right to independent living.

5.6 The ‘Big Society’ agenda provides opportunities for greater choice and control by disabled people. Many disabled people’s or user-led organisations are already involved in

local strategic decision-making on care services and support and some deliver core parts of the personal budget process. A recent study found that peer support has been found to achieve far greater long-term outcomes for disabled people. The Right to Control pilots give disabled people greater control of their lives. A more demand-led care and support system could cut considerable waste and bring about a shift from the existing capacity-driven model for service provision.

5.7 On 20 July Maria Miller, the Minister for Disabled People, launched a new programme to support disabled people’s user-led organisations. This provides £3 million over four years that will aim to promote the growth and improve the sustainability of user led organisations. However for this programme to have a real impact, it must be accompanied with measures to increase support from local councils and to advance greater co-production with local disabled people. We believe that the Government should explore—with disabled people’s organisations—how their legislative programme can provide such opportunities.

5.8 Clear rights and entitlements will form the most essential drivers for disabled people to bring in their expertise and take on such local challenges by themselves. In this context we believe that the Government should reinvigorate the Independent Living Strategy to build in the role of local user-led organisations, minimise barriers to disabled people to access the support they need to take control of their lives, and encourage disabled people to work together to maximise the use of state support.

6. Reporting and implementation

Are you satisfied that disabled people have been effectively involved in (a) the preparation of the UK’s first periodic report to the UN and (b) in the work on the national implementation mechanism?

6.1 The Office for Disability Issues set up a small working group of disabled people’s organisations, together with the UK Council of Disabled People, to feed into the drafting of the Government’s report. They also funded a ‘Network of Networks’ through which disability organisations gathered views from disabled people on independent living and the Disability Rights Convention. The Department of Health commissioned Radar to organise involvement events with disabled people to discuss the Convention rights relevant to its remit (independent living, health).

6.2 Whilst disabled people have been given an opportunity to provide feedback, it does not appear that the issues raised have been taken into account. The draft report is a list of activities and priorities (around the most prominent flagships such as the ‘Right to Control’ and ‘Personal Health Budgets’) but it does not show what steps the Government will take to manage and shift the necessary resources in order to progressively realise these rights.

6.3 The report should be an opportunity to identify progress in recent years as well as areas where progress needs to be made. This could inform future government’s strategies in major public policies. We expect that the UN Disability Committee will examine the UK reports after the summer of 2013. Given the long time between submission and actual examination, we hope that the Joint Committee of Human Rights will step in the vacuum and


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examine the report. This will be one way to raise the expectations on the Government, and encourage them to travel further on the road towards realisation of the full enjoyment of human rights by disabled people.

7. Machinery of Government

At the oral evidence session the chair asked us to reflect whether there ought to be a lead Minister with cross-cutting responsibilities.

7.1 Currently we have a Minister for Disabled People, yet her role is not clear. Previous Ministers for Disabled People have championed disabled people’s rights across the Government, some more successfully than others. However, this cross-government role appears to be lacking in the current Government.

7.2 In our earlier evidence we set out a number of benefits of an Independent Living strategy. With a well-designed strategy including outcomes, actions and timescales, co-produced with disabled people and with buy-in from government departments, the Minister for Disabled People could lead on the implementation of the strategy and hold government departments to account. The Office for Disability Issues provides a focal point and can act as a ‘centre of excellence’ to share expertise and good practice across the government and encourage joined-up working.

7.3 We hope that the Joint Committee on Human Rights will recognise the value of a champion of disability rights within Government.

29 September 2011
Thank you for the opportunity to provide this further evidence. I shall answer each question in turn.

- Baroness Campbell of Surbiton asked whether there were any specific changes to Government policy that you thought should be made that would help the UK better to meet the UK's obligations in the UN Convention without increased funding (Q 92). There was little time to answer this question so please feel free to provide any further detail in writing if you wish to.

  I apologise for repeating information I have provided in previous evidence but I suggest that the Government should remove the artificial barrier that prevents people in residential care from earning. This would be a change in regulations rather than a change in primary legislation and should therefore be relatively easy to implement. I can see no cost implications; indeed there is the potential for increased income / reduced cost of residential care.

  As I touched upon towards the end of the session, I would suggest consulting and involving user led organisations instead of charities or other bodies. Charities do not effectively represent their beneficiaries and in any case as service providers themselves have different vested interests than ULOs. ULOs are, in my experience and opinion, more likely to represent the experiences and valuable insight of disabled people as regards the right to independent living. As part of this I would strongly suggest stopping providing resources to the Big Four—Leonard Cheshire, Mencap, Scope and the RNIB – and instead channelling this funding towards disabled peoples' organizations—the UK Disabled Peoples' Council, centres for integrated/independent living and specific interest ULOs such as “Being the Boss”.

  I think it is key to reverse the medicalisation of disability and social care. Combined regulators, combined regulations and combined regimes result in environments and cultures that are counter to disabled peoples’ rights to independent living. The Disability Rights Commission and the Commission for Social Care Inspection were much more effective in achieving disabled peoples’ rights than their replacements, as social care and disabled peoples’ rights were inevitably diluted in the wider remits of the larger groups. Reversing this process would not necessarily cost more and could only be positive.

  The current regulatory framework in social care, particularly in residential care, is non-functional. The “one size fits all” approach to both provision and the relevant regulations (registration standards etc.) simply doesn’t work. Providers and service users alike are confused and unable to ascertain precisely what requirements and rights are set out. This follows a badly managed process of continual change in the regulation system which has left everybody involved unsure as to what they should
or shouldn’t be doing. I would strongly advocate for a change to social care specific regulations and bodies. Coupled with this, I would suggest that this new system should stay substantially static for a substantive period to “bed in” instead of constant changes. This would create a stable benchmark, enabling social care providers to assess their provision and improve it. Further the CQC, widely recognised as being essentially non-functional and bureaucratic, or its replacement would be better placed to enforce reasonable standards.

- It is absolutely imperative that the Mobility Allowance remains in place for people in residential care. The concept of “double funding” (that councils already provide for residents’ mobility needs) is a fallacy. The ability to travel is a key component of independent living. Removing this allowance would / will be a major backwards step, further disempowering and institutionalising an already considerably disempowered group of people.

- There is currently a legal impediment to the use of direct payments to pay for residential care. It is by no means clear that individual or personal budgets can be used in this fashion, as they are based upon creative interpretation of existing legislation. Clearing this up may clarify the position of some residents as customers with rights rather than as charity receivers—though I do not think this is the universal panacea.

- Can you describe the particular challenges of involving people living in residential or institutional settings?

- The additional barriers to effective involvement in residential care are so significant it is difficult to know where to start! Disabled people in residential care are known as a “hard to reach” group and are ineffectively represented. There are no true User Led Organisations that have significant input from residential care service users, so alternative measures must be considered. Once again, charities which themselves provide residential care have their own vested interests, are not democratic and do not represent their service users’ views and needs effectively. As a result there are no bodies that effectively represent such service users, so conventional consultation or involvement routes would not capture this population.

- People in residential or institutional settings often have the more “severe” of the range of impairments, thus they experience more barriers than others in genuine involvement. Coupled with this is the learned helplessness indicative of such environments. With the odd exception, and to varying degrees, all institutional environments consciously or unconsciously train their “customers” into expecting and accepting lower standards of quality of life. Service users have little community involvement; many people in residential care don’t leave the home for weeks at a time. Many people in residential care therefore have little concept of rights and what might be expected in an independent living situation outside of “careland”.

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There are major communication difficulties. Many adults in residential care have no or little functional literacy. Many also have difficulty in communicating orally, either due to their impairment or due to an inadequate and institutionalised education. People experiencing this barrier often expend considerable energy just expressing themselves for day-to-day purposes. Communication on more abstract concepts, important though they may be, simply doesn’t happen for many people in residential care.

Victimisation is rife in institutional settings. It can be overt or it can be insidious, which is often even more difficult to deal with. If residents express any opinion that could be considered to be critical of elements of the service they receive they run the very real risk of experiencing considerable victimisation, from management and from “coal face” staff. As residents rely on the residential or institutional environment for nearly everything in their daily life, this can have profound consequences for their quality of life. Residents are often genuinely and reasonably afraid of expressing themselves for fear of such consequences.

People in residential settings generally do not have their own personal assistants or their own transport. There are major practical barriers in attaining the relevant support and transport to attend any involvement related events.

I offer as additional evidence (enclosed) Northumbria University (John Swain)’s report on developing user involvement within Leonard Cheshire, a leading provider of residential care to adults with physical impairments. Whilst it is a little dated (2005) I am unaware of any more recent research which provides such a comprehensive and distressing catalogue of experiences of barriers to service users’ involvement.

- Some witnesses have told us that not enough is being done to make sure disabled people know what their rights are. What more could the Government be doing to raise awareness amongst disabled people of the rights protected under the UN Convention, including the right to independent living?

I hope the Committee indulges me in that I am going to answer this again from the position of a residential care service user; I believe my colleagues are better placed to provide their usual excellent expertise on this question from the wider setting.

In residential care I think it is crucial to start by empowering service users within the institutional environment in which they live. As it stands, residential care service users nearly exclusively only leave residential care feet foremost. People who escape residential care into community settings are very rare and a tiny proportion of service users. I don’t think that realistically this will change without first achieving considerably better empowerment within the residential setting.

For the reasons I have set out above in response to the question of effective involvement, it is very difficult to directly contact or “reach” many residential care
service users. In my experience, empowerment of service users and raising their awareness of their rights can only happen through changing the culture of the institutions where they live. This in itself is not an easy undertaking given the institutional momentum within the system; however my experience is that it can happen, if the right people are in the right places.

- Returning to a more localised, social care specific regulation and inspection would be a key step in achieving this.

- I mentioned in oral evidence the potential for a residential care service user’s commissioner, similar to the Victim’s Commissioner. I think this could be a possibility in raising awareness of disabled peoples’ rights, if handled correctly. This position, however, must be filled by an empowered and representative residential care service user—a rare breed!—and NOT by anybody without extensive, current personal direct experience of such environments.

- Residents’ rights (as opposed to unenforceable “best practise”) are an esoteric subject, set out in the minutiae of different impenetrable documents—the Charging for Residential Accommodation Guide, individual services’ Service User Guide, local authority contracts, DLA rules, Essential Standards of Quality and Safety, Safeguarding policies etc. After ten years of living in residential care, I am still discovering unknown rights that now enhance my quality of life and my independence. Such opaque documents can only serve to further disempower residents. I would therefore advocate for a nationally agreed comprehensive document of residents’ rights (NOT unenforceable best practise.) To be effective such a document would have to be written in an accessible manner yet “waterproof” in its expression and available in a variety of formats. Legislation should make distribution of this document to every resident mandatory in his or her preferred format.

11 September 2011
Many thanks for your letter of the 3rd August, requesting additional written evidence for the inquiry into the implementation of the right of disabled people to independent living.

I am pleased to provide the committee with the following responses to their specific questions.

**Question 1: In evidence to us, witnesses have suggested that low expectations about how much choice and control people in residential care should have and lack of funding create barriers to people in residential care having this choice and control. Do these barriers impact on your members as commissioners of residential care?**

- Adult social services have embraced and championed personalisation and been in the forefront of introducing personalisation within the public sector, giving the individual real choice and control over how their outcomes are commissioned and met. This has been a developing agenda for councils, providers and importantly service users, and as noted by the inquiry a significant challenge is managing expectations against scarce resources, as well as acknowledging certain “generational” groups have differing expectations.

- This shift towards outcome based commissioning is changing how services are organised and delivered with traditional “residential” responses over time being replaced by more universal individualised responses, although it is acknowledged the market is still adjusting to this new offer and further progress is still underway.

- ADASS is a key partner in the Think Local Act Personal (TLAP) partnership which seeks to bring together stakeholders together to deliver the Government’s Vision for Adult Social Care and this co-working is a critical pathway towards the emergence of universal and integrated responses to meet individual outcomes.

- It is noted that the ratio of services provided in the community compared to residential settings has been growing following a deliberate policy direction to extend independence choice and control.

