



## **Personal Independence Payment– response from The Disabilities Trust**

### **About the Trust**

The Disabilities Trust is a leading national charity, providing innovative care, rehabilitation and support solutions for people with profound physical impairments, acquired brain injury and learning disabilities as well as children and adults with autism.

We have residential and community-based services across England, a brain injury rehabilitation service in Glasgow with a further service planned for Llanelli. For more information, see [www.thedtgroup.org](http://www.thedtgroup.org)

The organisation was founded in 1979 and is registered as a charity no 800797 and in Scotland SCO38972.

For more information, please contact Erin Callaghan, Policy and Campaigns Officer, tel 01444 239123.

### **What are your views on the latest draft Daily Living Activities?**

The Disabilities Trust welcomes the changes to the descriptors, we feel they are more accurate and transparent consideration of the types of day to day activities those with a disability would engage with from the initial draft, though we still feel changes need to be identified and acted upon. For example, we are concerned that the needs of those with a cognitive impairment such as an acquired brain injury, autism and other learning disabilities are not taken into account within the descriptors of some of the daily living activities. Whilst we recognise that the Government wants to steer the benefit to only help those with the 'greatest need,' we believe that these descriptors do not reflect the struggles, isolation and confusing episodes our service users are subject to. The Government does not celebrate or

recognise that a median disability may be just that because of the financial help disability living allowance currently offers.

#### Daily Living Activity – Communication (7)

The Disabilities Trust welcomes the Department for Work and Pension's decision to class this as an individual activity to the eighth descriptor, 'engaging socially.' Currently the communication descriptor seems to assess a person's ability to understand and express verbal and written communication. The Disabilities Trust are extremely concerned that this does not reflect on the inability of an autistic person to understand and react well to non-verbal communication, such as body language, touch, eye contact and tone of voice. We feel strongly that the descriptor should be changed to reflect a claimants' ability to communicate both verbally and non-verbally. Further the descriptor states an individual will score zero points if they 'can communicate unaided and access written information unaided, or using spectacles or contact lenses.' Many autistic people can read and access written information unaided however they may not understand the context of what is written without it being phrased differently; this of course will cost extra resource and time.

#### Daily Living Activity – Engaging Socially (8)

We are particularly pleased that a new activity, 'engaging socially,' has been established as it is important to recognise the increase in social isolation that those with a disability may face and the problems that occur as a result of a loss or decrease in engaging socially such as depression, isolation and anxiety. However we strongly feel that the descriptor doesn't go far enough to take account the issues those with a cognitive impairment face. For example, one of the hallmarks of the Autism Spectrum Disorder is impairment in social cognitive skills; it can lead to extreme social isolation and therefore depression. However the descriptor only charts the most extreme response an autistic individual would have when engaging socially as 'overwhelming psychological distress,' or 'exhibiting uncontrollable episodes of behaviours which would result in a substantial risk of harm.'. This leaves us with a number of people who because of their level of impairment, rehabilitation or indeed increased social interaction because of their current DLA package have difficulties that still have a severe need whereby it will cause a negative emotive reaction such as confusion, distress and isolation and in some cases extreme teasing. However they will most likely not identify as having 'overwhelming psychological distress.' In short we feel that the emphasis is on those with the most extreme and highest need which though is rightly met, the median majority sufferer is neglected, which will cause problems later on potentially further costs to the Government.

Social inclusion is a priority for people with a disability. To reduce the payment which would enable them to do that would place the person at risk of total isolation. Please do not put the priority on personal care as the whole person's needs should be taken into consideration.

The Disabilities Trust also supports Lord Low of Dalston's recent question in Parliament (April 23<sup>rd</sup>, Hansard for House of Lords) stating the need for the PIP benefit to include a daily living descriptor that ensures that the maintenance of a home to a safe and hygienic standard is recognised in the final assessment criteria for the new personal independence payment, including the additional costs faced by some disabled people in this regard. We fully support this view and would urge the Government to add this as an extra daily living activity.

### **What are your views on the latest draft Mobility activities?**

The Disabilities Trust is concerned that only two of the eleven activities count towards mobility. We feel that those who have some but limited ability to walk unaided will be unfairly penalised because of the descriptors which seem only to award those with the most extreme difficulties. Whilst we feel it is most appropriate to award those with the most severe mobility issues, there are a number on the border who will miss out on this vital benefit when they too need it to alleviate social exclusion and more physical and mental distress. This is particularly prevalent in activity one of the mobility descriptor, which we discuss below.

