



Equal Rights for Parents of Disabled Children

Summary:

Parents of disabled children have often struggled to establish rights as individuals on a par with other carers of all ages and they are at particular risk of having their own rights overlooked as individuals.

Government is improving the rights of carers of adults in the draft Care and Support Bill:

- Removing the need to be providing regular and substantial care in order to receive an assessment
- Removing the need to request an assessment of their needs
- Placing a duty on local authorities to provide services to the carer following assessment
- Introducing a new well-being principle that focuses on basic human rights principles where assurances have been given that this will cover carers.

The draft Care and Support Bill only covers the rights of adults caring for adults.

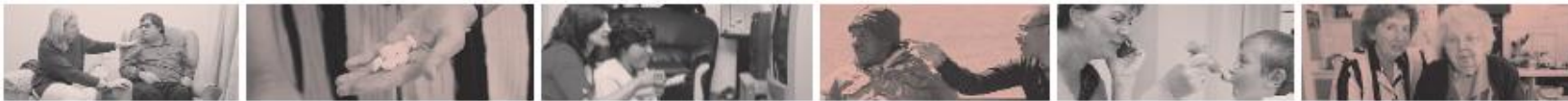
Young carers are not included in this legislation, but a clear case has been made that important measures need to be set in law around the identification, assessment and support for children who provide care. Government has said that they will look at the legislation in relation to young carers. Carers UK has supported Carers Trust in their work on this issue and both organisations have warmly welcomed this development.

Parents of disabled children, however, now have a rights imbalance that sits at the core of the principles of human rights.

Carers UK submitted evidence to the Education Select Committee which was scrutinizing the Children and Families Bill. However, the questions were drawn tightly, and the rights of parent carers were not examined by the Committee. Carers UK submitted evidence to the Joint Committee set up to scrutinize the draft Care and Support Bill. They recommended that the rights of parents of disabled children are reexamined but did not provide a more detailed recommendation.

Imbalance

Government has stated that they are not “taking away rights from parents of disabled children”. This is correct. However, the positive changes taking place for carers of adults and, hopefully, young carers, will leave parents of disabled children with fewer rights than others providing care. There is also still a question over the fact that practitioners do not seem to be operating under the



principles of the Human Rights Act 1998 in balancing the rights of the child with the rights of the parent. Many parents of severely disabled children report mental and physical health breakdowns as a result of caring for their children. It cannot be compatible with the Act for more work not to be done to prevent this.

The issue

Parents of disabled children currently have a right to request an assessment of their needs if they are caring for a child for whom the local authority may provide services under the Chronically Sick and Disabled Children Act 1970 or a disabled child who is defined as a child in need under s. 17 of the Children Act 1989.

Guidance focuses around assessments of the family and the needs of the whole family. However, Carers UK has evidence from years of working with parents of disabled children about the fact that the rights of the parent, as an individual, to have a life outside caring, are compromised daily. The Appendix sets out the evidence from a small number of parents of disabled children we consulted about the law and their experiences of assessments.

It shows:

- Parents of disabled children as not being seen as being individuals in their own right.
- An over-focus on the child by services, often to the detriment of the parent.
- An inability to get an assessment or services to help.
- The feeling that is often expressed to parents that this is what they should be caring for their a disabled child and they are not entitled to help. This shows a real lack of understanding and appreciation of the differences of caring for a disabled child. Many of the things that many parents take for granted are simply not possible for parents of disabled children – time with your partner, reading a book, pursuing a hobby, having a job, time for a rest. Whilst parents do care for their children, the impact of having little or no time to themselves to support relationships, health and work, are devastating.

Groundbreaking legislation that is not being built upon

There are three main Private Members' Bills covering the rights of parents of disabled children, but the two that are most important are the Carers (Recognition and Services) Act 1995 and the Carers Equal Opportunities Act 2004. The first established parents' right for the first time to an assessment of their own needs. The latter, radically, established the right to have the assessment look at the carer's wishes to work, learn and consider leisure.