- As well as shifting the setting, councils have also been instrumental in shifting the “tenure” of residential care home provision towards extra care housing / group homes / supported living which offer increased levels of independence choice and control.

- The ADASS Budget Survey 2011 confirmed the scale of budget reductions faced by Adult Social Care, with reductions of £1bn in 2011/12. The reduction of resources is acknowledged as a challenge but councils are working alongside individuals and with providers to encourage innovative solutions to meeting improved outcomes.

**Question 2: How could a cultural shift be made, using existing resources, to give people in residential settings more choice and control in their daily lives?**
Councils are widening the uptake of personalisation and are working towards the Government target of all eligible clients in receipt of personalisation by March 2013. This target will include eligible clients within residential settings.

Councils are well placed to act as a conduit to providing further advice, information and guidance for local individuals, including those within residential homes to make informed choices, as well as councils commissioning and supporting advocacy services on behalf of local communities.

Councils recognise and support residential homes to embrace person-centered care and support. This shift can be influenced through any contractual arrangement the council has the residential home or individual resident.

The Care Quality Commission can help support the increasing shift towards giving residents more choice and control through its registration and inspection process, with CQC working closely with providers, councils and increasingly residents to drive up standards that include supporting person-centred support.

It is important to recognize that the residential setting is a community, both of itself and within the community in which it is located - residents and staff can actively seek out opportunities for engagement with the wider community to personalise the services offered.

Teamwork and effective communication, staff development programmes and robust systems of quality assurance will be important in contributing to enhanced personalised support and engagement with residential homes.

Residential home managers are well placed to understand the needs of local communities, provide leadership, and work collaboratively with people using services, their families and carers in the design and delivery of services.

The increasing and welcomed shift to personalised care and support is largely driven by rising expectations, particularly amongst younger adults. This is a market driven approach applying to both councils and providers.

Both Councils and CQC are increasingly working closely with individual residents and their families/carers to drive up standards through the use of lay-visits, customer feedback mechanisms and engagement in commissioning activities. This new relationship is shifting the culture within residential care towards personalised support and care.

The role of Adult Safeguarding Boards are critical to giving reassurances to individuals and the public through tackling any abuse of vulnerable adults within residential settings and promoting good practice to ensure residents enjoy the full entitlement of rights to independence and control. ADASS has been instrumental in developing advice notes and frameworks to strengthen this reassurance.

Question 3: What role do user-led organisations play in enabling local government to fully involve local communities in decision-making? What more could be done to promote co-production and to enable disabled people's own organisations to play their full part?
• User Led Organisations (ULOs) are critical in supporting and encouraging disabled people to engage and be active productive participants in their local communities and as part of the ADASS role within Think Local Act Personal, councils are committed to establishing ULOs. There are numerous examples of active ULOs in operation, many of which are detailed on the TLAP website TLAP-ULOs.

• Council decisions are locally accountable and councils work closely with ULOs in planning and commissioning services as well as engaging ULO in scrutinizing services i.e. contract monitoring

• These approaches could be further extended through wider government support and initiatives (open government services consultation), and growing confidence in such approaches within the very communities these approaches serve. Councils play a large part in sustaining and encouraging this confidence through growing success of ULO engagement and the proposed reforms of health and social care creates further opportunity to extend the influence of the user voice through greater local accountability and engagement in localised commissioning of services and support.

29 September 2011
Are there any specific examples of how local authorities can integrate a positive approach to independent living across each of their areas of responsibility, particularly in relation to access to the community, housing, planning and transport?

Adult social care is on a journey to provide higher quality support and to be more responsive to people’s needs and wishes—to personalise their care—as well as be more cost effective. The move toward service reform, as envisaged in Think Local Act Personal, provides a mechanism for partnerships to deliver a new vision for adult social care that truly starts with the individual and his or her needs and aspirations.

However, the Local Government Group has long said that reforming adult social care is about more than just changes to the business of adult social care departments. Social care must be seen in the wider context of care and support and the very important relationships and inter-dependencies between care and other council services, such as housing, leisure and transport, and those of partner organisations, such as health.

We also need to use the capacity that exists in neighbourhoods and in community networks to enable people to take care of themselves and those around them. We need to take an asset-based approach to care and support reform at a local level to develop a system that maximises an area’s capacity, whilst also recognising that different communities and different individuals will inevitably have different capacities.

Central to this vision is the principle that when people need ongoing support, they do not cease to be citizens or members of their local community. The support they use should therefore help them to retain or regain their roles and the benefits of community membership, including living in their own homes, maintaining or gaining employment and making a positive contribution.

Councillors have a central role to play in ensuring these issues are integral to their council’s performance and strategic aims. As representatives of wards, they often have the greatest knowledge of the needs of different sections of the community and of changes in the population of their local area. Lead members can also work with other executive members to ensure that social care users have access to universal services, such as transport, leisure and education as well as information, advice and advocacy. We are aware that political leadership is needed to ensure that all aspects of the independent living agenda are focused on locally, including promoting the social model of disability, ensuring choice and control and making sure that that personalisation of social care accommodates the diversity of the community.

Ultimately and unfortunately, the current legal and policy framework does not allow for local government to really address the needs of local people. It is hoped that the reduction in performance management and the impact of the move towards a place-based approach to local services will be felt shortly. The Local Government Group has stated that we need a significant shift in accountability which would make local public services genuinely local; both in the way funding is allocated, and in the way decisions about services are made and accounted for. Community budgets offer a real opportunity to work across boundaries both
nationally and locally and we are pressing for these to be rolled out more widely. Joining up services locally will be crucial in assisting with putting social care right in the heart of community well-being and community based services.

Councils play a vital role in addressing housing needs. However, we need central and local government to work together to devolve, simplify and rationalise the housing and planning framework in order for councils to have the freedom and autonomy to develop housing strategies that meet the needs of their communities. Echoing this, the LGA has long lobbied for all local councils to be able to commission bus services so they can ensure that local transport meets the needs of all local people.

We do, however, anticipate that the long-overdue reforms to health and social care will improve the current cliff-edge between local services. We have welcomed the drive towards greater localisation, integration and inclusion of the user and carer voice in commissioning decisions in the Health & Social Care Bill. Health and Wellbeing Boards and Health and Wellbeing Strategies will be key levers in developing not just a cross-council approach but a unified vision across a locality. Joint Strategic Needs Assessments should facilitate an understanding of the social care needs of different groups of people, so that services can be designed appropriately. They will also include other groups whose needs may not be met by ‘mainstream’ services or who may require special efforts to understand their needs and reach out to them. Health also has a lot to learn from local government in terms of commissioning for outcomes.

The simplification of the legislative framework and move towards single processes outlined in the Law Commission also should provide transparency and clarity across the sector, benefiting the experience of users of the system in accessing the right services, advice, information and support at the right time.

The Dilnot Review recommended that any new system for funding of social care must ensure portability across Local Government boundaries. Witnesses have told us that lack of portability is a key barrier to independent living. Are there any specific barriers to a national approach to eligibility for care—and a guarantee of portability—for local authorities? Are these problems political or practical?

We support the idea of a part national/part local system of care and support, which would mean portability of assessments and outcomes but not portability of the actual funding allocated (or the expectation of receiving the exact same type and/or level of services when moving to a new area).

A single, transferable assessment of need that would be recognised anywhere in the country would go a long way to addressing the legitimate claims that the current system is unfair because it discriminates along geographical lines. However, decisions on how needs are met (and the amount to pay for them) must be made locally. Only in this way can unique local variables being accounted for—such as cost, how services have been developed and commissioned, partner resources and the community infrastructure that supports service delivery.

Giving local government the freedom and discretion to make local decisions on adult care is crucial. Council areas are unique, with no two the same—even at a regional or sub-regional level. Moreover, in many parts of the country services relevant to the adult social care
agenda are provided by both county councils and district councils. Some big cities may have high levels of deprivation and a high number of residents with chronic long term conditions, whilst other more rural areas may be relatively prosperous but have a high number of retired people more sparsely distributed with potentially higher delivery costs.

Additionally, with a clear shift to more personalised services, local areas are working hard to develop local markets that are responsive to local people’s needs. A personalised world is, by its very nature, one that seeks to meet an individual’s specific requirements and aspirations. It would be entirely unfeasible to try and scale up to a national level the very different local care ecologies that are developing in different communities across the country.

From a broader perspective, the question posed must also be put in the context of funding. The 2010 Spending Review in October last year set out real terms reductions of 28% in local government budgets over the next four years, which compared with overall cuts of 8.3% across all departmental budgets. The December local government finance settlement included a two-year settlement for 2011–12 and 2012–13, which saw central government Formula Grant funding for councils fall by 12.1% in 2011–12.

The additional money for social care announced in the Spending Review was certainly welcome but its impact would only be truly felt if we were in a settled state. It is clear that we are not. Given the expected rise in the annual cost of adult social care we therefore anticipate a multi-billion pound shortfall by 2014–15 and have concerns about this funding gap being met.

In addition to concerns about the overall quantum of resource to meet need, there are further issues around how resources are distributed. Although the LGA does not typically comment on allocation formula and resource distribution issues (given that, in the main, different systems are inevitably good for some councils and bad for others) one main issue is worth flagging up, which is damping. In simple terms this means that even if need goes up, any grant increases will be heavily scaled back, which explains some of the regional variations we are now experiencing. Such differentiation can jeopardise services available locally because the capping of Council Tax increases (crucial given that Council Tax funds about 40% of total local expenditure on adult social care) and the impact of the gearing effect would make it virtually impossible to raise additional revenue locally.

We have received evidence that a lack of accessible housing and delays in getting adaptations are together resulting in disabled and older people staying in hospital longer than necessary and/or being discharged into residential or nursing homes against their wishes. What more do you think needs to be done, in terms of housing policy and investment, to prevent this kind of situation?

Again, this question needs to be placed in the wider financial context outlined above and the stark reality that current funding levels are inadequate for meeting demand. That is precisely why we have been urging the Government to take forward the debate on reform of care funding. Also as above, we believe there are quantum and distributional issues that relate to Disabled Facilities Grant and a concern that, given the financial environment councils are now operating in, it will become harder for councils to continue the historical trend of topping up DFG payments.
The answer to the question is not just about funding, however. In some cases discharges may be delayed due to the need for new assessments to be conducted—and conducted in specific ways as per the client’s wishes. Some delays are also about accessing NHS community services. Thinking more broadly there are issues too around planning consents for accommodation that meets local need and demand. In some cases the availability of appropriate stock is inevitably an issue, which is why many councils are working with developers, RSLs and older and disabled people themselves to develop innovative models of housing.

As opportunities to build new homes will be constrained in the short-term we need to find ways of adapting existing (sometime under-occupied) housing stock to ensure that it is fit for purpose. This means investment in aids, adaptations, assistive technology and support services so that older and disabled people remain safe, supported and independent.

September 2011
The following are my comments in response to the additional questions posed by the JCHR inquiry into independent living.

**What contribution do you think the personalisation programme in adult social care will make to older disabled people’s access to independent living? Do you have any examples of good practice which could be replicated within existing resources?**

The concept of personalisation potentially includes a range of approaches which can benefit older people. Personalisation should not just be seen as enabling people to receive cash payments to purchase care. Indeed many older people will not want to or feel able to arrange their own care, so should not be forced to do so.

It should also be recognised that older people who need care and support face a range of obstacles to becoming empowered consumers. Some of these obstacles, such as lack of information, could be reduced by making appropriate support available. Others seem to be an inherent aspect of the way in which older people use care and support, so may be harder to overcome. Older people frequently start using care services following a crisis, where they are dealing with a new and unfamiliar situation. They may not know what their future care needs are, particularly if they are ill and their health is unstable, they may have to make decisions quickly and under pressure, for example if they are leaving hospital, and they may not easily be able to change their support arrangements if they are unhappy, particularly if they enter residential care. These factors will, for many older people, make managing a direct cash payment more difficult than would be the case if their need for care and support was stable.

Local Authorities should therefore also look at ways in which people who choose to continue to receive services arranged by the local authority can exercise increased choice and control. These might include;

- Managed budgets
- Pooled budgets
- Advocacy and support brokerage

Older people who pay for their own care, either from their own resources or using local authority cash payments, should also be supported by adequate advocacy, brokerage and information services.

