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Personal Independence Payment: assessment thresholds and consultation – response from Scope

About Scope

We all want to live in a world of opportunity – to be able to live our own life, play our part and be valued for the person we are. At Scope we're passionate about possibility. It inspires us every day and means we never set limits on people's potential.

We work with disabled people and their families at every stage of their lives. From offering day to day support and information, to challenging assumptions about disability and influencing decision makers - everything we do is about creating real and lasting change.

We believe that a world where all disabled people have the same opportunities as everyone else would be a pretty incredible place for all of us. Together we can make it happen

Comments

We welcome this opportunity to highlight our thoughts and ideas on the current assessment criteria and thresholds, as proposed by the DWP.

Grave concerns about the assessment criteria

However, we remain gravely concerned with the assessment; we were deeply disappointed to see that the DWP did not act on the recommendations – set out by Scope and endorsed by 24 other charities – in *The Future of PIP* report. Many of the department's responses to the report – discussed later – were unsatisfying and do not adequately address the widespread concern of disability charities, disabled people's organisations and disabled people themselves. We believe there is now a good likelihood of the Government failing to achieve its aim of ensuring "support is focused on those with the greatest barriers".¹ This will have profound effects on the financial stability and wellbeing of many disabled people and their families, and will diminish, not build, their capabilities for exercising choice and control and leading the types of lives they value.

We urge the Government to consider in full the concerns and recommendations made by the Work and Pensions Select Committee, to which Scope gave evidence. In particular, these are:

- That the Government should strive to learn the lessons from the mistakes made with the Work Capability Assessment (WCA); and
- That the draft assessment is still too reliant on the medical model of disability and may fail to take sufficient account of the social, practical and environmental barriers that impact on disabled people's ability to participate in and contribute to our society;

¹ DWP *Disability Living Allowance Reform – Impact – Assessment*, Oct 2011, www.dwp.gov.uk/docs/dla-reform-wr2011-ia.pdf (accessed April 2012)

Rushing through reform

We are perturbed with the Government's approach to seeking the views of the public, disabled people and charities like Scope, on the issue of reform. Holding the initial DLA Consultation over the 2010 Christmas period, a time when many stakeholders will have been unavailable to comment; launching the Welfare Reform Bill, which set out to abolish DLA and introduce PIP, in the midst of this consultation period; publishing – just hours before a vital debate in the House of Lords – the second draft criteria for the PIP assessment; and the speed with which the points – and now the thresholds – have been introduced all constitute what we believe to be an attempt by the Government to artificially move the debate on and shift public scrutiny away from the criteria itself. Throughout all this, we remain convinced that – for reasons outlined below – the criteria remain unfit for purpose and there is a real risk of repeating the same mistakes as those connected to the controversial Work Capability Assessment.

Reneging on a commitment

We are deeply disappointed that the Government has reneged on its commitment to the social model of disability. In the initial DLA consultation document, it says PIP “will continue to take account of the social model of disability”.² Elsewhere it says: “we remain committed to the social model of disability”.³ On November 30th 2010, before the launch of the DLA consultation, the Minister for Disabled People, Maria Miller, insisted that the Government was “absolutely committed to a social model for [the reform of DLA], not a medical model.”⁴ In January 2011, in reference to Article 8 of the UN Convention on the rights of disabled people, the Minister again reaffirmed the DWP's “strong public commitment to the social model of disability”.⁵

Disabled activists and disability rights campaigners fought long and hard for the social model of disability to emerge and thrive. With this in mind, we were disturbed to hear the Minister for Welfare Reform, Lord Freud, say: “*I do accept that it is not a full social model assessment; it is not intended to be.*”⁶ We believe it to be of paramount importance that the Government fulfil this commitment to disabled people – all the more because DLA and PIP are designed to contribute to disabled people's additional costs, which themselves arise from the same social barriers that lie at the heart of the social model of disability. The new criteria fixate on assessing an individual's ability as determined by their impairment – be this “physical, sensory, mental, intellectual or cognitive; or any combination of these”.⁷ Clearly, this is another medical model test – the type that the Minister had previously insisted would be avoided.⁸

Fudging language

The policy objectives for DLA Reform are outlined in the October 2011 impact and equality impact assessments and state that PIP will support “disabled people to overcome the barriers