The experience of parents set out in the Appendix shows quite clearly that assessments, even when requested, do not materialize. Carers UK feels that it is even more important to counter the prejudice that exists around parents of disabled children, to ensure that they have equal rights under the legislation.

Young carers' rights and those of adults caring for adults

Young carers are protected by s. 17 of the Children Act 1989 with an important provision looking the educational, social and physical development of the child. Adults caring for adults under the new legislation will have an important principle of well-being attached to the whole direction and



principle of social care and assessments that flow from them. This includes a right to family life, relationships, social and economic well-being. If the rights for parents of disabled children are not rebalanced and redressed, they will be the only group of carers who will not have a similar broadly drawn principle of well-being.

Ironically, young carers and carers of adults will have better rights to assessments and support. Parents of disabled children will not have these rights until the child reaches the age of transition and they then achieve all the new enhanced rights. The logic of excluding parents of disabled children is unclear, particularly when there are clear prejudices around balancing the rights of the child with the rights of the parent. This strikes at the heart of human rights principles.

Common experiences of parents of disabled children¹:

- Three times more costly to bring up a disabled child than an non-disabled child
- More likely be reliant on income-based state support.
- Less likely to be in work.
- More likely to suffer relationship breakdown and divorce.
- Three or more times more likely to suffer ill-health and health breakdown than parents of non-disabled children.

Parents also commonly report an inability to get support which fits the whole family. For example, a play worker would come to play with a disabled child and it was clear that they needed more one-to-one play support. The parent, however, was stretched to the limit looking after the child and her other children. She wanted support for the washing and ironing so that she had a rare chance to play with her disabled child. She said, "I would love to play with my child, but caring for them and the other children and the house just take up all my time. Why can't I get someone do the housework so that I get a few precious minutes of playtime with my child? Why does it have to be a worker that gets that joy? Not me?"

Parents quite often need space and time to be able to devote to their own lives, and to the lives of their other children in the family. The last person the parent often considers is themselves until it is too late. An earlier assessment, removing the barriers to assessments and in establishing the overarching principle of well-being to a group that currently misses out could have to improve the rights of thousands of parents in England. This is a vital role that could and should be played by services.

Recommendations for change:

- Ensure that the well-being principle as set out currently in Clause 1 of the draft Care and Support Bill is also applied to parents of disabled children. This could come as an amendment to the draft Bill or as a new Clause in the Children and Families Bill.
- Joint work between both the Department for Education and Department of Health, Ministers in particular, to commit to improving parents' rights. This issue must NOT be passed from one Department to another.
- Remove the bar to be providing regular and substantial care.

¹ Managing More than Most: A statistical analysis of families with sick or disabled children
<http://www.cafamily.org.uk/media/381150/caringforsickanddisabledchildren2006appendix.pdf>



- Remove the need to request an assessment
- Introduce a duty to provide services to meet the parent's needs following assessment and ensure that these are met under s. 17 of the Children Act 1989.

Costs of making change:

The costs of making the changes are relatively minor. The Government has set aside £180 million for making the changes for adults caring for adults in terms of assessments and a duty to provide services. 8% of all carers in England care for a disabled child. The very positive change of this for parents of disabled children would be only £14.4 million (by proportion) and yet would send a clear message of the importance of this.

Government's Regulatory Impact Assessment and rationale in improving the rights for carers of adults focuses on the positive changes that this would bring – fitting in with prevention of ill-health, increased ability to work and to prevent loss of employment, job and finances, better preparation for caring over a long period. In implementing these changes, these would be positive changes wrought locally.

The Government in Wales already considers it important that parents of disabled children have equal rights with carers of adults in the draft Social Services and Well-being (Wales) Bill.

Appendix

Evidence gathered from parents of disabled children on access to a carer's assessment.

- **Have you found it difficult to get an assessment of what support you need to care for a loved one?**

"I put in for one in September 2012 and still not got one on 14 March 2013."

Tell us what difference having early access to an assessment would have made to you.