Personalisation should also apply to residents of care homes. The quality of care provided in residential settings is often heavily influenced by the quality of interpersonal relationships. Such relationships are not commodities to be purchased but are co-created between residents and staff.

Age UK’s ‘My Home Life’ project has placed this model of ‘relational’ or ‘relation centred’ care at the centre of its work. ‘My Home Life’ originated as a three year project to bring
together knowledge of good practice in the provision of residential care for older people and has since concentrated on disseminating this expertise and on training care staff and managers.

You have responded to the recent EHRC report on the findings of its home care report that basic human rights of older people receiving home care are being breached. Do you think that these findings suggest that the Committee should have considered the prevention of the violation of individual rights like the right to be free from inhuman and degrading treatment through the mistreatment and abuse of disabled people rather than the right to independent living?

Most of Age UK’s comments to the EHRC review of homecare referred to people’s access to local authority funded home care rather than to the conduct of home care providers.

In a climate of cuts to local authority funding for social care many local authorities are restricting eligibility for care to people with the highest needs. In some cases councils are restricting care to people with critical needs. A current judicial review case concerns proposals by the Isle of White County Council to restrict eligibility for people with substantial needs to situations where the need relates to safety or avoidance of going into a care home. The latter is of particular concern because, apart from being at odds with the prioritising need guidance, it potentially excludes people who have substantial needs for care in order to live with dignity, or to participate in society.

There is, at present, no minimum level of help that people with care and support needs are entitled to. This means that it is unclear how far a local authority needs to go to take positive action to safeguard the human rights of people for whom it arranges care. Current statutory guidance, ‘Prioritising Needs in the Context of Putting People First’ suggests a decision making framework but this is not, as was the case under the preceding guidance, ‘Fair Access to Care Services’, mandatory. If local authorities use the guidance they should divide levels of need into critical, substantial, moderate and low but nothing in the guidance limits how tightly eligibility should be limited. A few local authorities have limited eligibility to people with critical needs and at one point one local authority proposed limiting eligibility only to people with personal care needs who met critical eligibility criteria.

The main issues which Age UK have raised therefore relate to the extent to which local authorities have, or should have, positive duties to ensure that the human rights of people who need care and support are supported. Whether ‘critical only’ criteria, or ‘substantial only if related to safety or not having to go into residential care, would meet these obligations is debateable and a legal challenge to such policies is overdue.

So in response to the question, if the Committee had based it’s enquiry around human rights rather than independent living it would have needed to go beyond the extent to which human rights are infringed and would have needed to look at how human rights should be actively supported.

Some organisations have told us that older disabled people receive lower levels of services from adult social care than younger disabled people. Do you have any evidence of this practice and why do you think it is occurring?

Part of the difficulty of demonstrating that there is discrimination against older people in levels of service provision is that it can be argued that differences are due to differences in
levels of need or in the outcomes that older people want from services. In this respect work which Prof. Julian Forder of the Personal Social Services Research Institute carried out as part of the IBSEN evaluation of individual budget pilot projects is particularly valuable. This report\textsuperscript{415} sets out to compare spending on different age groups, taking into account different levels of need. The conclusion of this work was that personal budgets allocated to older people would need to be increased by 25\% to give parity with younger adults.

Whilst the personal budget pilots were in progress a number of organisations representing older and disabled people, including Age Concern and Help the Aged, submitted Freedom of Information requests to all local authorities to obtain documentation relating to how budgets were being calculated. As a result three ways in which local authorities could potentially discriminate against older people in allocating resources were identified:

- By using different resource allocation systems for older people and younger adults. The resource allocation system recommended by ‘In Control’, for example, uses different resource tools for younger adults and for older people. The two tools cover broadly similar areas but with different weightings; the one for younger adults places more emphasis on social involvement whereas the one for older people places more emphasis on health conditions.

- Where a ‘points based’ system was used to allocate resources, older people might receive less points for the same level of need.

- Points based systems entailed allocating a sum of money per point; in some cases older people would receive lower amounts per point.

It would be easier to show whether the social care system was discriminating against older people if support was always provided with the aim of achieving clear outcomes for the individual. This would make it possible to identify whether differences in expenditure on different age groups were due to different costs involved in achieving similar outcomes, or whether such differences were a result of support for older people being intended to produce more limited outcomes.

Do you think that there are any specific barriers to the UK meeting its obligation under the UN Convention to involve disabled people in decision making? What steps do you think that the Government can take to remove those barriers?

The traditional Institutional ethos of care homes for older people is a barrier to involvement. Residential care of younger adults has undergone a transformation, with much greater expectations that residents will be involved in the way that the home is run. This was reflected in the original national minimum standards for care homes which were published under the Care Standards Act 2000. The standards for younger adults included extensive requirements for involving residents. There were no similar requirements in the standards for homes for older people. This has now changed and the Care Quality Commission uses similar criteria for assessing compliance with regulations by homes for younger and older

\textsuperscript{415} The Costs of Addressing Age Discrimination in social care—Julien Forder—PSSRU discussion paper 2538 April 2008
Written Evidence submitted by Age UK (IL 120)

adults but there is little sign that this change reflects changing attitudes to care. Regulation and local authority commissioning should both place much greater emphasis on how homes are involving residents and their families in day to day decisions about, for example, activities, décor, meals and recruitment of staff.

Age UK's submission to the EHRC notes the problems resulting from people with dementia who do not speak the same first language as their carers. This is an issue for both the growing number of older people from minority ethnic groups and for English speakers in homes where many staff do not have English as a first language.

Workers who have to communicate with people with dementia should receive appropriate training.

Age UK runs a number of services which seek to communicate with and involve older people who might otherwise be marginalised. For example;

- Shropshire, Telford and Wrekin has a multi lingual outreach project based on recognition of the fact that older people from minority ethnic communities can be particularly isolated where communities are dispersed.
- Age UK’s ‘men in sheds’ project seeks to engage with older men who would not use mainstream services such as day centres;
- Age UK Norfolk has a community development project working with older gypsies and travellers;
- Several age UK projects work with lesbian, gay, bisexual and transgender older people. Age UK Camden has projects which provide information, befriending and social events, including a project specifically for lesbian, bisexual and transgender women, and age UK Highland Scotland seeks to raise awareness particularly amongst health and social care professionals.

What contribution does the mobility component of Disability Living Allowance make towards access to independent living for older disabled people who are in residential care? What would be the consequences of a withdrawal of their eligibility for this type of benefit?

This issue does not affect large numbers of older people. However it is apparent on the basis of the experience of older people in residential care that in some cases local authorities are only commissioning services that meet essential needs. Such narrowly targeted services are no substitute for a benefit that seeks to compensate for the costs of disability. It is therefore not true to say that care which local authorities commission from care homes could or is intended to replace services that people might buy using DLA Mobility Component.

30 September 2011
Introduction

The Equality and Human Rights Commission (EHRC), the Equality Commission for Northern Ireland (ECNI), the Northern Ireland Human Rights Commission (NIHRC) and the Scottish Human Rights Commission (SHRC) are designated, by Article 33(2), as the UK Independent Mechanism (UKIM), to promote, protect and monitor the implementation of the UN Convention on the Rights of Persons with Disabilities (UN CRPD) in the UK.

It is in this capacity that we submitted oral evidence to the Joint Committee on Human Rights (JCHR) inquiry into independent living on 14 June 2011. We subsequently received a letter from the Committee requesting further information in respect to a number of issues that arose during the oral evidence session and a response to questions which the Committee did not get time to ask during the oral evidence session. This submission contains the additional information as requested by JCHR.

This submission presents additional written evidence from UKIM and should be read alongside the three original written submissions presented by the members of UKIM in May 2011, and the oral evidence presented on 14 June 2011 by Mike Smith, Bob Collins, Monica McWilliams and Duncan Wilson on behalf of UKIM.

Question 1

Could you provide copies of any relevant legal advice which you have been given in relation to the violation of the right to independent living (Q42).

Our response

The Commissions in Scotland are seeking the consent of the author of the legal opinion they received to share it with the Committee. But please find the following information attached to this submission:

- Extract from Legal Opinion commissioned by the Northern Ireland Human Rights Commission on behalf of the Independent Mechanism for Northern Ireland: ‘Compliance of the Domestic Law of Northern Ireland with the UNCRPD’ Mark McEvoy BL, Belfast, 15 June 2010; and

- Extract from Counsel’s opinion on the UNCRPD commissioned by the Equality and Human Rights Commission, Catherine Casserley, February 2010

Please also find attached for your information:

- UKIM Letter to UK Minister for Disabled People, Maria Miller MP, 10 June 2011

Question 2
Can the right to independent living be considered as “hard law”, which judges can interpret and apply or “soft law” which is largely aspirational and is intended to be heeded by governments?

Our response

A full consideration of the nature of legal obligations flowing from the Convention on the Rights of Persons with Disabilities (CRPD), and their “hard” or “soft” law character will need to consider its effects as matters of universal international law, regional (i.e. European Union and Council of Europe) law, and domestic law.

Firstly, as a matter of international law the CRPD, in its totality, is binding international law—i.e. “hard” law. It is an international treaty which has been entered into by State Parties and is subject to the law of treaties and the principle of *pacta sunt servanda*. That is the principle, codified in the Vienna Convention on the Law of Treaties, that States enter into international agreements and implement those obligations in good faith. The CRPD was ratified by the UK Parliament on 8 June 2009. Since that date the UK has had “hard” international law obligations under Article 19 of the CRPD, the scope of which was outlined in part in response to the JCHR’s first question during the evidence session.

“Soft law” is generally taken to mean non-binding documents such as resolutions or declarations. There is, however, a debate in academic human rights circles as to the legal nature of interpretations of such binding obligations—whether in the form of concluding observations or general comments or recommendations. Some view these as “soft law”—not least as a number of States have made clear that they do not consider such statements to be binding, and practice on the basis of a consideration of obligation is a source of international law. It may, however, be more appropriate to see them, particularly general comments, as authoritative interpretations of binding obligations.

Stating that all elements of Article 19 are binding as a matter of international law does not imply all obligations are equivalent. Human rights obligations come in a variety of forms from absolute, limited to qualified rights, and from immediate obligations to rights which are to be fully realised progressively. Various types of obligations may even exist with respect to the same article, a position which may apply to Article 19. As has been said elsewhere, “In considering the nature of a treaty obligation, be it ‘soft’ or ‘hard’, it should never be presumed that a provision—be it an article or even a sub-paragraph of an article—will have only one type of obligation.”

The language of the CRPD may provide an indication of the nature of the obligations within it. For example, the use of the imperative “shall” in relation to a number of obligations in the

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416 *Pacta sunt servanda* literally means “agreements must be kept”.

417 The University of Bristol is currently evaluating the impact of one soft law agreement in practice, see: [http://www.bristol.ac.uk/law/research/centres-themes/ihrsp/aboutproject.html](http://www.bristol.ac.uk/law/research/centres-themes/ihrsp/aboutproject.html)

CRPD, including the primary obligation in Article 19, that States Parties “shall take effective and appropriate measures to facilitate full enjoyment of this right by disabled people and their full inclusion and participation in the community”. It should be noted here that the imperative of action to achieve a certain result (an obligation of conduct and an obligation of result) does not determine the exact form of that action, merely that it be “effective and appropriate”. There may be a number of means by which that obligation can be fulfilled. The choice of the exact measure is for the State Party, in accordance with general provisions of the Convention such as those requiring the participation of disabled people in decisions which affect their rights. In interpreting and applying this provision it is for a national or international court or other body to consider two questions: has the State Party taken measures which are designed to achieve the end required? And, are those measures effective and appropriate? In the case that either question is answered in the negative, the finding may be that the State Party is in violation.