² DWP [Disability Living Allowance reform - Public consultation](#) (London: DWP, 2010)

³ DWP [Disability Living Allowance reform - Public consultation](#) (London: DWP, 2010)

⁴ Miller, M, *Hansard*, 30 Nov 2010, col 220WH,

<http://www.publications.parliament.uk/pa/cm201011/cmhansrd/cm101130/halltext/101130h0001.htm#101130300002>

70 (accessed February 2012)

⁵ Miller, M, *Hansard*, 10 Jan 2011, col 136W, <http://www.publications.parliament.uk/pa/cm201011/cmhansrd/cm110110/text/110110w0005.htm> (accessed February 2012)

⁶ Freud, L quoted in transcript of De Havilland 'Lords Committee Stage – Welfare Reform Bill (Day Thirteen)', De Havilland, 14 Nov '11,

<http://www.dehavilland.co.uk/infostream/item.aspx?id=18214347&src=alerts&searchtext=Scope%20Scope%20Scope%20Scope%20Scope%20Scope%20Scope%20Scope%20Scope%20Scope%20Scope> (accessed November 2011)

⁷ DWP *Personal Independence Payment: second draft of assessment criteria - An explanatory note to support the second draft of the assessment regulations* (London: DWP, 2011)

⁸ Miller, M, *Hansard*, 30 Nov 2010, col 220WH,

<http://www.publications.parliament.uk/pa/cm201011/cmhansrd/cm101130/halltext/101130h0001.htm#101130300002>

70 (accessed February 2012)

they face to leading full and independent lives” and that the Government will “ensure that support is focussed on those with the greatest barriers”. Scope is very supportive of this aim. However, we are very concerned about what appears to be a consistent ‘fudging’ of language – when the Government describes who it is they envisage will be entitled to PIP – and the use of descriptions that creep further and further away from the wording used in the policy objectives. Such examples include

- Maria Miller, the Minister for Disabled People, asserting that the assessment will “assess people’s support needs” – a description that is much more commonly used to describe social care needs.⁹
- The Minister has also spoken of reforming DLA so that it targets “those with the greatest need”.¹⁰ The initial draft assessment criteria also referred to individuals or those with “the greatest need” – understanding this to be “needs arising from a health condition or impairment”.¹¹
- The recently revised assessment criteria explain that underlying the initial draft was the priority that PIP “goes to those most affected by their health condition or impairment”.¹² Later in the second draft it says: “Personal Independence Payment is intended to provide financial support for those individuals who face the greatest barriers to participating in everyday life.”¹³

Scope believes that in order to fulfil its commitment to the social model of disability, the Government needs to clarify that PIP is in fact intended to support those with “the greatest barriers”, and that this is quite different from an individual’s medical or support needs. We strongly support the Government’s aim of ensuring PIP “supports disabled people to overcome the barriers they face to leading full and independent lives”, and would urge the Government to be consistent in using language that reflects its policy objectives.

Tweaks are not enough

We accept that the second draft of the criteria is an improvement on its predecessor. Scope welcomes changes such as the expansion of the definition of medication and therapy so that it includes that which is recommended and not just prescribed. However, the Government is far from where it needs to be if it is to achieve its aim of ensuring the new benefit supports disabled people to overcome the barriers they face. Tweaks are not enough. As it says in the recently released assessment documents, “*the broad principles of the criteria remain unchanged.*”¹⁴ It says in the new draft that among the comments made most frequently during the informal summer consultation were “strong feelings that the initial proposals did not adequately assess disability-related costs, and that issues such as utility bills, access to

⁹ Miller, M, *Hansard*, 30 Nov 2010, col 219WH, <http://www.publications.parliament.uk/pa/cm201011/cmhansrd/cm101130/halltext/101130h0001.htm> (accessed November 2011)

¹⁰ Miller, M, *Hansard*, 6 Dec 2010, col 9WS,

<http://www.publications.parliament.uk/pa/cm201011/cmhansrd/cm101206/wmstext/101206m0001.htm#1012063000114> (accessed November 2011)

¹¹ DWP *Personal Independence Payment: initial draft of assessment criteria – a technical note to support the initial draft of the assessment regulations* (London: DWP, 2011)

¹² DWP *Personal Independence Payment: second draft of assessment criteria – an explanatory note to support the second draft of the assessment regulations* (London: DWP, 2011)

¹³ DWP *Personal Independence Payment: second draft of assessment criteria – an explanatory note to support the second draft of the assessment regulations* (London: DWP, 2011)

¹⁴ DWP *Personal Independence Payment: second draft of assessment criteria – an explanatory note to support the second draft of the assessment regulations* (London: DWP, 2011)

transport and suitability of housing should be included”.¹⁵ There is little in the new draft to suggest that these ‘strong feelings’ have been adequately addressed.

