

Northern Ireland Welfare Reform Group

Department for Social Development

Personal Independence Payment: assessment threshold and consultation

April 2012

The Northern Ireland Welfare Reform Group welcomes the opportunity to comment on the Department for Social Development's Personal Independence Payment assessment threshold consultation.

About the Welfare Reform Group

The Welfare Reform Group is an umbrella grouping of organisations that campaign for positive changes to policy, service provision and legislation for those in receipt of social security while also providing advice and support to other advice giving organisations and disadvantaged persons in their capacity as individual members of the Group.

The Group supports an equality and human rights-based approach to the provision of social security which demonstrates an understanding of and focus on the needs and choices of all in receipt of benefits.

This response has been endorsed by the following organisations:

Action for Children	Advice NI
Ashton Community Trust	Barnardos
CAB	Carers NI
Disability Action	ICTU
Law Centre NI	Macmillan Cancer Support
Mencap	NICVA
WRDA	

Introduction

Disability Living Allowance is a tax free, non means tested benefit for adults and children with disabilities, intended to provide financial assistance towards the extra costs associated with disability and can be awarded both in and out of work. The extra costs associated with disability may include heating, transport, fuel, housing, shopping, clothing, aids and equipment and care.¹

There are currently 187, 950 people in receipt of DLA, 120,829 of these are of working age.² A report by the Centre for Social Justice noted ‘the majority of people claiming illness-related out of work benefits do so on account of mental and behavioural disorders...this demonstrates a significant and widespread problem in Northern Ireland given its comparatively small population’.³

The Welfare Reform Group welcomes the Government’s commitment ‘to supporting disabled people to exercise choice and control and lead independent lives’. We are concerned, however, that the report to date appears to focus on the prediction of caseload and consequently expenditure to be saved rather than the effects of the changes on disabled people.

We are also concerned about the enormity, timeframe and intention of these proposed changes to DLA given the high number of people in receipt of the benefit in Northern Ireland. We do not think that reform should be driven primarily by the need to meet financial targets set by the Treasury. Instead reform should be based on sound principles to ensure the purpose and policy behind supporting disabled people is being met.

During the previous consultation on the draft regulations last summer, excluding the inclusion of descriptor weightings and entitlement threshold, it was difficult to understand the impact of the criteria and therefore to fully remark on the new proposals. We welcome the opportunity to provide comment now and offer insight. We remain concerned about being asked to comment on components when the rates for the benefit are not yet known.

¹ See Mike Tibble., Review of existing research on the extra cost of disability, DWP 2005

² DSD Benefit Summary of Statistics , Disability Living Allowance, November 2011

³ ³ Centre for Social Justice , *Breakthrough Northern Ireland* ,September 2010 pg15

The Department appears satisfied that 900 volunteers participated in testing the criteria. We believe this approach to be ill conceived. All activities should be located in the context and environment (both physical and attitudinal) in which an individual with disabilities lives. People with the same named condition will exhibit different effects depending on their personal attitude, the circumstances in which they live or work, etc. Testing 900 disabled people (0.009%⁴ of the disabled population of the United Kingdom) does not provide reliable quantitative evidence on which to make such substantial changes to disabled peoples' lives.

We give further details of our thoughts on a number of the proposals below:

Assessment Process

The Welfare Reform Group is concerned by the shift from a social to a medical model of assessment. In particular, the introduction of an assessment notably comparable to the Work Capability Assessment of Employment and Support Allowance which predominantly looks at the medical impact of an individual's impairment rather than how this interacts with society to create barriers to independence for the individual.

Furthermore, these changes are being implemented while some of the Harrington Report's more recent recommendations have yet to be fully implemented and evaluated. The introduction of a person-centred, focused assessment, sensitive to the needs of individuals and, the inclusion of evidence from health familiar professionals familiar with the claimant, would be more appropriate for those with disabilities.

