



Multiple Sclerosis Society

MS National Centre

372 Edgware Road
London NW2 6ND

Phone 020 8438 0700

Fax 020 8438 0701

info@mssociety.org.uk

www.mssociety.org.uk

Helpline 0808 800 8000

Lord Goodlad
Chairman, Secondary Legislation Scrutiny Committee
House of Lords
London
SW1A 0PW

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Dear Lord Goodlad

Multiple sclerosis (MS) is the most common disabling neurological condition affecting young adults; more than 100,000 people in the UK have MS. The MS Society is the UK's largest charity dedicated to supporting everyone whose life is affected by MS and exists to help people living with MS across the UK by funding research, providing high quality information and support and raising standards of care.

Over 65,000 people with MS receive some form of DLA. They rely on DLA to allow them to manage the high costs of living with the condition, spending it on a wide range of essentials, including help around the house, informal care and prepared meals, better incontinence pads, the cost of prescriptions, the extra costs of heating, specialist equipment and transport. Making PIP as fair as it can be for people MS is therefore essential.

We welcome the recent changes the government has made to the PIP regulations and criteria. For example, we strongly welcome the broadened definition of aids and appliances, and the addition of supervision to a number of activities. However, we also have a number of serious concerns regarding the way that some of the regulations have been shaped and phrased, and the impact this could have on people with MS. We outline our concerns under a series of sub-headings below and hope that you are able to take them into account in your forthcoming scrutiny of the legislation.

Assessing people with fluctuating conditions

The approach being taken to assess people with fluctuating conditions is set out in **Regulation 7** of the **Social Security (PIP) Regulations 2013**.

For people with a complex, unpredictable and fluctuating condition like MS, assessing whether someone fits in to a particular descriptor on at least 50% of days will be an extremely complicated and difficult task. In testing the descriptors on people with MS, we have found that many are confused by this approach and how it applies to them, and how it will be assessed. People with the condition find it extremely difficult to quantify how many days in the previous year they have been able to complete an activity.

The approach proposed fails in particular to recognise the additional barriers and costs faced by the following people in two common situations:

1. **Those who have short but severe fluctuations** – after the second draft of the criteria was published, we tested them on 20 people with MS. These people often scored zero points despite facing severe barriers to daily living and mobility for a significant period of time, as they were unable to satisfy the ‘50% of days’ rule. The Government stated in the second draft of the criteria that they do not believe that support needs arising from short, acute periods of impairment should be met by the benefit, as it is targeted at long-term impairments. However, this neglects the fact that unexpected and severe fluctuations can be a regular feature of a long-term condition like MS. The nature of the fluctuating condition itself means that the impact of preparing for and dealing with sudden and unpredictable relapses (involving exacerbations of both needs and costs) is long-term, if not continuous.

Example: Shana has issues with double vision quite frequently, but for the majority of the time feels able to get around safely unaided. However, during some relapses she has lost her vision completely. This can last for a few weeks, and happens two or three times a year. When this happens, she requires 24 hour support for all daily activities. Under the current descriptors she will score no additional points to recognise this, although it leads to enormous exacerbations of cost on a reasonably regular basis.

2. **Those who meet the requirements of two descriptors in the same activity but for less than 100% of the time** - While satisfying the ‘50% of days’ rule, the descriptor that impacts these people for the largest part of the time is applied and, crucially, this could be the barrier that carries the lowest amount of points. This means that individuals will not be compensated for the additional, and potentially higher costs of the other barrier(s) they face.

Example: Kiran, 52, diagnosed with primary progressive MS 2009

Kiran struggles with using knives and forks much of the time. She often drops them and regularly spills food on herself when eating. She has to use a particular knife and fork set (although not specifically adapted) which are lightweight and small with thick handles, and occasionally needs someone to cut her food up for her, if she is having a bad day. She also states that when her partner is not around to prompt her, she occasionally forgets to eat, or lacks the motivation, as “the thought of having to prepare and eat something can be overwhelming”. She has suffered from anorexia in the past, so the cumulative impact of the lack of motivation to eat alongside physical difficulties eating could cause serious problems. However, as she only needs prompting some of the time, she is likely to only score 2 points under descriptor B (in the ‘Taking Nutrition’ activity), which applies for most of the time – as opposed to 4 points under descriptor D. We believe that it would be more appropriate to award Kiran more points than this.