The CRPD also includes an overarching reference to the standard of obligation regarding economic, social and cultural rights. This largely echoes the language of Article 2(1) of the International Covenant on Economic, Social and Cultural Rights (ESC rights), although the CRPD notes that some obligations related to ESC rights are immediate—a position which has developed clearly from the practice of the UN Committee on ESC rights. Those include the immediate obligation to take concrete, targeted and effective measures to achieve progressively the full realisation of those rights. The text of the CRPD does not indicate which rights should be considered ESC rights, and it may be that elements of the right to independent living will be considered ESC rights.

It is worth emphasising that each of these obligations, whilst of a different character, are “hard” law and capable of judicial interpretation and enforcement. The experience of the South African Constitutional Court (SACC), for example, demonstrates how a superior domestic court can uphold ESC rights, and determine the “reasonableness” of the States’ measures to progressively realise those rights. Whilst the SACC is applying the South

419 See inter alia, UN Committee on Economic, Social and Cultural Rights, General Comment no. 3, The nature of States parties obligations (Art. 2(1)), 14/12/1990.

420 Ibid.


422 See for example Treatment Action Campaign and others v Minister of Health and others 2002 (4) BCLR 356.
In terms of European Union (EU) law there has been some consideration as to whether, upon ratification (or “conclusion”) by the European Council, the CRPD became part of the European legal order, and the impact this would have on the enforceability of its provisions by the EU population, either in respect of the EU directly, or in respect of Member States. A major study supported by the European Commission noted that, upon conclusion by the EU, international treaties are binding on EU institutions and Member States, according to Article 300(7) of the Treaty establishing the European Community. The report further noted that so-called “mixed” international agreements, to which both the EU and Member States are parties (as is the case with the CRPD), are binding on the EU institutions, and Member States have a community law, as well as an international law, obligation to implement a mixed agreement—in respect of “all provisions of the agreement falling within EU competence”.

On the basis of European Court of Justice case law, the report considers that international treaties concluded by the European Council form an “integral part” of EU law, and in the hierarchy of obligations they fall below EU primary law (i.e. the treaties establishing the European Community or on the functioning of the European Union) and above secondary EU law (including regulations, directives, decisions, recommendations and opinions). The authors of the report do not, however, consider that the CRPD will have “direct effect”. Nevertheless, “the primacy of international agreements concluded by the Community over provisions of secondary Community legislation means that such provisions must, so far as is possible, be interpreted in a manner that is consistent with those agreements”. If this view is upheld it will mean that the European Court of Justice would be likely to interpret EU law in a manner that is most consistent with the CRPD, and that European Institutions and Member States will be required to do so. The study also includes a number of examples of EU Regulations and Directives of relevance to the right to independent living which ought to be interpreted in a manner consistent with Article 19 of the CRPD.
Across the jurisdictions of the UK, section 2(1) and (4) of the European Communities Act 1972 provide that EU law which has direct effect should, where a conflict arises, take precedence over a UK statute. In the case of EU law which does not have direct effect, UK statutes should be read as far as possible in a manner consistent with EU law. The consequence then of the EU conclusion of the CRPD would be that EU law should itself be interpreted, to the extent possible, in a manner which accords with the CRPD. This would mean that the CRPD, albeit indirectly, could be cited as a relevant source for the interpretation of EU law in the UK courts.

Outside of the EU law context, similar rules of interpretation in the UK apply to other non-incorporated treaties. As a dualist system, in the absence of legislation which incorporates the CRPD into our jurisdictions, the CRPD cannot be directly applied. It is nevertheless open to our courts to follow a rule of interpretation similar to that outlined above. Where the rights in the Human Rights Act (HRA) apply, of course, section 3 requires all legislation to be interpreted in light of the HRA, and the practice of the European Court of Human Rights indicates its willingness to interpret those rights through the lens of the CRPD, where relevant. This may be relevant to the elements of Article 19 which could be seen as developing understanding of the requirements of Article 8 of the European Convention on Human Rights (ECHR) in respect of disabled people (for example, in respect of autonomy, involvement in community and involvement in decision making, which have been interpreted by the European Court of Human Rights to be elements of Article 8) and Article 3 ECHR (for example, in respect of legal thresholds regarding inhuman and degrading treatment). There are, however, recent high profile cases in which the superior courts in the UK have not adopted such an approach, although the picture is mixed. The UKIM remains convinced that public authorities across the UK should, as a matter of law and of good policy, assess the impact on equality and human rights of budget and other relevant decisions. In particular, the impact of decisions on the allocation of resources in the social care sector on the right to private and family life and independent living of disabled people should be assessed prior to those decisions being made. A short presentation of three recent cases is provided in Annex 1.

Question 3

The disabled people’s organisations told the Committee that consultation exercises involving disabled people or their organisations did not generally meet the standard

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429 For useful discussions of the approach of the superior courts to the interpretation of domestic law in the light of international obligations see Lord Hope of Craighead, First Lord Alexander of Weedon Lecture, and Lord Neuberger of Abbotsbury, Master Of The Rolls, Who Are The Masters Now? Second Lord Alexander of Weedon Lecture, 6 April 2011. Not all courts in the UK necessarily apply this principle consistently, contrast has for example been made between the approach of the UK Supreme Court in ZH (Tanzania) v Secretary of State for the Home Department [2011] UKSC 4 at paras 21–23 and the approach of the Inner House of the Court of Session in HS v Secretary of State for the Home Department [2010] CSIH 97 at paras 4–7, 12.

430 The European Court of Human Rights has referred to the Convention in, among others, cases involving reasonable accommodation (Glor v Switzerland, (application no. 13444/04) judgment of 30 April 2009); guardianship, legal capacity and voting rights (Alajos Kiss v Hungary, (application no. 38832/06), decision of 20 May 2010).
required by the UN Convention on the Rights of Persons with Disabilities. What do you think the Convention requires, and what steps have you taken to ensure that disabled people are involved and participate in your work and that of the UK and devolved Governments to implement the Convention?

Our response

Full and effective participation and inclusion in society is a general principle of CRPD, while consultation, involvement and participation of disabled people is mentioned in a number of its articles. The General Obligations in Article 4 (3) require that States Parties “shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organisations” in the development and implementation of law, policy and other decisions on the implementation of the CRPD. This is complemented by Article 33 (3) which requires that civil society, in particular persons with disabilities and their representative organisations, shall be involved and participate fully in the monitoring process. The Committee will notice that these are imperative and immediate obligations. Similarly in Article 29(b), States Parties undertake to promote actively an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs and, inter alia, encourage their participation in non-governmental organisations and associations and, through forming and joining organisations of disabled peoples, to represent disabled people at all levels.

In reality the type and extent of consultation varies across the UK. The true test is of course whether consultation and involvement has influenced decisions or the course of events. At the UK level, the Office of Disability Issues (ODI) supported the United Kingdom Disabled People’s Council to scrutinise government implementation of the UNCRPD, as well as seeking feedback from its 'network of networks' and from Equality 2025. But it is unclear what, if any, influence this has had on the recently published draft UK State report. 431

In response to the second part of this question, the individual Commissions have taken different approaches to engaging with disabled people, and through regular meetings of the UKIM, the Commissions have exchanged information and learning to assist them in the development of their engagement activities. Their respective approaches are outlined more thoroughly below.

Scotland (EHRC and SHRC)

As the Committee will be aware from the Commissions' previous written evidence, the SHRC and EHRC in Scotland work jointly to fulfil their role as the Independent Mechanisms for Scotland. Both have held a number of participation events over the last two years, involving several hundred people. Most recently the Commissions used new technologies to raise awareness of the CRPD among disabled people across the country, particularly in rural

Written Evidence submitted by the Equality and Human Rights Commission, the Equality Commission for Northern Ireland, the Northern Ireland Human Rights Commission and the Scottish Human Rights Commission (IL 122)

and remote areas and to gather their experiences for the purposes of monitoring. This approach was a response to views of disabled people in rural areas, who reported that they are often unable to participate in decision-making processes because of location, cost and inaccessibility. The Commissions also hosted a training event for disabled peoples’ organisations and other relevant NGOs on the parallel reporting and individual communications mechanisms under the Convention and Optional Protocol.

The Commissions in Scotland have adopted an approach to participation and monitoring work that seeks to involve disabled people and disabled people’s organisations in the planning and implementation stages of their work. This appears to be working well and allows the Commissions to focus limited resources in such a way that will have a broad impact. By building relationships with disabled people’s organisations, such as the Independent Living in Scotland (ILiS) project and Glasgow Disability Alliance, the Commissions have also been invited to participate in their events and share information about promoting and monitoring the implementation of the CRPD in Scotland.

Both the EHRC in Scotland and SHRC have dedicated sections of their websites on the CRPD. Details of previous and future events are published on these sites, as well as consultation responses, submissions and other relevant pieces of work that link to the CRPD. All are available in accessible formats. Reports of events and what disabled people have told the Commissions so far about where progress needs to be made to fully implement the CRPD are also published on the website and available in accessible formats.

**Northern Ireland (NIHRC and ECNI)**

The NIHRC and ECNI (the Independent Mechanism for Northern Ireland or IMNI) have published a series of guides for the promotion of the CRPD and the Optional Protocol. In December 2010, IMNI hosted a platform event with disabled people, their representative organisations and civil society which provided information to assist its work to identify gaps within current law, policy and programmes and the rights held within CRPD.

Between 1 March and 15 June 2011, IMNI hosted nine training sessions along with interactive evidence gathering sessions in range of locations throughout Northern Ireland. The training sessions were on the Disability Discrimination Act, positive duties on public authorities, transport and disability, education and disability, and health and disability. These interactive sessions sought the views of disabled people on the key issues that impact on the right to an adequate standard of living and social protection (Article 28). However, as the ability to obtain an adequate standard of living is often conditional on other related issues, the sessions also sought information on accessing education, employment, benefits, personal mobility and independent living. The information-gathering sessions will inform a jurisdictional monitoring report by IMNI on Northern Ireland Executive and UK government’s implementation of the CRPD in Northern Ireland. IMNI will also hold further


http://www.equalityni.org/archive/Research%20docs/ToR_UNCRDP_v1-Final_090710_amended.pdf

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Written Evidence submitted by the Equality and Human Rights Commission, the Equality Commission for Northern Ireland, the Northern Ireland Human Rights Commission and the Scottish Human Rights Commission (IL 122)

engagement events, focused on obtaining the views of disability policy experts in the preparation of evidence for it jurisdictional report.

In its role as focal point for Northern Ireland, the Office of the First and deputy First Minister (OFMdFM) has, in preparation for its contribution to the draft State Party Report, held a series of focus groups to obtain the views of disabled people. In its role to promote, protect and monitor the CRPD, IMNI has actively engaged with OFMdFM on issues relating to the implementation of the Convention. Acting for the Northern Ireland Executive, OFMdFM will shortly engage on the pre- and public consultation of a strategy and action plan for the implementation of recommendations held within the Promoting Social Inclusion (PSI) Report on Disability. The PSI strategy and associated action plan are considered by OFMdFM to be the primary vehicle for the implementation of many, but not all, of the CRPD rights within Northern Ireland. IMNI will engage with OFMdFM over the coming months to ensure that it fully considers its responsibilities to closely consult with, and actively involve persons with disabilities in the development and implementation of law, policy and other decisions (Article 4.3). In addition, IMNI will remind OFMdFM to further involve and ensure full participation of disabled people in the monitoring process (Article 33.3.). OFMdFM is obligated to undertake to promote actively an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs (Article 29).

England and Wales (EHRC)

In addition to its work as part of UKIM, the EHRC is committed to ensuring its work to promote, protect and monitor implementation of the Convention engages and involves disabled people in all parts of Britain. One element of this is its commitment to improving and facilitating the participation of ‘hard to reach’ and marginalised groups in the promotion, protection and monitoring of CRPD implementation. For example, the EHRC believes it is imperative to capture the views and experiences of disabled children in order to begin to engender a rights discourse around disabled children and young people in England and Wales. The EHRC recently commissioned the Council for Disabled Children (CDC) to conduct a scoping report on the experiences of disabled children and young people in relation to the Convention rights.

The EHRC plans to develop this work further, holding a series of workshops with disabled children and young people, as well as parents and representative groups, later this year. These sessions will help inform the UKIM parallel report and the EHRC’s influencing work with Government departments, local authorities and other public bodies.