⁴ Note based on ODI figure of 10million people with limiting long term illness, impairment or disability in Great Britain. <http://odi.dwp.gov.uk/disability-statistics-and-research/disability-facts-and-figures.php#gd>

Fluctuating conditions reflect difficulties caused by exertion, exhaustion and repetition of tasks and highlight the broader spectrum of disability. We believe that ‘information from healthcare and other professionals who work with and support the individual such as a GP or social worker’ should be considered as a matter of course as these are the people most familiar with claimants, particularly the individual’s situation and have a holistic understanding of the condition. Therefore, it is vital that Health Care Professionals have a good insight into the particular difficulties individuals may face and the impact this may have on their health and mobility. This also must be reflected in the procurement process of those who will be carrying out the assessments

We also recommend the enhanced training of frontline staff carrying out the assessment. For example, at present we remain concerned about HCPs conducting the Work Capacity Assessment of the Employment and Support Allowance. The Citizen’s Advice Report ‘*Not Working*’ has provided quantitative research whereby claimants have reported ‘hurried medicals in which the HCP does not look at them but at the computer screen’. Similarly, Citizen’s Advice (NI) has highlighted delays in processing claims resulting in financial hardship for clients.⁵ Delays are often caused by the loss of documentation supporting a claim or a lack of communication of follow up from the Social Security Agency. We believe the Department should seek to learn from the problems created within the ESA assessment process and ensure safeguards and appropriate pilots are put in place before plunging into the new PIP assessment arrangements.

We believe that the document relies too heavily on the supposition that every disabled person receives family or other support. More emphasis needs to be given to people with multiple disabilities, particularly relating to intellectual disability and environmental factors in the descriptors and in the self-assessment form.

⁵ CAB (NI) Evidence Briefing available at <http://www.citizensadvice.co.uk/en/publications/Social-Policy-Reports/ESA-Evidence-Briefing/>

Descriptors

The Welfare Reform Group is disappointed with the limited number of essential activities presented despite the DWP emphasis that PIP is being designed to support people to be active and independent. We believe that additional activities are required concerning staying safe, assistance at night and moving about inside the home.

We are very concerned that the significance of assessing danger, risk and safety issues have not been factored into or linked throughout the descriptors. The need for supervision is only referred to in three of the nine daily living descriptors. We believe that many of the descriptors, particularly in the daily living activities, could pose potential harm to those carrying out the activities. For example, in the first descriptor 'preparing food and drink', an individual may be able to carry out all the steps of preparing a meal but may require supervision and prompting with each step not to leave the oven or hob unattended.

Many of the proposed descriptors will apply at night. For example, one would expect that someone requiring assistance managing toilet needs during the day will also require similar assistance at night. At present the middle rate of the care component of DLA is paid to people who need help during the day or during the night, while the high rate is paid to people who need help during the day and the night. We note that the proposed test does not specifically refer to when supervision, assistance or prompting is required, but that the vast majority of the descriptors relate to activities that are usually performed during the day. This is a significant departure from DLA and poses considerable problems for many disabled people. We recommend that an additional activity relating to the need for assistance, prompting or supervision during the night be introduced and appropriate descriptors devised.

We are concerned about the low scoring scheme and the weighting given to certain descriptors, in particular 'preparing food and drink', 'making financial

decision' and 'bathing and grooming', which will result in claimants failing to accumulate a number of lower scoring points. Rather, they will have to prove that their condition is particularly severe hence undermining the effect of the condition and the broader spectrum of disability. In addition, descriptors do not take into account the combined effect of low lying problems and conditions of a fluctuating nature which can often affect people differently and at various times. We are also concerned with the mathematical approach to fluctuating conditions. A person with a severely debilitating condition 40% of the time fails the test against someone with a less debilitating condition over 50% of the time will qualify. This is not an equitable reflection of the impact of a condition. As a result severity and frequency should be reflected in the assessment.

Furthermore, a recent analysis by Disability Rights UK as to the impact of lower numbers of claimants being eligible for support found that there will be a knock on effect in other areas of government spending i.e dependence on other benefits, loss of Treasury NI/income tax losses, and increased NHS and assessment costs. 'Consideration of cutting welfare has appeared to view DLA payments as deadweight expenditure'.⁶ The idea that DLA represents a 'nil return' means of supporting people is inaccurate and it is essential that accounting for the additional cost of disability remains at the forefront of PIP development.