"Get more things put in place and get support required."

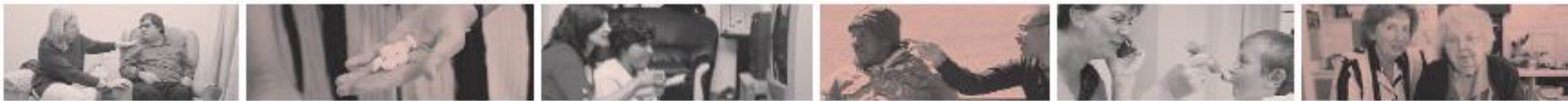
- **Have you found it difficult to get an assessment of what support you need to care for a loved one?**

"Yes, I have no one seem to listen to you"

Tell us what difference having early access to an assessment would have made to you.

"The earliest I could get access to the assessment the better it would be for my child"

- **Have you found it difficult to get an assessment of what support you need to care for a loved one?**



"I am in the unfortunate situation whereby the child I care for is not "disabled enough" to obtain a full assessment."

Tell us what difference having early access to an assessment would have made to you.

Having access to an early assessment would be both beneficial for myself and the child who I care for. At present we do not qualify for any support from the local authority

○ **Have you found it difficult to get an assessment of what support you need to care for a loved one?**

"I don't believe I've had an assessment on what support 'I' need. My son receives respite care which does have benefits for me but I have to be careful how I word my discussions with Social Services in order to get/keep this support. If I state that I need support then they take no notice, if I say he needs to support to get into the community or to play independently then they will help. When I spoke to a quite high ranking LA officer about this he stated categorically that any respite care/short break etc was purely for the needs of the child NOT the family as a whole. I find this extremely worrying.

○ **Have you found it difficult to get an assessment of what support you need to care for a loved one?**

"Both my daughters with HFA [*High-functioning Autism*] were so badly treated by their schools. I had to fight to get my daughters assessed and withdrew them from main stream school. They both received statements 4 months ago but the damage is done."

○ **Have you found it difficult to get an assessment of what support you need to care for a loved one?**

"Yes in the end had to employ a solicitor"

Tell us what difference having early access to an assessment would have made to you.

"Less stress, more opportunities to buy appropriate services"

○ **Have you found it difficult to get an assessment of what support you need to care for a loved one?**

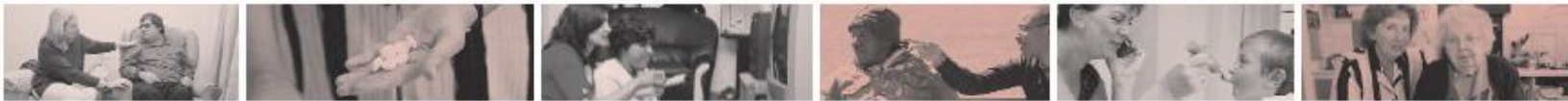
"I have found everything to do with caring....only time services of any kind get involved is when I feel I'm having a breakdown then I get a bit of support for a few days then nothing, I'm absolutely drained with the stress of being without continuous help plus my concerns not being listened to."

Tell us what difference having early access to an assessment would have made to you.

"it would help me loads, I feel very alone with massive pressure on my shoulders ,I desperately need a key worker for my son, and a lot more time for me before I crack upI lost my job because I was taking too much time away from work ... caring as caused me nothing but sadness and loss of all dignity"

○ **Have you found it difficult to get an assessment of what support you need to care for a loved one?**

"I am a lone parent/disabled carer of disabled child as well as two other children. As a family we have various different issues that we could benefit from having support with. I have been involved with social services for most of my life and have always found it difficult to access support or even



information about support that may be available to suit my needs. My youngest child has Autism and I have been asking for a community care assessment for the past year and half, but nobody seems to be listening.”

Tell us what difference having early access to an assessment would have made to you.