More broadly, the EHRC has convened an external working group of disability experts to support its work raising awareness of and its activities to monitor and promote implementation of the CRPD, including CRPD capacity building in the advice sector. The

http://www.ofmdfmni.gov.uk/report_of_the_promoting_social_inclusion_working_group_on_disability_pdf_1.38mb.pdf
advisory group has representatives from disabled people's organisations and representatives from Scotland and Wales.

Internally, the EHRC has a Disability Committee whose members inform its CRPD work, including its participation and involvement initiatives. Mike Smith, who chairs the Committee, was a witness at the JCHR inquiry session on 14 June 2011. Diane Mulligan, who is also a member of the Disability Committee, gave evidence on the same day.

The EHRC has also produced a range of practical resources to assist disabled people and their organisations to understand and assert their CRPD rights and to be informed and empowered participants in the monitoring and implementation processes. It has produced guidance ‘UNCRPD: What the Convention means for you’ to help disabled people and their organisations make practical use of the CRPD in their own work. The publication is available in accessible formats. The EHRC has also launched web pages to provide an overview of the CRPD and its role as an independent mechanism. These pages are updated regularly with details of EHRC projects to promote the CRPD, and links to other pieces of work which relate to it, for example, its inquiry into disability related harassment.

In England specifically, the EHRC hosted roadshows round the country for disabled people and their organisations to develop understanding of the CRPD and explore ways to work together to promote and monitor its implementation. The feedback and evidence gathered at these events has been used to determine key pinch points in terms of the UK's compliance with and progress towards CRPD implementation and have helped determine the EHRC's monitoring and promotional activities going forward.

In relation specifically to independent living, the EHRC recently undertook a project to build capacity to influence reform of social care and for personalisation. The EHRC commissioned a number of user-lead disabled people's organisations (DPULO) to undertake work on the personalisation of care and support. Four pilot projects were carried out across the English regions which explored how personalisation is working in practice for four specific groups who use social care services. Those groups were: lesbian, gay and transgender people, young adult mental health users, disabled gypsies and travellers, and older people. The project findings are published in 'Making the personalisation of care and support work for all communities in the English regions'.

The committee may also be interested to know that the EHRC is conducting a formal inquiry to find out whether the human rights of older people wanting or receiving home care are fully promoted and protected. One of the areas examined by the inquiry is the extent to which home care services support older people’s autonomy and self-determination, by enabling them to live independently in their homes for as long as possible.


435 http://www.equalityhumanrights.com/publications/our-research/research-reports/unnumbered-research-reports/
In Wales, the EHRC hosted conferences with disabled people to explore the CRPD rights and to prioritise action areas. The participants’ views and feedback on what a CRPD-aware Wales would look like were captured in the conference report, ‘Rights of way’. EHRC Wales is monitoring progress against the goals and priorities identified in the report and as part of that process, the EHRC recently hosted an UN CRPD roundtable event with disabled people and policy leads from the Welsh Government to discuss progress and next steps. The specific policy areas covered at the event were housing, workforce, communities and social inclusion, and a range of actions were agreed. The EHRC will continue to involve disabled people and their representative organisations in monitoring and promoting progress against the ‘Rights of way’ priorities and CRPD implementation.

**Question 4**

*Have you made any significant changes to your role under the UN Convention in light of revised funding priorities?*

**Our response**

Broadly within the Commissions, work on promoting, protecting and monitoring implementation of the Convention has, where possible, been mainstreamed into existing operational plans. As the Committee will appreciate, the roles designated to the Commissions under Article 33.2 of the CRPD are new and required significant planning and co-ordination. Through regular liaison and cooperation, as the UK Independent Mechanism (UKIM) the Commissions have developed significant bodies of work both individually and collectively.

The Commissions have been unable to receive additional or increased core funding to enable them to take forward their designated functions under Article 33.2 of the CRPD from either central government or the devolved administrations. However, in previous years the Commissions in Scotland and Northern Ireland received small ad hoc grants from the Office of Disability Issues (ODI), to facilitate the delivery of project focused activities, such as participation or platform events, commissioning legal analyses and the publication of CRPD-related materials.

**Question 5**

*The UK recently published its draft first report to the UN Committee of Experts for four weeks consultation:*

- **What involvement have you had so far in the preparation of the draft report?**

- **Are you satisfied that the steps which the Government have taken to involve disabled people in the preparation of the Report have complied with the standards required by the Convention?**

**Our response**

In 2009, the Commissions were involved in discussions with the ODI and focal points from the devolved administrations on the process which would be followed for the development of the draft UK report. At that stage, it was considered that each devolved administration
would develop a jurisdictional report, from which it would extract an agreed number of words to be included in a draft State report under each article.

In Scotland, the Scottish Government focal point (the Equality Unit) organised a seminar on the Convention for all relevant departments. The EHRC and SHRC, together with the Independent Living in Scotland Steering Committee helped deliver that seminar. In addition to introducing the Convention, the seminar introduced reporting templates which the Equality Unit had developed on each article—based on the UN Committee’s Reporting Guidelines. The Government then developed an 80 page report on the Convention in Scotland. The Commissions’ feel they were adequately involved in the process of developing the Scottish Government report.

In Northern Ireland, IMNI has liaised with OFMdFM on State Party reporting. OFMdFM adopted a similar method of engagement with the devolved Northern Ireland Executive departments to that used by the Equality Unit of the Scottish Government. In meetings, IMNI raised concerns that the draft State Party report did not report the significant and substantive differences in both policy and legislation between Northern Ireland and Great Britain. As a consequence of this difference, disabled people in Northern Ireland receive poorer policy and service delivery provision and less protection from discrimination and harassment than their counterparts in Great Britain.

After the contributions from the devolved administrations were passed to the ODI (the designated co-ordination mechanism for the UK government), they were heavily edited. UKIM, in its engagement with ODI, has clearly stated that the draft State Party report does not, in our view, comply with the UN Committee’s reporting guidelines. In particular we expressed concern that the report contained insufficient specific and analytical information relating to the implementation, in law and in fact, of Articles 1 to 33 of the CRPD. In addition, we were concerned that the draft report lacked disaggregated statistics and data sources (although some initial work to identify these has now been published); failed to adequately identify resources available to implement the articles; lacked reference to specific examples of relevant legal cases; and failed adequately to identify the remedies available to enable victims to obtain redress when their CRPD rights are violated.

UKIM is concerned that there should be more opportunity for the participation of everyone—including disabled people—in the finalisation of the UK report.

The ODI placed the draft State report on its website for comment on 16 May 2011 for a five week consultation period until 20 June 2011. UKIM arranged a meeting with ODI on 27 May to provide comments on the draft report and to present our overall concerns with the report. Subsequently, UKIM wrote to the UK Minister for Disabled People, Maria Miller MP on 10 June 2011. In that letter UKIM outlined its concern that the report did not meet the information needs of the UN Committee, nor did it provide a genuine and meaningful account to disabled people in the UK of the UK’s implementation of the Convention. UKIM recommended to the Minister that she consider delaying submission of the report to bring it up to the standards required by the UN Committee guidelines. The consultation period was extended to 25 July 2011. UKIM provided further detailed comments to ODI on 26 July

436 See attached letter
Written Evidence submitted by the Equality and Human Rights Commission, the Equality Commission for Northern Ireland, the Northern Ireland Human Rights Commission and the Scottish Human Rights Commission (IL 122)

2011. Following this correspondence another meeting was arranged on 2 August between UKIM and ODI to discuss progress on the draft report and future work on implementation of the Convention. UKIM is currently seeking a meeting with officials from ODI and the devolved administrations to discuss implementation of CRPD within the devolved jurisdictions and across the United Kingdom (please refer to the conclusion).

Further information

Devolution arrangements and the CRPD

During the Committee’s evidence session, questions were asked regarding differing approaches across the UK jurisdictions and a request was made to develop a devolution “map” as it is relevant to CRPD implementation.

In terms of international legal obligations to ensure that the rights in the CRPD are respected, protected and fulfilled, these of course lie with the UK as the State Party. The CRPD is one of a few international human rights conventions which specifically provides, in Article 4(5), that the provisions of the CRPD extend to all parts of Federal (and presumably by extension devolved) States. There is therefore, an international legal obligation on the UK to ensure that the right to independent living is respected, protected and fulfilled in all parts of the UK. This does not mean that the UK is obliged to ensure one common approach to implementing that right. On the contrary there can be a variety of ways in which obligations can be complied with, in accordance with the doctrine of margin of appreciation and the comments above on the choice of measures to implement obligations which are most appropriate to the context.

The devolution settlements in the UK deal differently with international human rights obligations, with the Scotland Act 1998, for example, specifically placing the responsibility to ensure compliance with international obligations on the Scottish Parliament and Scottish Ministers, within their areas of competence. Furthermore in Scotland the Government has negotiated a “concordat” with Scotland’s 32 local authorities providing them with autonomy in the determination of measures to achieve agreed national outcomes.

It is of course one of the benefits of devolution that it permits different approaches to strategy and policy to be adopted across the country in response to local context. In the context of the passage of the Scotland Bill, there has been discussion on steps to further clarify common responsibilities of the UK and Scottish administrations for the implementation of international obligations.

In Wales, the devolution settlement is contained principally within the Government of Wales Act 2006 (GOWA 2006). Sections 80 to 82 of GOWA 2006 make provision in respect of community law, human rights and international obligations respectively. Section 82 specifically requires that Welsh Ministers cannot act in a manner that is incompatible with an international obligation, and allows the Secretary of State to direct an action is not taken by the Welsh Ministers if it is incompatible (section 82 (1)). Conversely if an action is thought necessary by the Secretary of State to give effect to an international obligation the Welsh Ministers can be directed by the Secretary of State to take such action (section 82 (2)) that is within their power. Section 81 provides that the Welsh Ministers must act within the scope of the European Convention on Human Rights.
The Welsh Government does not currently have a national strategy on independent living, although its paper ‘Sustainable social services in Wales’ (March 2011) included commitments to portability of assessments and national eligibility criteria for adult social care. The Welsh Government has also committed to Direct Payment Schemes and to developing Citizen Centred Services in social care. The EHRC will be monitoring the effectiveness of this approach in delivering Article 19 rights in Wales.

In the Northern Ireland context, reference is made to international obligations under the Northern Ireland Act 1998. The purpose of the Northern Ireland Act 1998 was to put into legal effect the Good Friday Agreement of April 1998 and established a devolved legislature for Northern Ireland, the Northern Ireland Assembly. Primarily ‘observing and implementing international obligations’ is an ‘excepted matter’ under Schedule 2 of the Act. Specifically, Section 26 of the Act refers to ‘International Obligations’ which allows the Secretary of State for Northern Ireland the opportunity to consider ‘any action proposed to be taken by a Minister or Northern Ireland department’ which would be ‘incompatible with any international obligations [...]’ to direct that the proposed action shall not be taken’. In respect to devolved matters, IMNI views the Northern Ireland Executive, and its departments, responsible for implementing CRPD in Northern Ireland.

As the Committee will be aware, the furtherance of human rights for disabled people is based not only on human rights legislation but on the effective implementation of equality legislation. The enactment of the Equality Act 2010 has created a sharp difference between Northern Ireland and Great Britain. The provisions held within equality legislation in Northern Ireland now lag substantively behind the provisions contained within the Equality Act 2010 for the rest of the United Kingdom. In respect to the furtherance of human rights for disabled people this difference imposes a significant disadvantage on those persons living in Northern Ireland. Furthermore, the confusion between what is the law, and any related policy provisions, in Great Britain and what is required in Northern Ireland, is also a disadvantage for employers and service providers, both private and public, who trade and operate in both jurisdictions.

The ECNI has recommended that the Northern Ireland Executive to make urgent changes to the disability, and other, equality legislation in Northern Ireland. A copy of the ECNI’s detailed proposals paper to OFM&FM outlining a number of areas in Northern Ireland equality law which require urgent amendment is available on the Commission’s website.