Specific comments

Because we believe that the Government’s approach to the PIP assessment and the proxy (impact of impairment) it intends to use is fundamentally flawed, we do not see much value in commenting on weightings or descriptors in an assessment that we believe is systemically unfit for purpose. Instead, we would like to use this opportunity to respond to particular points set out in the second draft of the assessment that we believe are either related or directed to our *Future of PIP* model and to explain in more detail why we think the assessment needs radical reform.

- 1. Pg. 13 (box): Drivers of disability costs vs. actual extra costs:** in the new criteria it states: “Rather than assess the actual extra costs incurred by an individual, which could be subjective, inconsistent and expensive to administer, we proposed [in the first initial draft criteria] assessing ability to carry out key everyday activities”.¹⁶ Scope would agree: assessing actual extra costs would be very difficult and expensive; but, we would argue it is vital that an assessment for PIP should be designed to flag the barriers *that give rise* to these costs – the *drivers* of disability costs. Otherwise, ensuring “that support is focussed on those with the greatest barriers”¹⁷ will prove problematic and could result in the new benefit being badly targeted.
- 2. Pg. 28 (4.6): Assessing every activity where individuals may face barriers to participation or where extra costs may be incurred.** Scope agrees that assessing *every* activity where disabled people face barriers or incur extra costs would make for a complex and most cumbersome test. This acknowledgement is explicit in our recent report: *The Future of PIP – a social model based approach*.¹⁸ Instead of attempting to design descriptors that could capture the *whole range* of activities and connected costs, Scope suggested that the assessor should get the *claimants themselves* to provide information about the activities that are important to them, and then to pursue a series of probing questions that would capture information as to: how the individual usually manage when doing said activity/ies; how – if – they are supported, in what way, and by whom; and how they would like to be able to do the activity in question (as disabled people often downplay the extent to which their impairment, pain, etc. prevents them from carrying on with their daily routine). We suggested that this process could then be repeated for several activities, one of which would fall into one of four categories (how the disabled person manages their condition; what barriers to they face to participation; what issues arise as a direct or indirect result of their impairment or condition when trying to meet family responsibilities; and, what difficulties they experience to living as independently as possible). They would then be scored according to the impact of certain barriers – both as a direct result of their impairment or condition and as a result of external factors. Finally, they would receive a score,

¹⁵ DWP *Personal Independence Payment: second draft of assessment criteria – an explanatory note to support the second draft of the assessment regulations* (London: DWP, 2011)

¹⁶ DWP *Personal Independence Payment: second draft of assessment criteria – an explanatory note to support the second draft of the assessment regulations* (London: DWP, 2011)

¹⁷ DWP *Disability Living Allowance Reform – impact assessment – October 2011* (London: DWP, 2011)

¹⁸ Grant, E *The Future of PIP: a social model based approach* (London: Scope, 2011)

amalgamated *across* barriers, which would determine their eligibility for PIP – and for what rate.