We are also concerned that the proposed £2.17 billion cut to the budget for Disability Living Allowance, which will result in significant numbers of disabled people losing their entitlement to Personal Independence Payment (PIP), will have a knock on impact on carers.

Carers supporting these individuals will, as a result, lose their entitlement to Carer's Allowance. Two thirds of carers currently use their own incomes to pay for care for the people they look after. Any reduction in income from disability benefits will only increase the pressure on carers, potentially forcing

⁶ Disability Rights UK., *Impact Assessing the Abolition of Working Age DLA*, April 2012

them to give up their caring roles. We recommend that further consideration should be given to this matter.

Activities:

Preparing Food and Drink

The Welfare Reform Group welcomes the removal of frozen food from this descriptor which helps to promote healthy eating, reduce high salt intake and encourage the use of fresh food. We are concerned by the low weighting attached to this activity, given the importance of this activity in an individual's daily routine. The maximum score is only 8 points and will be awarded to those who 'cannot prepare and cook food and drink at all'. Consideration should not only be given to preparing food and drink but also to budgeting, the purchasing of fresh foods and the knowledge of how to safely prepare and cook for a balanced diet. We would also ask for the removal of microwave cooking in this descriptor and the inclusion of a traditional oven and cooker. Using a microwave is not a true description of what is involved in making a fresh meal from scratch.

Taking Nutrition

We believe that the needs of disabled people with eating disorders and/or particular dietary requirements should also be reflected in this descriptor and technical notes. Special diets can be more expensive to provide for and may require unique shopping methods (one particular store or online provider for example of rare goods) which need taking into account to prevent some disabled people missing out on essential criteria. The weighting of descriptors D&E should be increased as nourishment is essential and should be recognised as such.

Managing Therapy or Monitoring a Health Condition

We are concerned that 'managing therapy or monitoring a health condition' may be interpreted narrowly, and will not extend to cover the broad range of activities that are involved with managing a health condition and maintaining general health. For example, exercise, accessing social support networks, maintaining a routine and certain activities, or complementary therapies may not be 'prescribed or recommended' by healthcare professionals, but may be an extremely important element of an individual's management of their physical or mental health condition. All of these could incur significant additional costs and support.

By focusing on prescribed treatments, those with conditions for which there are few licensed treatments available (such as progressive forms of MS) are less likely to be able to access support through PIP, although the lack of support and treatment they may therefore receive from the health system could mean that their needs are even greater.

We recommend enhancing this descriptor to ensure a broader outlook on disability which would not only include managing medication and prescribed therapies, but also maintaining a healthy lifestyle.

Safety should also be a consideration in descriptor B and the weighting of other descriptors should be increased.

Bathing and Grooming

The Welfare Reform Group welcomes the removal of 'self neglect' from this descriptor which we believe would have set a very low standard of hygiene, thus preventing people with mental health and learning difficulties from actively participating in general life. The descriptor should also include the ability to independently wash using a shower/bath and dry the whole body. Grooming should include shaving and the maintenance of personal appearance. We are disappointed that the maximum point score allocated to this activity is 4 points considering the central role of this activity in a daily

routine. Moreover, the focus on cleaning the body, brushing teeth and cleaning and brushing hair means that the descriptor does not take into account the ability to maintain hygiene beyond the body. This would include washing clothes and keeping a clean and safe living environment. We recommend that a separate descriptor should be added considering the ability of the individual to maintain a clean and safe living environment unaided. Safety should also be considered in the descriptors and the weighing increased.

Managing Toilet Needs or Incontinence

We are aware that this descriptor may cause embarrassment for some claimants, particularly in a face to face assessment situation, and is of a personal nature. Individuals may be uncomfortable to disclose such information, hence undermining the effectiveness of this descriptor. We recommend that assessors are trained to sensitively disseminate information from individuals on this matter.

We are concerned that this descriptor does not fully account for difficulties experienced accessing a toilet while inside or outside the home, or the frequency of toilet needs. Reaching the toilet is often more difficult at night time, and some people may need assistance with this.

Another difficulty for people with continence problems or leakage from stoma appliances is the need for assistance with changing bedding during the night. The need for assistance throughout the night should be particularly addressed. We are concerned that there is no proviso present that gives special recognition to night time care needs which is a departure from the current structure of the DLA care component.