**National action plan**

It is crucial that there is no accountability gap in ensuring compliance with the CRPD. The process of producing both the individual jurisdictional reports and the UK State Report has required an assessment of where progress has been made and where more could be done in

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437 Proposals for legislative reform. Equality Commission for Northern Ireland. February 2009. The proposals paper is available at:
implementing the CRPD. The period between now and the UN examination provides a unique opportunity for the UK Government, with the devolved administrations, to set out the actions they intend to take to address areas of rights deficits and to protect existing CRPD rights from regression.

The UKIM view is that a national action plan specifically directed at the implementation of CRPD, across each of the jurisdictions would provide the most effective practical framework to achieve this. Any national action plan should of course be developed with the effective participation of disabled people and their representative organisations.

We recommend that the JCHR consider raising the issue of a national implementation Action Plan with the government.

Conclusion

The UKIM is grateful for this opportunity to submit further evidence to this inquiry into the UNCRPD Article 19 right to independent living. In the process of compiling this response and having reviewed the evidence, we have gathered to date and the priorities identified to us by disabled people and disabled people’s organisations, we have identified a number of areas which the JCHR may wish to explore when it takes evidence from the government later in the year. These are:

- What structural indicators (relevant laws and strategies), process indicators (relevant policy and other process steps) and outcome indicators (qualitative and quantitative data on the realisation of the rights set in practice including relevant disaggregated data, relevant court cases, results of independent evaluations, concrete examples of good or bad practice) that the government used in respect of its analysis of progress on the implementation of Article 19?

- What areas of priority and concern were identified to ODI and focal points for the devolved administrations by disabled people and disabled people’s organisations (for example, via the UNCRPD Working Group chaired by the UK DPC) in relation to Article 19? What specific actions are planned to address these and how will they be incorporated into a revised initial State report?

- What assessment and analysis has been carried out by the government into the actual and foreseeable impact of budget cuts on Article 19 rights? What steps have been put in place to monitor the immediate and ongoing impact on disabled people once reforms and budget cuts take effect? Where any potential negative impact may have been or are identified, what mitigation actions have been considered?

- What actions specifically in relation to Article 19 compliance will the government be making following submission of the revised initial state report?

As the JCHR is aware, UKIM has outlined to the government a number of areas where its draft initial State report could be improved. We welcomed the government’s initiative in conducting a public consultation on the draft report and in subsequently extending the consultation period to increase the ability of disabled people and disabled peoples’ organisations to participate in it. We also recognise that Government is reviewing its draft
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report in light of the responses it received to the consultation and that it aims to submit the finalised report to the UNCRPD Committee in October 2011.

However, the following recommendations are relevant not only to the production of the State report, but as a practical framework for the effective implementation of UNCRPD rights on a UK-wide basis. The Committee may wish to consider the following points as recommendations when it compiles its final inquiry report.

1. **We recommend the ODI and devolved administrations develop an explicitly rights-based approach and UK-wide national action plan to advance the implementation of the Convention.** With the involvement of disabled people, disabled people’s organisations and UKIM, they should develop a high-level and co-ordinated national action plan for the implementation of the Convention in the UK jurisdictions. The national action plan should include specific, measurable, achievable, relevant and time-bound objectives for all relevant levels of governance, from national to local and other public authorities against which progress on implementation on Article 19 can be monitored. Indicators for monitoring these objectives should be developed. All action which affects the rights of disabled people, including the development of this national action plan to implement the CRPD should be undertaken in a manner which complies with all elements of Article 33, including that it is with the effective participation of disabled people and their representative organisations.

2. **The JCHR may also wish to consider and comment in its final report on the impact of recent decisions of the UK superior courts on Article 19 and the right to independent living.**

**ANNEX I**

**Interpreting and applying Article 19 CRPD rights: UK caselaw**

As discussed in our response to Question 2, as a matter of EU law and in accordance with section 3 of the Human Rights Act and European Court of Human Rights jurisprudence, domestic equality and human rights legislation should be interpreted and applied through the lens of the CRPD, where relevant.

In a number of recent UK cases the courts do not appear to have maximised the use of the CRPD as a lens through which to view domestic law. The Commissions note that some of these cases may be ongoing. At this stage we simply note that, in our view, the right to independent living and the CRPD in general can and should be borne in mind as an interpretative tool to related areas of domestic law. In accordance with our Article 33 mandate to promote, protect and monitor implementation of the Convention, UKIM will monitor the impact of these decisions and whether they are changing policy and practice in relation to independent living, raising concerns as necessary.

- **McDonald) (Appellant) v Royal Borough of Kensington and Chelsea (Respondent)**
The well documented case of McDonald v Kensington and Chelsea involved challenge to a decision, the result of which was the withdrawal of night care. This required Ms McDonald, who was not incontinent, to use incontinence pads throughout the night.

In that case, the Supreme Court considered that “There is no dispute that in principle [Article 8 of the ECHR] can impose a positive obligation on a state to take measures to provide support and no dispute either that the provision of home-based community care falls within the scope of the article provided the applicant can establish both (i) “a direct and immediate link between the measures sought by an applicant and the latter’s private life” and (ii) “a special link between the situation complained of and the particular needs of [the applicant’s] private life”. Nevertheless, the majority of Supreme Court considered that the measures adopted by the Council fell within the scope of the State’s margin of appreciation which, according to Strasbourg jurisprudence is “even wider when [...] the issues involve an assessment of the priorities in the context of the allocation of limited state resources”.

In this way the Court considered only very briefly the proportionality of the interference with Ms McDonald’s right to private and family life, stating for example, “even if such an interference were established, it would be clearly justified under Article 8(2) [...] on the grounds that it is necessary for the economic well-being of the respondents and the interests of their other service-users and is a proportionate response to the appellant’s needs because it affords her the maximum protection from injury, greater privacy and independence, and results in a substantial costs saving.”

There is a risk that this ruling may be seen by local authorities as suggesting that they have greater discretion in determining the allocation of resources in the care sector, even where these have an impact on the right to independent living and the right to private and family life, than that they currently exercise. It is UKIM’s view that in reaching such decisions local authorities and others must consider their impact on the human rights of everyone involved, this includes a requirement to consider the proportionality of impacts on the right to private and family life, interpreted alongside the right to independent living where appropriate. In order to be assured of their compliance with human rights law and certainly good practice, public authorities should increasingly undertake human rights impact assessments prior to reaching such decisions.

438 R (on the application of McDonald) (Appellant) v Royal Borough of Kensington and Chelsea (Respondent), [2011] UKSC 33, 6 July 2011.

439 Ibid, para 15

440 Ibid, para 16.

441 Ibid, para 19.

442 Ibid.
Written Evidence submitted by the Equality and Human Rights Commission, the Equality Commission for Northern Ireland, the Northern Ireland Human Rights Commission and the Scottish Human Rights Commission (IL 122)

Other recent cases however, including the Steven Neary case and the Birmingham City Council case, indicate the importance of consideration of equality and human rights impact of decisions, as well as a human rights approach to decision making.

- **JR37’s application for Judicial Review**

In Northern Ireland in 2011, a judicial review application was brought by the brother and carer of a disabled man on his behalf (as next friend), seeking to challenge decisions made by the local health trust, in relation to the level of direct payments for care being provided.

The case presented by the applicant was that the level and amount of direct payment for care being provided to the applicant was unlawful and in breach of the applicant’s rights under Article 8 of ECHR and in breach of Article 19 CRPD. The applicant sought an order compelling the trust to provide direct payments or provide care on the basis of the basis of the applicant’s assessed needs being a need for 24 hour care and supervision. The disabled man was considered to suffer from a severe learning disability and a large range of disabilities.

The judge raised issues around the mental capacity of the disabled man noting that he had no capacity to consent to a direct payment scheme, therefore there was no underlying legal basis for the scheme and that the trust must reconsider its position in light of the fact that any funding of care must be provided on a different legal basis.

The judge ruled that there was no breach by the trust of the Article 8 rights of the applicant. His right to family life had not been infringed by anything the trust had done. If the applicant’s brother asserted that the lack of proper recompense of the services he had provided to his brother infringed his Article 8 rights, that is not a claim that could be asserted in these proceedings.

However, the judge did assert that the applicant received excellent care at home and that it was clearly in the applicant’s interest to remain at home in a safe and secure environment, even if the trust had argued that residential care was economically cheaper.

The judge presented a case for ‘reasonable proportionality’ between providing a level of appropriate care for the applicant and balancing the need for proper use of state resources by the trust. However, the judge did warn the trust not to fix the direct payment at an unfairly low level by recourse to the argument that it is up to the family to provide unfunded the extent of the care required.

One area of concern with the judgement was that it recognised the rights contained in Article 19, but noted that the article did not deal with the question of legal capacity to enter into contractual arrangements. No link had been made to Article 12 of CRPD.

- **JR47’s application for Judicial Review**

443 Re Steven Neary; LB Hillingdon v Steven Neary (2011) EWHC 1377 (COP)

444 R (W) v Birmingham City Council [2011] EWHC 1147 (Admin)

445 PF+Anor, Application for Judicial Review, 2011, NIQB20
The second recent case was taken by the Law Centre NI on behalf of a man with learning disabilities residing in a learning disability hospital for 11 years longer than necessary when he should have been resettled in the community, in line with trust policy.

Mr Justice McCloskey dismissed claims that the authorities had neither complied with their duties under health and social care legislation, nor done enough to deliver on expectations raised by policy statements that long-term patients would be resettled. He also held that the department had not breached his right to privacy and right to freedom from discrimination under the European Convention on Human Rights: "All in all, I find that the failure of which (he) accuses the department does not interfere with his right to respect for his private life".  

ANNEX 2

About the Commissions

Equality and Human Rights Commission

The Equality and Human Rights Commission is an independent statutory body established under the Equality Act 2006. The Commission works to reduce inequality, eliminate discrimination, strengthen good relations, and promote and protect human rights.

As a regulator, the Commission is responsible for enforcing equality legislation on age, disability, gender, race, religion or belief, sexual orientation or transgender status, and encouraging compliance with the Human Rights Act. It also gives advice and guidance on businesses, the voluntary and public sectors, and to individuals.

www.equalityhumanrights.com

Equality Commission for Northern Ireland

The Commission is an independent public body established under the Northern Ireland Act 1998. The Commission is responsible for implementing the legislation on fair employment and treatment, sex discrimination and equal pay, race relations, age, sexual orientation and disability. The Commission’s remit also includes overseeing the statutory duties on public authorities to promote equality of opportunity and good relations under Section 75 of the Northern Ireland Act 1998 (Section 75) and the disability duties under the Disability Discrimination Act 1995.

The Commission’s general duties include:

- working towards the elimination of discrimination;
- promoting equality of opportunity and encouraging good practice;
- promoting positive / affirmative action;

446 JR47’s application for Judicial Review, 2011, NIQB47
Written Evidence submitted by the Equality and Human Rights Commission, the Equality Commission for Northern Ireland, the Northern Ireland Human Rights Commission and the Scottish Human Rights Commission (IL 122)

- promoting good relations between people of different racial groups;
- overseeing the implementation and effectiveness of the statutory duty on relevant public authorities; and
- keeping the legislation under review.

