

Spinal Injuries Association (SIA) response to the ‘Personal Independence Payments assessment and thresholds consultation’ by the Department for Work and Pensions

Introduction

The Spinal Injuries Association (SIA) welcomes the opportunity to comment on the Government’s proposals to reform Disability Living Allowance (DLA) by introducing Personal Independence Payments (PIPs).

Disability Living Allowance is of primary concern to disabled people who rely on these payments to mitigate the costs they incur to manage their disability. For disabled people who have been enabled to have a basic standard of living through DLA, the idea of a reduction or loss of these payments is devastating and the potential impact could be immense on both their mobility and their ability to live independently.

About SIA

SIA was established in 1974 and not only works to support and promote the wellbeing of the 40,000 spinal cord injured (SCI) people in the UK but also to provide assistance to their families, friends and health care professionals. We work to support, advise and campaign on all aspects of spinal cord injury. Our vision is the full integration and participation of spinal cord injured people in society. Through our services and publications, we aim to equip spinal cord injured people with the knowledge and skills they require to successfully rebuild their lives after injury. Core activities include our Freephone Advice Line, Peer Advice Service and employment service."

As a true user-led organisation, which was founded and continues to be managed by spinal cord injured people, we fully understand the needs of the people we exist to serve.

Our aims are to:

- Provide a spinal cord injured person, and their relatives and friends, with life-long assistance that spans right from the moment of injury and throughout the remainder of their lives.
- Provide services to increase an individual’s quality of life.
- Increase the knowledge and awareness of the causes and consequences of spinal cord injury.
- Campaign for the best medical and social care for spinal cord injured people.

Q1 – What are your views on the latest draft Daily Living activities?

The second draft of the assessment is still based around a limited number of descriptors which will not adequately reflect all the disability related expenditure that disabled people may incur in their lives.

Although this component has been renamed the ‘Daily Living’ component, it seems less based on daily living costs than the previous ‘Care’ component of DLA. SIA remains concerned that by limiting the focus of this component to

nine descriptors an individual applying for PIPs will be unable to truly represent the costs they incur as a result of their disability, and will no longer be financially supported to meet them.

Currently disabled people will not be entitled to the 'care' component of DLA whilst in a hospital or care home as their care needs are considered to be met. By focusing the 'Daily Living' component on care related costs, SIA is concerned that an argument might be made that PIP payments would be similarly not payable to those in receipt of NHS Continuing Healthcare, and seeks assurances that costs incurred in relation to these descriptors will continue to be met by PIPs.

SIA has a number of concerns regarding the definitions of terms in the Daily Living descriptors, most notably to "bathe", "cook" and "manage incontinence". It is clear that the limited definitions of these terms will not truly reflect a Spinal Cord Injured person's needs in these categories. Please refer to our answer question 8 where we outline our concerns.

Q2 – What are your views on the weightings and entitlement thresholds for the Daily Living activities?

As discussed above and in the answer to Question 8, SIA feels that several of the descriptors do not give an individual the opportunity to adequately reflect their needs in several of the descriptors. The limiting definitions of "bathe", "cook" and "manage incontinence" do not suitably cover the disability related needs which people with SCI may experience.

Whilst the weightings appear to be largely suitable to each category, the needs which they should meet are not adequately reflected because of the limitations of these definitions. By limiting a needs assessment to the top half of the body, or the ability to achieve actions above waist height, there is no opportunity for an applicant to be judged on those issues which they face below this level. This is of particular pertinence to Spinal Cord Injured people, most of whom will experience some level of paralysis and loss of sensation in the lower half of their body. Their ability – or lack of - to clean themselves and to reach things below this level 'safely and reliably' must be reflected in the assessment process and must be addressed in the next draft assessment.

For a full explanation of our concerns with each of these definitions please refer to our answer to question 8.

Q3 – What are your views on the latest draft Mobility activities?

SIA broadly agrees with the draft of the latest Mobility activities. However, whilst those Spinal Cord Injured people solely reliant on wheelchairs should – rightly – receive the enhanced rate of the Mobility component, we feel that the arbitrary limit of being able to walk 50 meters does not reflect true limited independence. Whilst it may be suitable for walking from a car park to a supermarket, it would be insufficient distance to walk around that supermarket. It is likely that someone in this category would require

assistance to shop at said supermarket, to reach for high items whilst maintaining balance and subsequently to carry any bags. The weightings for those in this category should be increased.