A separate descriptor should also be added for the ability to manage personal feminine hygiene.

Dressing and Undressing

We feel that this activity could be enhanced further with the inclusion of 'appropriate clothing' to reflect an individual's capacity to dress accordingly to changeable climate and weather conditions. We would ask for the removal of slip on shoes as this restricts the choice that disabled people have over their personal appearance.

Communicating

Currently the communication descriptor assesses a person's ability to understand and express verbal and written communication and the support they may be required to do so. In addition, to speech and written information we recommend that non verbal aspects of communication such as body language, eye contact and tone of voice are also taken into consideration with the assessment criteria. Some individuals with autism, for example, may not fully understand the meaning of the context without it being phrased differently while other others may need more time to process the information.

Consideration also needs to be given to support such as encouragement, reassurance or motivation that may be required. The assessment fails to take account of the nature and complexity of the needs of a person with a long-term illness or disability.

Engaging Socially

Difficulties with social interaction such as knowing how to behave around other people, making and keeping friends and understanding social norms, are often core difficulties facing people with mental health and learning difficulties. We recommend that these descriptors are amended to include factors such as preparing for change, being in different environments, engaging with familiar and unfamiliar people and safety issues. Currently, 'risk of harm' only appears to relate to the physical but should also refer to vulnerable individuals who may be susceptible to exploitation.

Furthermore, we are concerned that this activity may be difficult for assessors to ascertain in a single face to face assessment and we would welcome the prominence given to additional evidence within these descriptors.

We are concerned by the points weighting given to this activity with a maximum award of only 8 points in comparison to the communication descriptor of 12 points. We believe that both these descriptors are of equal importance, particularly for those with mental health and learning difficulties, and should therefore both have a maximum award of 12 points.

Making Financial Decisions

We welcome the inclusion of this new activity 'managing financial decisions', which can be an area of difficulty for many people with mental health problems. However, we remain unconvinced that the breadth and detail of activities to be considered is sufficient to properly capture the barriers to participation faced by people with mental health problems. We are also very concerned that the thresholds for scoring points in these areas are very high and that people with substantial needs will not be eligible for the new benefit.

We believe that the scale needs to be adjusted to give greater weight to this activity. An impaired decision making capacity to make financial decisions is a clear impairment for an individual and should be recognised as such by the PIP descriptors.

Planning and Following a Journey

Claimants with a sensory impairment will find it difficult to satisfy the higher scoring descriptors. We are disappointed that the recent extension of DLA higher rate mobility to those who are severely visually impaired has not been replicated within PIP. We note, there is a reference to this group potentially satisfying descriptors 'depending upon the extent to which they have adapted to their impairment.' We would welcome further information as to what this will

mean in practice. For individuals with mental health and learning difficulties, recognition has to be given to an individual's inability to plan and execute a journey unless rehearsed or familiar. We recommend that a descriptor should be included regarding an individual's ability to plan, execute a journey and cope when unexpected events occur.

Moving Around

We note there is a new distinction in the moving around activity between those who can walk under 50 metres, between 50-200 metres, and over 200 metres. We are disappointed that there is no inclusion as to what level of pain may be involved in moving around. We would welcome an explicit reference to 'and without experiencing discomfort' at the end of the relevant descriptors.

The ability to stand and sit should also be considered. Those who experience significant fatigue when standing for a period of time will find it particularly difficult to make use of public transport, as will those who struggle to rise from sitting to standing and they may therefore rely on expensive taxis, or require support or a companion when travelling around.

We believe the assessment should also include some consideration of an individual's ability to get up and down stairs. The lack of ability to do this can make a wide range of places inaccessible, and indeed can determine the ability for some people to get around their own home.

The descriptors give no recognition to the effects of challenging behaviour, for example the ability for the individual to deal with changing circumstances or moving into or around a crowd. A descriptor needs to be added to take regard of safeguarding vulnerable adults.

Overall the descriptors are unclear and misleading and indicate that the underlying thinking is confused.

Conclusion

The Welfare Reform Group is pleased to comment on the Personal Independence Payment assessment threshold consultation. If there is any other way in which we can contribute to the process we would welcome the opportunity to do so.