The Commission, along with the Northern Ireland Human Rights Commission, has been designated under the United Nations Convention on the Rights of Persons with Disabilities (Convention), as the independent mechanism tasked with promoting, protecting and monitoring implementation of the Convention in Northern Ireland. www.equalityni.org

Northern Ireland Human Rights Commission

The Northern Ireland Human Rights Commission (the Commission) is a statutory body created by the Northern Ireland Act 1998. It has a range of functions including reviewing the adequacy and effectiveness of Northern Ireland law and practice relating to the protection of human rights, providing legal advice and representation in human rights proceedings, and advising on whether a Bill is compatible with human rights. In all of that work, the Commission bases its positions on the full range of internationally accepted human rights standards, including the European Convention on Human Rights (ECHR), other treaty obligations in the Council of Europe and United Nations systems, and the non-binding ‘soft law’ standards developed by the human rights bodies. In accordance with its mandate, the Commission also delivered advice to government on the content of a Bill of Rights for Northern Ireland on 10 December 2008. www.nihrc.org

Scottish Human Rights Commission

The Scottish Human Rights Commission was established by The Scottish Commission for Human Rights Act 2006, and formed in 2008. The Commission is a public body and is entirely independent in the exercise of its functions. The Commission mandate is to promote and protect human rights for everyone in Scotland. The Commission has been designated as an independent mechanism to promote, protect and monitor implementation of the UN Disability Convention in Scotland. www.scottishhumanrights.com

3 October 2011

Extract from Northern Ireland Legal Opinion on Article 19

FIVE: SOCIAL CARE AND INDEPENDENT LIVING

447 Northern Ireland Act 1998, s.69(1).
448 Ibid, s.70.
449 Ibid, s.69(4).
450 Ibid, s.69(7).
1. The concept of independent living has been a centrepiece of disability rights activism and advocacy internationally. It has been described as a philosophy underpinning the work of disabled people to achieve “self determination, equal opportunities and full participation in society as equal citizens.”\(^{451}\) Although the UNCRPD does not provide a specific definition of independent living, the values at its core, including the autonomy, freedom and equality of the individual are reflected throughout. Article 19, however, seeks to address the concept directly by making it incumbent on States parties to ensure that

“(a) persons with disabilities have the opportunity to chose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;

(b) persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

(c) community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs”.

2. In a similar vein, Article 20 imposes an obligation on States parties to take effective measures to ensure that persons with disabilities enjoy the greatest possible independence regarding their personal mobility and to facilitate, provide and encourage everything necessary to achieve that end.

**EXISTING NORTHERN IRELAND LAW PROVISION**

3. In the Northern Ireland context, independent living is intended to be facilitated through Social Care legislation and principally in the Carers and Direct Payments Act (Northern Ireland) 2002 (CDPA). This statutory scheme provides for direct payments as cash payments given to persons in lieu of services that would otherwise have been arranged for them by their Health & Social Care Trusts so that they can arrange for the provision of their own services. The scheme is intended to allow for greater flexibility for service users, allowing them to make arrangements with providers of their choice and that payments can be made to them. Support organisations such as the Centre for Independent Living operate within the voluntary sector to provide assistance and advocacy for persons with disabilities in the encouragement and use of the Direct Payments Scheme.

4. The theory behind the scheme is entirely consistent with the aspirations contained in Article 19 UNCRPD. However, without a guarantee of adequate resourcing, the scheme is at risk of lapsing into failure. In an era of strictures on spending in the Health Service, it will be for health service policy and guideline makers to confront the reality of falling foul of the standards set by Article 19 UNCRPD.

5. Prior to the introduction of the UNCRPD, challenges to the resourcing of social care provision and the seeking of redress for unmet need taken by way of Judicial Review have

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Written Evidence submitted by the Equality and Human Rights Commission, the Equality Commission for Northern Ireland, the Northern Ireland Human Rights Commission and the Scottish Human Rights Commission (IL 122)

had to rely on established principles of domestic law and the (comparatively limited) provisions of the Human Rights Act in relation to persons with disabilities—with finite prospects for success, certainly in England and Wales. 452

6. Advocacy through the strategic use of Judicial Review proceedings by Law Centre (NI) to ensure that Health and Social Care Trusts meet their obligations toward persons with disabilities has been the most important weapon in the battle to ensure that needs in social care provision are effectively met. Often, senior Trust officials will agree to put packages in place without the need for going to court, but not before proceedings are threatened and/or lodged. 453 At present, a number of judicial review applications yet to be determined by the High Court in Northern Ireland will examine the extent to which the Trusts set up under the Health and Social Care (Reform) Act (NI) 2009 adhere to their duties under the CDPA. A particular focus of criticism in these proceedings will be the extent to which current departmental guidance (in force since March 2004) is compatible with the Human Rights Act and EHCR.

7. Articles 19 and 20 UNCRPD provide plenty of scope for persons with disabilities who have been disappointed in public authority provision in relation to their social care arrangements to attack those failings.

8. The provision of community social care arrangements will inevitably focus on the question of resourcing, and I would be careful to add that while Articles 19 and 20 UNCRPD could be used to strengthen a challenge in relation to the failure or refusal of an authority to provide a particular service or meet an identifiable need, I suspect that the Courts will be mindful of the budgetary constraints to which public authorities are subject. Indeed, there have already been examples of a tendency to overly sympathise with public authorities in their reliance on these sorts of argument in this regard in Great Britain. 454 The approach of courts in Northern Ireland to the same issue is an area worth supervising closely.

452 R (RJM) op cit n.7.

453 Practice Note: Judicial Review (revised 30 September 2008) and the annexed Pre-Action Protocol require parties to exchange correspondence prior to the commencement of proceedings in an effort to encourage the possibility of resolution at an early stage to avoid accrual of costs.

454 For an example of judicial mindfulness of budgetary constraints vis-à-vis the provision of services to persons with disabilities see R (Domb) v Hammersmith and Fulham BC [2008] EWHC 3277 Admin per Harrison J and, affirming that judgement, the decision of the Court of Appeal [2009] EWCA 941. It is however worth noting the judgement of Sedley LJ, who in refusing the appeal, observed that “I do so with very considerable misgivings because the appeal itself has had to be conducted on a highly debatable premise—that the prior decision of the local authority that council tax was to be cut by 3% had to be implemented. Once this was given, the only practical choice for social services was going to be to raise the eligibility threshold or to charge for home care. That, accordingly, was what the entire consultation and ultimate decision addressed [...] But these lose significance against the backdrop of a predetermined budget cut. The object of this exercise was the sacrifice of free home care on the altar of a council tax reduction for which there was no legal requirement. The only real issue was how it was to be accomplished [...] there is at the back of this a major question of public law: can a local authority, by tying its own fiscal hands for electoral ends, rely on the consequent budgetary deficit to modify its performance of its statutory duties? But it is not the issue before this court.” (at 78–80).
Summary

1. This memorandum provides a response to the points that were raised in the Joint Committee’s evidence sessions with national human rights institutions (NHRIs) on 14 June 2011, and with UK Ministers on 25 October 2011.

2. The response is being provided following a written request, dated 25 October 2011, from Dr Hywel Francis MP, Chair of the Joint Committee.

3. In this paper the topics are grouped around the points raised in the evidence sessions held on 14 June and 25 October, under the following headings:

   - Specific Equality Duties
   - Equality Impact assessments
   - Social care
   - Housing
   - Welfare Reform

The United Nations Convention on the Rights of People with Disabilities

4. The Office for Disability Issues (ODI) coordinates reporting for the Convention on behalf of the UK. The Welsh Government feeds in on areas of devolved competence. However, due to limits on the word-count of the report, this is not done as fully as we may wish.

5. The draft report, including Welsh content is published for consultation and made available for public comment. Following the consultation on the latest report, we have inserted a line to direct people to contact us directly for information on what the Welsh Government is doing to support independent living.

6. It is inevitable that, with devolution, the separate administrations will diverge in their approach to policy development. It means we can all develop new ideas and can learn about what works from each other. In Wales we have a duty under the Government of Wales Act 2006 to pay due regard to the principle that there should be equality of opportunity for all people, and all of our policies and programmes are developed in line with that duty.

7. Our Inclusive Policy Making Process, which is the Welsh Government version of Equality Impact Assessment, assesses all policies to embed consideration of the equality duties as set out in the Equality Act 2010. Included in that consideration is the possible impact of policies and programmes on disabled people and we use the Social Model of Disability as the basis
Written Evidence submitted by Jane Hutt AM, Minister for Finance and Leader of the House, Welsh Government (IL 124)

for that assessment. By doing so we ensure that the focus is on removing the barriers to inclusion, and supporting people to live independent lives.

8. Inclusive Policy Making increases the efficiency and sustainability of our policies and practices and helps us to consider the diverse needs of citizens and their communities in Wales. It is a systematic process that makes us consider whether there are any potential negative or disproportionate impacts, and think of ways to address them.

9. Throughout this process we encourage officials to act in a way that is consistent with the UNCRPD and other UN Treaties and the Human Rights Conventions as appropriate. Our approach is to move beyond treating human rights as a compliance issue, to one which embraces the values of dignity, equality, fairness and respect.

10. In some cases, we have found it helpful to work closely with equality groups at the start of policy development. This approach has many advantages, not least that it often makes the formal stages of Inclusive Policy Making easier to follow.

11. In cases where it becomes apparent that there is a lack of evidence on which to base the assessment we undertake more detailed engagement with people from equality groups and their representatives to get their views and experiences.

12. We also work closely with the Equality and Human Rights Commission in Wales. Together with the EHRC we held an event with disabled people’s groups in February 2011 to look at how the UNCRPD can be implemented in Wales.

Specific Equality Duties

13. The Equality Act 2010 contains a general public sector equality duty, which came into force on 5 April 2011. The general duty says that public bodies are required to have ‘due regard’ to the need to:

- Eliminate unlawful discrimination, harassment and victimisation and other conduct that is prohibited by the Act;
- Advance equality of opportunity between people who share a relevant protected characteristic and those who do not; and
- Foster good relations between people who share a relevant protected characteristic and those who do not

14. To support performance of the general public sector equality duty, the Equality Act 2010 (Statutory Duties) (Wales) Regulations 2011 specify what public bodies (including the Welsh Government) in Wales must undertake to fulfil their legal obligations and perform better on equality and good relations. The focus of these Welsh specific duties is on outcome focused equality objectives.

15. In this era of financial constraint, the Welsh Government has recognised that we must move away from strategies and towards delivery-focused frameworks. We are therefore developing our approach to Independent Living for disabled people under the specific equality duties. The duties will help us to mainstream actions that will support Independent Living across all Welsh Government departments.
16. In developing the specific equality objectives in relation to disability we are engaging extensively with organisations representing disabled people and with individuals themselves. We are asking them to tell us about any experiences they have had living in Wales, where they think more could have been done to treat them fairly, or where being disabled might have put them at a disadvantage.

17. A questionnaire has been published on our web-site at http://wales.gov.uk/topics/equality/equalityactatwork/?lang=en and is being distributed in hard copy via our stakeholders and third sector organisations. We are also engaging through face-to-face events and meetings. The information we gather during this period will help us decide what changes we need to make and the goals we need to set ourselves.

18. In April 2012 we will publish the results of this Wales-wide conversation in the form of our plan of action—the Equality Objectives and the Welsh Government’s Strategic Equality Plan. The Strategic Equality Plan, which will set out our equality objectives, will be a high-level document and, in relation to independent living for disabled people, will be underpinned by a Framework for Action, to be published later in 2012.

19. The Framework for Action on Independent Living will also be informed by the feedback from our questionnaire and by wider engagement with disabled people and their representative organisations. It will contain the detail of what will be undertaken across Welsh Government departments and with our external partners to support independent living. It will take a positive approach, focused on removing barriers to equality.

20. The Framework is in the early stages of development. We are currently in discussion with disability organisations, and with policy leads across Welsh Government. This will ensure that we bring together into a coherent delivery plan the many policies and strategies that already support independent living and identify areas where action is needed.

21. Specific policy initiatives arising from the framework will be subject to our Inclusive Policy Making process as outlined above, which considers potential impacts and ways to address them, and which embraces the values of dignity, equality, fairness and respect.

Equality Impact Assessment

22. I have set out in paragraphs 7–11 above how we assess the impact of our policies and programmes on people from the protected groups. In addition to this, in 2010 the Welsh Government was the first administration in the UK to publish an Equality Impact Assessment on its budget. This detailed Impact Assessment was on the 3-year budget in its entirety.

23. This provided us with important evidence, which informed our decision making even further. For example, it guided our thinking on support for social services and services for vulnerable people. This year, we have published an update to last year’s Equality Impact Assessment reflecting any changes that may have occurred.

24. Our assessment of the equality impacts as part of the 3 year budget last year went beyond the strict legal requirements. Due regard has been paid to the impact on the equality groups potentially affected i.e. gender, disability, race, age, religion and belief, sexual orientation and pregnancy and maternity.
25. I am in no doubt that we face a challenge from budget cuts, particularly the impact that they will have on equality. Budget decisions made by the UK Government, including cuts to benefits and allowances will have a direct impact on vulnerable groups. That is why we have ensured that we carried out detailed impact equality assessments on our own budget decisions, to reassure ourselves and the people of Wales that they will not impact adversely upon disadvantaged groups.