Q4 – What are your views on the weightings and entitlement thresholds for the Mobility activities?

SIA feels that it is right and appropriate that those who are fully reliant on wheelchairs for their mobility will continue to be eligible for the highest award of the mobility component.

However, SIA would like to seek clarity on a particular issue. A user of a self-propelled manual wheelchair will receive 12 points, and therefore qualify for the enhanced rate of the mobility component, a user of a powered wheelchair or someone who needs to be pushed in their manual wheelchair will receive 15. Whilst there is obviously a difference in need between these two categories, it is not clear why any descriptor has a value of 15 when only 12 is required to receive the enhanced rate of PIPs. SIA is concerned that this may indicate a future change in weightings for PIPs where the bar for qualification is raised beyond 12 points to 15, therefore disenfranchising those wheelchair users who are able to self propel. SIA seeks clarity on this point and assurances that anyone who is fully reliant on a wheelchair for their mobility will continue to qualify for enhanced rate of PIPs in the future.

Q5 – What are your views on how the regulations work regarding benefit entitlement?

SIA is content that people with a Spinal Cord Injury should be considered eligible to apply for PIPs under these guidelines. However, SIA also urges the DWP to listen to organisations who represent people with mental, cognitive and intellectual difficulties who may feel that the regulations disenfranchise the people they represent in this regard.

Q6 – What are your views on how we are dealing with fluctuating conditions?

The effects of Spinal Cord Injury are permanent and do not fluctuate. As such SIA feels this question is more suitably answered by organisations which represent those with fluctuating conditions.

Q7 – What are your views on the definitions of ‘safely’, ‘timely’, ‘repeatedly’ and ‘in a timely’ manner?

Universally understood definitions of ‘safely’, ‘timely’, ‘reliably’ and ‘repeatedly’ will be paramount when reflecting the true needs of disabled people applying for PIPs. As mere words they are open to objective definition by each applicant and, more importantly, each assessor. As such it is of the utmost importance that the definitions are included in guidance. Due to the frequency

with which the words are used throughout the assessment, it would seem logical to define them once, clearly at the outset of the application form.

If clarity can be brought to these definitions then it will go some way to making the process more transparent and will hopefully increase applicant understanding of the application process and the criteria under which their disability related needs are being defined.

Q8 – What are your views on the definitions in the regulations?

SIA would like to make the following comments on the definitions of the draft regulations:

“Bathe” means clean one’s torso, face, hands and underarms.

“Bathing” should also include the cleansing of the lower half of one’s body. Whilst a paraplegic may have no problems cleaning the upper half of their body, due to paralysis of the lower limbs will find cleansing the lower half of the body considerably more difficult. This can be amplified in cases where the individual has experienced incontinence, yet the difficulties they could experience in this regard will be completely missed by the current descriptor.

“cook” means heat food at or above waist height;

SIA must once again question the specific reference to the upper half of the body. Many conventional cookers are placed at below waist height, causing considerable difficulties for those unable to bend or with paralysis of the abdominal muscles which would prevent them from removing something from the oven ‘reliably and safely’. In terms of nutrition, this must also recognise the greater breadth of meals which can be made using an oven as opposed to merely a hob.

“manage incontinence” means manage evacuation of the bowel or bladder including using a collecting device or self-catheterisation;

The management of incontinence must also consider the applicant’s ability to manage the after effects of incontinence. Whilst a Spinal Cord Injured person may be able to manage their bowel and bladder from day to day, it is an unfortunate reality that an ‘accident’ can nonetheless occur at any time, causing

The definition must also reflect an individual’s ability to undress and clean themselves in such an event, to strip and wash bed clothes etc. For somebody who is paralysed in the lower or lower and upper limbs, such activities are especially hard to accomplish ‘reliably, repeatedly and in a timely fashion’ and this must be recognised in the descriptor.

Q9 – Do you have any other comments on the draft regulations?

The case studies which are included in the consultation document go some way to explaining how people with different impairments may expect to be supported by the introduction of PIPs, yet there is a crucial detail which is missing and would better illustrate how these changes could affect disabled people. Whilst there is mention of the benefit award these disabled people can expect, there is no mention of the award they could currently receive under DLA. Had this information been included in the consultation document then the consultation process would have been more transparent.