Applications to claim PIP

Regulation 7(1) of the **PIP (Transitional Provisions) Regulations 2012** states that those claiming DLA must claim PIP within 28 days of the date that they are invited to do so. **Regulation 9** then states that where a notified person makes no claim before the end of this period, payment of their DLA will be suspended, and (according to **Regulation 10**) after a further 28 days, terminated. **Regulation 8, paragraph 3 (b)** says that the secretary of state may extend the claim period by such further period as the secretary of state think fits. It is therefore unclear under what circumstances an extension of the deadline may be given. In addition, the time limit given to claimants to return the claimant questionnaire is limited to one calendar month. It is also unclear under what circumstances an extension to this deadline may be granted.

People with MS are likely to face a number of barriers to engaging with this process in the allotted time frames. Examples include those experiencing an MS relapse that may be too ill to fill out the forms, those with very high support needs who will need significant amounts of support to take part in the claims process at all, and those who are living with enduring symptoms of MS such as problems with concentration, manual dexterity, sight and fatigue. Many of these people will be reliant on support to engage with the process, but the current pressure being placed on advice agencies means that waiting lists for appointments can be as long as two months. Meanwhile, if an individual is simply on holiday or staying away from home receiving respite care for as little as two of the four weeks provided, and they are subsequently unable to secure the support they need to fill in the forms, they may risk losing their benefit.

Face to face assessments

Regulation 9 of the **Social Security (PIP) Regulations 2013** refers to how individuals may be required to attend a face to face assessment.

According to **Paragraph 3 (a)** claimants must only be provided with written notice of their appointment 7 days in advance. Where the claimant fails to attend without 'good reason', they will not qualify for the benefit. We believe that this period of time is unreasonably short and that adequate safeguards have not been built in to the definition of 'good reason' to protect people who may very reasonably be unable to attend.

Regulation 10 outlines the matters to be taken into account in determining good reason. Situations are limited to those relating to the claimant's health or disability. In their response to the consultation on the PIP assessment criteria and regulations the government states that the "...ability to reschedule is a discretionary right that the department is offering individuals and is not contained in the regulations". There is therefore no guarantee that individuals will be able to reschedule appointments if they are inconvenient. This could be for a number of reasons including:

- Unavailability of a carer, advocate, family or friend (who they require to physically get to the centre, or for support during the assessment)
- Work commitments
- Planned holidays
- Family crisis or bereavement

Reassessments

Regulation 11 of the **Social Security (PIP) Regulations 2013** states that the secretary of state may, for any reason and at any time, determine afresh whether a claimant continues to have limited ability. We read this to mean that claimants can be called for reassessment for PIP at any time.

It is vital that those with long-term conditions or impairments which are unlikely to change over time are awarded suitably long-term awards, and are not subject to unnecessary, costly and stressful reassessments. For those who have a long-term degenerative and incurable condition like MS, and who are receiving the highest rates, we believe that a long-term award with little or no review would be most appropriate. Once someone with MS has been assessed as needing PIP their condition will never improve to a stage where they no longer need the benefit. Assessments inevitably cause a great deal of undue stress to individuals and stress has been shown to exacerbate MS, and in some cases even to bring on serious relapses. We do not believe that adequate safeguards have been built into the regulations to protect people with long-term conditions like MS from being reassessed inappropriately frequently. Over a third of people with MS who have been through a Work Capability Assessment for Employment and Support Allowance in the last three years have already been reassessed more than once. We are extremely concerned that this could also be the case for PIP.

The assessment criteria

The Mobility Activities – planning and following a journey

The criteria for this activity are unclear. We recognise that they are aimed at assessing a claimant's sensory, mental, cognitive and intellectual ability – but further clarity is needed on whether symptoms such as dizziness and disorientation would be included here. These are common symptoms of MS and frequently prevent people with the condition getting out and about unaided.

The definition of 'overwhelming psychological distress' does not recognise anxiety or panic attacks that could arise from a wider range of issues. As mentioned above, people with MS can become easily disorientated, which can make the prospect of planning and following a journey significantly more complex, and potentially too daunting to manage.