Social Care

27. On 12 July 2011, the First Minister announced the Welsh Government’s legislative programme for 2011–2016. Within this statement he announced his intention to introduce, in October 2012, a Social Services Bill that would “.provide, for the first time, a coherent Welsh legal framework for social services that is based on the principles that we hold dear in Wales”.

28. The Bill will provide, for the first time, a unified legislative framework for social services in Wales and provide the legislative basis to take forward the commitments contained within "Sustainable Social Services for Wales: A Framework for Action". These include a commitment to work with stakeholders to introduce a national eligibility framework and a portable assessment of need.

29. Work is currently underway to develop the Bill. A public consultation on the content of the Bill will be launched this Winter.

30. Currently, individuals' care needs are assessed by local authorities in line with the Welsh Government's statutory guidance "Creating a Unified and Fair System for Assessing and Managing Care". Authorities will then make a decision on whether to provide services to meet needs identified in line with their eligibility criteria for services.

31. Once an authority has decided to provide a service it is under a statutory duty to provide this within a reasonable time and to provide the service a person requires to meet their assessed needs. Operational issues, such as finance, are not a legitimate reason for a delay in this provision or in providing a service that is not the appropriate service an individual requires.

32. Our Programme for Government contains a commitment to refreshing the Carers Strategy for Wales during 2012–13. A key focus will be on enabling and supporting local authorities, the NHS and the Third Sector to deliver services and support to carers. It will cover carers of all ages, including young carers and older people. We will be engaging with all key stakeholders as part of this work, and will ensure that the needs and expectations of older carers and carers of older people are addressed throughout.

33. With regard to the discussion over the treatment of earnings in relation to charging for residential care it is case that the situation in Wales in this regard to similar to that in England. Under the regulations governing charging for residential care the net amount of any earnings a resident receives forms part of their eligible income and as such is taken into account when setting the amount they will pay for their care and accommodation costs. However, a disregard of £5 per week is applied to a resident's net earnings and
this can increase up to £20 per week where they are also in receipt of certain forms of benefits or allowances. Hence residents in employment will be able to retain a small proportion of their earnings dependent upon their particular financial circumstances.

34. In saying this I should add that in Wales residents in receipt of financial assistance from a local authority towards the cost of their care and accommodation are allowed to retain a minimum amount of £23 per week of their income for their own personal expenses (the Personal Expenses Allowance) which is slightly higher than in the rest of the UK. Local authorities also have a discretionary power to increase this weekly amount if they wish upon assessing a person’s circumstances. For example, where a resident was in employment it could apply an increased allowance in order to help them lead a more independent life such employment would bring.

35. Both the UK Government and the Welsh Government have acknowledged the unfairness and inequalities in the current system for paying for care with both seeking to address these. You will be aware of the recommendations of the Dilnot Commission on the future funding of care and support in England and that the UK Government will be responding to this in the Spring next year with the publication of a White Paper, following an engagement it is currently undertaking with stakeholders. While it was for England, the recommendations of the Commission potentially have implications for Wales given that some of the areas it touches upon are non-devolved, such as taxation or benefits. As a result Gwenda Thomas AM, Deputy Minister for Children and Social Services, has arranged to meet Paul Barstow MP, the Minister for Care Services at the Department for Health, to discuss the way forward.

**Housing**

36. The Welsh Government is committed to increasing the supply and choice of affordable housing, although this is increasingly difficult in the light of significant budget cuts. As a result, social housing in Wales is an increasingly finite resource and in order to ensure fairness for everyone it is allocated on the basis of need. The Housing Act 1996 ensures that local authorities have to prioritise applicants and this may include disabled people or households including someone who is disabled, dependent on their individual circumstances.

37. In order to make best use of existing adapted properties, the recently revised Code of Guidance for Local Authorities on Allocation of Accommodation and Homelessness has issued guidance encouraging local authorities to have Adapted Housing Registers. They allow housing providers to match adapted properties that become available with the needs and choices of disabled people on the register thereby meeting their needs and potentially allowing future budget savings.

38. The Welsh Government provides funding for adaptation works such as the installation of stair lifts, level access showers and hand rails which are designed to enable disabled tenants, or tenants with disabled children, to remain and live as independently as possible in their own homes. We are continuing to support services such as Care and Repair, Disabled Facilities Grants, and Physical Adaptation Grants.

39. Waiting times for Disabled Facilities Grants in Wales have declined steadily over the last few years and, on an average basis across the County, are now within the statutory timeframe. It is still recognised that more needs to be done to speed up the process and the
Welsh Government recently allocated an additional £1.5 million to fund a new Independent Living Grant which is being delivered by Care & Repair services across Wales in partnership with local authorities. The new grant is specifically targeting people who have been waiting for long periods for adaptations to take place and to facilitate hospital discharge.

New affordable homes built by housing associations are required to meet ‘Lifetime Homes’ standards, so that people do not necessarily need to move if their circumstances change. The increasing emphasis on sustainability and making homes more energy efficient can also have a significant benefit for disabled people, making it easier to keep their homes warm and cheaper to run.

40. The Strategy for Older People in Wales (2008-13) has improving well being and independence as key objectives to ensure that older people - especially those with disabilities - have access to the help they need to remain in their own homes including timely access to heating, adaptations, repairs, and telecare, as well as other assistive technologies and supported housing programmes.

Welfare Reform

42. The NHRIs raised the welfare reforms of the UK government and the possible impact on independent living. Proposed cuts to Disability Living Allowance (DLA) and the current and upcoming changes to Housing Benefit and the Independent Living Fund were particularly mentioned.

43. The UK Government’s agenda on welfare reform is a real concern to us and will undoubtedly have a big impact on disabled people’s incomes and therefore on their standard of living and ability to live independently.

44. The impact that changes to DLA and to the Independent Living Fund will have on the capacity of Social Services departments in particular, is also a major concern. It is clear that the UK Government expect local authorities to meet any shortfall in provision caused by the changes and we have received no indication that the UK Government will provide additional funding to Wales to assist in this regard.

45. The impact on the incomes of individual people and on local authority budgets, taken together, could prove to be a major constraint on our ability to deliver on our aims for supporting Independent Living.

46. I was pleased to see that the UK Government has said in its response to the public consultation on DLA reform that they have listened to the strong concerns raised by individuals and organisations about the Spending Review proposal to withdraw the DLA mobility component from people in residential care. The UK Government has decided that it will not now introduce this measure as planned in October 2012. I understand that this will now be considered as part of the wider reform of DLA and I await further developments.

47. Based upon current valuations the local housing allowance caps do not ‘bite’ in Wales. However, if these are not up-rated in the future it is possible with increasing rental values that they could have an impact in the future.

48. We have made arrangements to evaluate the action that is being taken to mitigate the impacts of the wider changes to Housing Benefit payments. In Wales, 99%+ of all claimants
are worse off by an average of £9.00 per week since the changes that took effect in April 2011.

49. The impacts will also be monitored by a study that is being undertaken jointly with DWP. The study, to which the Welsh Government is contributing a share of the cost, will seek to assess social, demographic and economic impacts on tenants, landlords and local authorities. The impact on different groups will also be assessed e.g. working claimants on low incomes, unemployed people, black minority ethnic people, older people, large families, disabled people.

50. Since the research was commissioned, the UK Government has introduced transitional protection for existing claimants and allowed for unspent discretionary housing payments funds to be transferred from the 2010/11 budget to 2011/12 budget for all local authorities across the UK.

51. These moves are welcomed but are likely to result in the social and demographic impacts being delayed so that they fall outside the timeframe for the research programme.

52. Officials in Welsh Government have written to the Department for Work and Pensions to highlight this issue and requested that the period of research is extended. If it is not extended, then the research will be of no real value.

November 2011
Supporting People is the government programme for funding, planning and monitoring housing related support services. Its aim is to improve the quality and effectiveness of support services at a local level and help vulnerable people live as independently as possible in the community. The programme established the means to manage accommodation on a partnership basis and strategically commission housing related support services that aim to tackle social exclusion by preventing crisis and more costly social interventions.

Individuals and households supported through the programme are shown below:

<table>
<thead>
<tr>
<th>Category</th>
<th>% of contracted SP units</th>
<th>% of SP Budget</th>
</tr>
</thead>
<tbody>
<tr>
<td>Homeless People</td>
<td>10.1</td>
<td>22.2</td>
</tr>
<tr>
<td>People with a Learning Disability</td>
<td>8.2</td>
<td>21.9</td>
</tr>
<tr>
<td>People with Mental Health Issues</td>
<td>7.7</td>
<td>16.9</td>
</tr>
<tr>
<td>Older People</td>
<td>59.0</td>
<td>13.9</td>
</tr>
<tr>
<td>Women at risk of Domestic Violence</td>
<td>4.8</td>
<td>6.4</td>
</tr>
<tr>
<td>Young People at risk</td>
<td>3.1</td>
<td>5.5</td>
</tr>
<tr>
<td>People with Drug and Alcohol use problems</td>
<td>2.0</td>
<td>5.5</td>
</tr>
<tr>
<td>People with a Physical or Sensory Disability</td>
<td>3.4</td>
<td>4.1</td>
</tr>
<tr>
<td>Offenders or People at risk of Offending</td>
<td>1.0</td>
<td>2.6</td>
</tr>
<tr>
<td>Other Vulnerable People</td>
<td>0.7</td>
<td>0.9</td>
</tr>
</tbody>
</table>

At March 2011 the programme in Northern Ireland was made up of 875 services that supported over 17,000 vulnerable people at any time. The programme is delivered via approximately 110 organisations, the majority of whom are voluntary and community organisations, ranging from small providers who deliver a single service to larger providers of up to 20 services. Other service providers include Housing Associations, Health and Social Care Trusts and the Northern Ireland Housing Executive (NIHE).

**What SP services do**

‘Supporting People’ is intended to provide high quality and strategically planned housing-related support services which are cost-effective and provide value for money. ‘Supporting
People’ services can, and should, be provided in a complementary fashion alongside care or other services wherever possible, but are not personal care.

This is through the provision of:

- Short term accommodation based support for those also in housing need (eg homeless hostels).
- Short term support to help set up a new home (eg through the provision of a floating support service).
- Longer term support to enable someone to sustain a home (eg in accommodation based services where the person has a tenancy and housing related support is provided to assist a person to maintain their tenancy).

In addition to short and long term accommodation based services, SP also funds a range of housing related floating support services which assist vulnerable adults to help them to maintain independence in their own home, regardless of tenure type.

The Department for Social Development (DSD) has overall responsibility for the programme and the NIHE is the administering authority with responsibility for:

- Strategic planning of service development based on need
- Implementation of the programme
- Commissioning services in partnership with Health and Social Services and the Probation Board (NI)
- Monitoring and evaluation of the services provided
- Developing and implementing the SP strategy

Supporting People Grant is used to fund those services identified and agreed as priorities by the Commissioning Body with approval for funding being made by the Housing Executive Board in its strategic ‘Supporting People’ role.

The Commissioning Body which is responsible for the commissioning of services is chaired by the NIHE with representatives from DHSS&PS, Trusts, and PBNI. DSD and RQIA currently sit on the Commissioning Body as observers.

**Funding the programme**

Funding for the Supporting People programme was not subject to efficiency savings and is baselined at £61m per annum.

Additional capital and revenue funding has been made available over the 4 year CSR period. This funding will facilitate the outworking of the DHSS&PS Bamford Review of Mental Health & Learning Disability.
### Written Evidence submitted by the Northern Ireland Executive (IL 126)

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</thead>
<tbody>
<tr>
<td><strong>Capital</strong></td>
<td>£27.3m</td>
<td>£30.0m</td>
<td>£25.0m</td>
<td>£11.63m</td>
</tr>
<tr>
<td><strong>Revenue</strong></td>
<td>£1.3m</td>
<td>£4.5m</td>
<td>£11.7m</td>
<td>£16.7m</td>
</tr>
</tbody>
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12 January 2012