“Made life a tiny bit easier”

○ **Have you found it difficult to get an assessment of what support you need to care for a loved one?**

“I have found it very difficult to get an assessment for my disabled son. As well as looking after my son I have spent several hours overall trying to get a response. I was being told someone would ring me back but this did not happen. It was only after sending many emails that that I eventually got a response. I began requesting an assessment in September 2012. I have been told I am on a waiting list, it is now April 2013. I therefore believe if assessments were automatic I would not have to spend precious time chasing up.”

Tell us what difference having early access to an assessment would have made to you.

“If an early assessment would have been made possible I believe I would be accessing vital help I need, instead of being under stress and having to cope on my own with no help.”

○ **Have you found it difficult to get an assessment of what support you need to care for a loved one?**

“Yes I have found it really difficult to get what support & help I need for my son who had open heart surgery at 14 weeks old I have brought him up on my own had no help at all it has had a great impact on my life as well as my health I am on medication round the clock only now have social services got their act together & found us some help not a great deal but they are assessing the situation perhaps if they would of done it sooner I wouldn't have all the health problems I have”

Tell us what difference having early access to an assessment would have made to you.

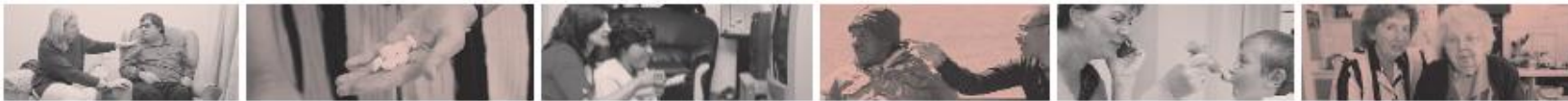
“The difference an earlier assessment would have made would be that I could probably have had more time to myself & be able to rest more & my son wouldn't have been so isolated as well as me”

○ **Have you found it difficult to get an assessment of what support you need to care for a loved one?**

“Yes. I look after my 15 year old twins with severe autism who both need a round the clock high level of care. We as a family have been left to get to crisis state before anyone took any notice (despite regular Meetings with my social worker). We didn't have any idea that we had to ask for a care assessment. And as a result they have been working off the one they did when the children were three! The system is uncaring and broken and has torn our family apart. As a parent of twins I was seen as a buy one get one free offer and only given the support that all my friends were getting even though they only had one child with special needs.”

Tell us what difference having early access to an assessment would have made to you.

“We feel that it takes so long for services to be provided as they have to go to panels which do not meet regularly so the earlier you get your assessment the quicker you can get services in place.”



- **Have you found it difficult to get an assessment of what support you need to care for a loved one?**

“I've found it difficult to get an assessment of what support I need to care for my disabled daughter. It took going into crisis before I managed to get any help and then I had to make a formal complaint before Social Care took any notice of my situation. I've still not been offered any training in manual handling and yet my daughter's medical professionals are constantly telling me that my back is in jeopardy due to the lifting I have to do with her.”

Tell us what difference having early access to an assessment would have made to you.

“An early assessment would have meant I could care for my daughter without my own health and wellbeing becoming damaged as much as it has. I am now suffering from constant pain in my shoulders and neck, muscle spasms in my neck and my marriage has dissolved through the stress.”

- **Have you found it difficult to get an assessment of what support you need to care for a loved one?**

“It has been extremely difficult to get the support needed and as a result there is deterioration, both of our health and wellbeing has suffered as a direct result of medical negligence, direct and indirect discrimination, harassment and the gross misconduct of certain professionals that have been involved in the process up to now.....”

Tell us what difference having early access to an assessment would have made to you

“A major difference would have been made if early access to an assessment would have been made as the long term damage caused by not following procedures despite my continuous phone calls and demands made to the relevant professionals.”