The Mobility Activities – moving around

We welcome the government's clarification that individuals who do not use a wheelchair may still qualify for the enhanced rate of the benefit. However, we are alarmed at how high the bar is set for people to qualify for the Mobility Component of PIP. The way that the descriptors are worded and scored in the 'Moving Around' activity mean that those only scoring points in this activity:

- Will not qualify for the standard rate of the Mobility Component of PIP if they can stand and then move unaided even slightly further than 50 metres (this is the length of 3 and a half double decker buses, and not far enough to be able to walk around a supermarket).
- Will not qualify for the standard rate of the Mobility Component of PIP if they can stand and then move even slightly further than 50 metres using an aid or appliance to do so.
- Will not qualify for the enhanced rate of the Mobility Component of PIP if they can move even slightly further than 20 metres, either aided or unaided (this is the length of just over 1 double decker bus, and is barely the distance an individual may need to cover to travel around their own home).

These people will be missing out on the higher rate Mobility Component of PIP, or indeed the Mobility Component altogether, despite facing significant barriers to participation and high costs – often needing to use taxis or cars to get around. In its response to the consultation on the PIP assessment criteria and regulations the government provides projections of how many people are set to lose out under the PIP mobility criteria. They predict that the number of people receiving the highest rate of the Mobility Component will be around 428,000 lower in PIP than would have been the case for DLA. This is extremely worrying in the case of people with MS. Around 65,000 people with MS currently receive DLA, of whom over 46,000 are of working age, and 95% receive the higher rate Mobility Component. These criteria therefore represent a major concern. The strictness of the criteria mean that it is even more important that assessors take into account whether individuals can perform activities reliably, repeatedly, safely and in a timely manner – please see our discussion of this in the section below entitled 'Reliably, repeatedly, safely and in a timely manner'.

The Daily Living Activities

We have a number of concerns relating to the Daily Living activities, as follows:

- The 'Washing and bathing' activity now fails to take grooming into account. This means that difficulties performing basic and essential tasks such as shaving and brushing hair will no longer be taken into account.
- Menstruation is not covered in the 'Managing toilet needs and incontinence' activity, despite the added assistance many women with disabilities will require to hygienically manage this.
- There are no criteria to assess an individual's ability to maintain a safe and healthy living environment, despite this representing a significant set of extra costs for disabled people.

- The 'Managing a therapy or monitoring a health condition' activity fails to take to take condition management into account. For people with MS there are few licensed disease modifying drugs (and none for secondary progressive and primary progressive MS), so individuals are more likely to rely on complementary therapies and health management techniques, which can represent a significant additional cost.

Reliably, repeatedly, safely and in a timely manner

Considering whether claimants can perform tasks reliably, repeatedly, safely and in a timely manner is an extremely important part of the assessment for people with fluctuating conditions like MS, but the terms have not been included in the regulations.

In the Work Capability Assessment (WCA) for Employment and Support Allowance (ESA), these terms are only contained in guidance, and as a result, they are not applied to the descriptors in assessments as consistently as they should be. We strongly feel that it is important that these terms are included within the regulations. This would give the strongest force of law to the implementation of these terms within assessments, and would give claimants enforceable rights to ensure that these terms are considered.

We would like to draw attention to the government's stated intention to place broad definitions of these terms in the PIP assessment guidance. We are concerned that the revised definitions are now too vague to enable assessors to apply them in a consistent and accurate way. We are particularly alarmed at the decision to omit references to side effects such as **pain and fatigue**. These are common side effects of MS, and considering them is crucial to assessing whether a person with the condition can undertake an activity reliably. They are especially important to assessing an individual's capacity to move around. Given the number of people set to lose out under the mobility descriptors it is essential that such symptoms are properly considered. Many assessors will not have a particular knowledge of MS, or fluctuating conditions more generally, and could easily underestimate the impact of these symptoms. The government argues that listing such side effects could be too definitive and mean that other symptoms are not considered – we strongly reject this argument. Firstly, we believe that the generalised nature of these side effects mean that they will apply to a broad range of disabilities. Secondly, providing *examples* of side effects that are often underestimated or missed does not prohibit consideration of others. Instead, it alerts assessors to issues that should be considered but are often missed.

Definitions

We are concerned about the following definitions in the **Social Security (PIP) Regulations 2013**:

- The definitions of 'Communication support' and 'social support' do not place enough emphasis on the role a friend or family member might play in helping people manage their disability.
- The definition of 'supervision' is very strict and only applies if another individual is continuously present.

I thank you for your time and hope that you find the above concerns informative throughout your examination of the regulations

Yours faithfully

Claire Nurden
Senior Policy and Campaigns Officer
MS Society