#### **Activity one of mobility – Planning and Following a journey**

The Disabilities Trust finds the wording in activity one of the mobility activities difficult to decipher, we would welcome a clearer understanding of what 'overwhelming psychological distress,' means in PIP terms.

The Disabilities Trust also feels that those with a cognitive impairment have been somewhat disregarded in this descriptor. For example those with a cognitive impairment sometimes are not able to realise or react well to dangerous situations, their intuitiveness is decreased which may lead to them believing they 'can plan and follow a journey unaided,' when in fact if they did, they would need to be supervised to avoid causing danger to themselves or others. Further we feel there is a significant jump between (a) can plan and follow a journey unaided to (b) needs prompting for all journeys to avoid overwhelming psychological distress. Those with a cognitive impairment such as an acquired brain injury as part of their rehabilitation plan may have succeeded in making a solo journey to a local shop if they are then awarded a zero weighting there would be less appeal to continue to stretch one's abilities if there is no middle way or award. Further we feel the descriptor should include an ability to plan part of a journey unaided as there many with a cognitive impairment who may be able to a part of a journey that involved a familiar route for

example a walk into their local town, but not to a specific area such as the post office or local charity shop.

**What are your views on the weightings and entitlement thresholds for the Mobility Activities?**

The Disabilities Trust does not agree with the weighting and entitlement thresholds for the mobility activities, we feel that the Government, despite continued protestations, is not putting those with an ambulant disability on the same footing as those who are wheelchair bound. We feel this is a huge step back from the previous government's reforms that allowed those with a visual impairment and other severe cognitive needs to be considered and awarded the higher rate of mobility component. The barriers for a person with a severe ambulant disability to those with a wheelchair disability may not be the same but we believe would still be on par with each other in terms of the issues they face.

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

The Disabilities Trust questions how 'a consideration of a twelve month period,' works when a new applicant is assessed? For example under current guidelines, a person with a new disability can claim after the first six months of them requiring DLA and we believe this will be the same for Personal Independence Payment, how then will fluctuation of conditions be taken into account for twelve months? Will the individual be reassessed twice? The 'variable and fluctuating conditions,' discuss in detail about percentages of need. We are concerned that those with a learning disability or an acquired brain injury would not have the capability to answer this question fully. Mentioned below is our absolute belief that an advocate should be present in the assessment or reassessment of the service users we represent.

**What are your views on the definitions of 'safely,' 'timely,' 'repeatedly,' and 'in a timely manner?'**

The Disabilities Trust is anxious that the definitions of 'safely,' 'timely,' 'repeatedly' and in a 'timely manner' are dissimilar to using the words in normal everyday conversation. We would urge the definitions to be defined at the beginning of an assessment to an individual (and their advocate) as well as being included within the criteria and/or regulations rather than just in the guidance.

**Do you have any other comments on the draft regulations?**

The Disabilities Trust welcomes the chance to comment on elements of the assessment process for Personal Independence Payment around the requirement to provide information and attend face-to-face consultations. Whilst the Disabilities

Trust recognises and supports the Department for Work and Pensions in requiring all information to be present and correct before assessing or reassessing an individual we question whether a face-to-face consultation is necessary for the a number of claimants who have either received life-long awards of DLA, because their health conditions will never change or whose application and supporting evidence makes them a clear cut case to receive the enhanced standards of payment for PIP. This would not only lessen anxiety for the individual, his carer and family it would also benefit the government's plans to reduce administrative costs by implementing a simple rule that decreases the amount of one-to-one interview the assessor has to make.

The Disabilities Trust is extremely concerned about the lack of guidance and text on an individual being accompanied into the assessment by an advocate and the level of authority they would be afforded when helping to decipher an individual's true difficulties. For example, someone with a brain injury who looks quite "normal" and, during assessment, will answer questions but has no or little insight into their deficits, they will answer questions in an affirmative manner because they do not see that they have a disability. The assessor could ask them if they could walk on water and they would say yes. You could ask them how they would make a sandwich and they would be able to tell you but if you ask them to go into the kitchen and complete the task, they would be unable to do so, because they are not able to process the information. The Disabilities Trust needs to be confident that the unseen disability is not ignored, how does the DWP propose to overcome this barrier?

We firmly believe that the personal independent payment should provide fair access for all. This can only be done by involving professionals who know the person in question and family members. We also feel that if this is rectified the number of appeals on PIP assessments and reassessments could be significantly reduced saving both time and resource for the Government. We therefore urge that the right to an advocate for an individual should be present if they are involved in the safeguarding process or where their active participation during the process of assessment/reassessment won't be fully attainable without an advocate.