- **Have you found it difficult to get an assessment of what support you need to care for a loved one?**

“I have cared for three disabled children - my second child had to be nebulised every 4 hours night and day I received no help which affected my health, the health of my other children and lead to a breakdown in my marriage, and poverty to extent we have been evicted two times a frightening situation with disabled children. She lived through this long term medical condition. “

“I now care for my youngest child who was born with medical problems and my son who has Asperger's again I have received no help leading to me having health problems, poverty, I am trying to study to get out the poverty trap but with no help my grades are constantly effected with often 10% less than I would get if I had help or did not have caring responsibilities.”

Tell us what difference having early access to an assessment would have made to you:

“I feel that with the right kind of help and assistance I would not live in poverty, my son would not have Asperger's as the doctor explained it was induced by stress in his life, and I would have better grades”

- **Have you found it difficult to get an assessment of what support you need to care for a loved one?:**

“Assessment done but it takes too long to hear the outcome.”



Tell us what difference having early access to an assessment would have made to you: “No outcome for my carers assessment.”

- **Have you found it difficult to get an assessment of what support you need to care for a loved one?:**

“It was difficult to get an assessment for my son and therefore I was never offered an assessment for myself. I had to demand an assessment for my son before I was recognised as a carer.”

Tell us what difference having early access to an assessment would have made to you:

“It may have got my son a direct payment earlier.”

- **Have you found it difficult to get an assessment of what support you need to care for a loved one?:**

“I am a young parent of a child with disabilities. After reading about this I feel that it is clear the new bill will not create equal rights. Also I asked for an assessment in Oct 2012, my first face to face contact was 28th Feb and I am still waiting to hear the outcome of the assessment.”

Tell us what difference having early access to an assessment would have made to you:

“I feel that if I did not have to request my assessment we made have been assessed sooner and that the outcomes, ie support, information and financial help would happen sooner, and for some people it could make all the difference. "Prevention is better than Cure".”

- **Have you found it difficult to get an assessment of what support you need to care for a loved one?:**

As a parent carer you are used to thinking about yourself as naturally having to care for your child. However, there is a point where you realise how much more care you are having to provide for your child; mine is autistic and now epileptic too.

The carers' assessment wasn't offered to me, I had to ask our SW [social worker]. It is 8 years on, and not only am I not getting the support it suggests, but it also needs updating, and I'm having to ask for that (among other things) too.”

Tell us what difference having early access to an assessment would have made to you:

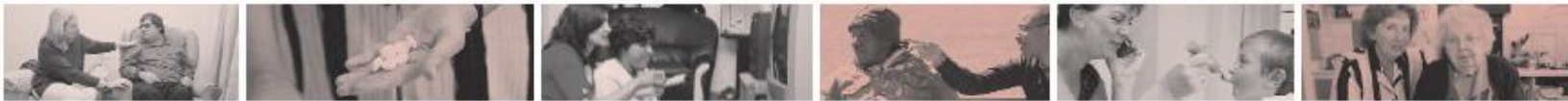
“It would have helped me consolidate in my own mind exactly the extent of what I do for my child, and make me feel it is ok to ask for help around here, the Sw's seem to say to parents who ask for an assessment that they are doing ok and don't need one now, even though their child has a lifelong disorder such as autism. It puts parents off asking, but I guess that may be the objective.”

Tell us what difference having early access to an assessment would have made to you:

“mentally it made me feel I mattered”

About Carers UK

Carers UK is a charity set up to help the 6.5 million people who care for family or friends. At some point in our lives every one of us will be involved in looking after an older relative, a sick friend or a disabled family member. Whilst



caring is part and parcel of life, it can affect your job, your health and your finances. Without the right support the personal costs can be high.

Carers UK is a membership organisation of carers, run by carers, for carers. We have 17,000 members and a reach of many more. We provide information and advice about caring alongside practical and emotional support for carers. Carers UK also campaigns to make life better for carers and influences policy makers, employers and service providers, to help them improve carers' lives.

Carers UK has offices in Wales, Scotland and Northern Ireland. This response reflects the views of the organisation, UK-wide.

Keep up to date with our campaigns and research:

Web: www.carersuk.org, Facebook: www.facebook.com/carersuk. Twitter: www.twitter.com/carersuk

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