- 3. Pg. 29 (4.8): many of the costs that have been flagged in the new draft assessment criteria have already been taken into account within the proxy of impact of impairments.** The Government is arguing that the criteria, which focus on impact of impairment, will automatically flag disability costs that arise from social, practical and environmental barriers. As suggested in the new draft: “individuals who have difficulties getting out are likely to have higher utility bills, while those who need support planning a journey and moving about are likely to have higher transport costs”. We are unsatisfied with this explanation. An individual who is incontinent – even intermittently so – is likely to have very high utility bills from increased washing and drying but may experience relatively few problems getting out and about. Alternatively, an individual may be able to prepare food and drink, but, because of their condition, require a particular diet, which may well result in extra costs. We believe it is very risky to assume that problems a disabled person experiences in one area will be readily brought to light by an assessment or descriptor that focuses on another. Worryingly, such an approach risks homogenising the plethora of barriers that disabled people face in their daily lives. It is important to note that the proxy the Government proposes – ‘the impact of impairment’ – still does not take it any closer to fulfilling the commitment it has repeatedly made to the social model of disability – a commitment on which disabled people and activists, charities and DPOs expect them to follow through.
- 4. Pg. 29 (4.9a): taking account of issues such as housing, access to transport, informal support and utilities would make the assessment more subjective and lead to inconsistent outcomes.** Scope believes that the priority here should be about creating an assessment that is accurate, and which is the most beneficial for the Government in the pursuit of its goal of ensuring that those who face the greatest barriers receive support. We understand and appreciate that the Government is concerned about subjectivity and that this might lead to inconsistency; but, we are concerned that this has been taken as a reason to push through a relatively simplistic draft criteria, which will allow the assessor to only see half the picture. Further to this, Scope would argue that no assessment is fully objective – even the decisions in tests that employ a points-based approach akin to the Work Capability Assessment (WCA) (which, it should be noted, has continually been the cause of much criticism and consternation – including from one of its designers, Professor Paul Gregg¹⁹ - and has sparked the need for a series of internal and independent reviews) are ultimately dependent on the subjective decisions made by the assessors themselves (and then, typically, the DWP/JCP decision-maker). At a presentation by DWP and the company Atos, which carries out the WCA, it emerged that the rate at which the DWP decision makers are overturning initial decisions by Atos’ assessors has *trebled*.²⁰ In these instances, the decision by DWP to overturn the initial Atos assessment is based on the DWP decision maker’s judgement – with or without the benefit of additional information to interpret. Furthermore, as we argue in *The Future of PIP*, using only a points-based, tick box descriptor approach will fail to capture adequate information about the barriers disabled people face on a daily basis, and this could compromise the accuracy of the assessment and its utility in meeting the

¹⁹ Gentleman, A “‘New disability test is a complete mess”, says expert’ , *Guardian*, 22 Feb 2011, <http://www.guardian.co.uk/politics/2011/feb/22/new-disability-test-is-a-complete-mess> (accessed November 2011)

²⁰ Presentation by DWP and Atos Healthcare at ‘Tackling disability poverty’ conference, 22 Nov 2011, London, UK

objective of focussing support on those who face the greatest barriers. The Government appears to be using concerns about inconsistency as an excuse to standardise disabled people's experiences, difficulties and barriers. We know from our experience as a disability charity and from the conversations we have with disabled people on a daily basis that their difficulties and extra costs arise from a multitude of barriers. It is precisely because of this that two disabled people with the same health condition or impairment could face different social, practical and environmental barriers as a result of their disability, and so each have a different set of disability-related costs. We believe that recognising this in the criteria will make the assessment *more, not less, accurate* and move it closer towards the Government's objective of ensuring that those who face the greatest barriers to participation are those who get the most support.

5. Pg. 29 (4.9b): incorporating social, practical and environmental factors such as accessibility of public transport will result in local variation and different results according to location.

In the new criteria it says: "Many of these issues [*i.e.*, housing, access to transport, informal support and utilities] will be dependent on local circumstances and availability of services, meaning that results might differ depending on location". We would not agree with this analysis, and would stress that *accessibility is not the same thing as 'availability'*. Whether an individual can access public transport or not is, in this instance, down to whether or not they are disabled, not on the frequency of their local bus service is. The blueprint for assessment that Scope proposed targets disabled people and is 'blind' to the location in which they live. We believe an assessment for PIP should take into account the barriers an individual faces *as a disabled person living with a health condition or impairment*. We would argue that if an individual is disabled and as a result is unable to use public transport and so has to pay for private taxis – which comes at huge extra costs – then it does not matter if they live in London or the Lake District; the fact remains that because they cannot use public transport in the first instance they have to pay extra costs that *a non-disabled person wouldn't have to pay*.

6. Pg. 29 (49c): incorporating social, practical and environmental factors would effectively introduce a form of means- or needs-testing.

Scope does not believe that widening the criteria so that it incorporates external barriers such as those aforementioned would introduce means-testing. We strongly support DLA being, and PIP continuing to be, benefits that are not means-tested. However, in response to the above point, we argue that it is critically important that Government does not lose sight of the fact that DLA and PIP are designed to provide support with the extra costs that disabled people incur as a consequence of living with an impairment of health condition in our society. These are costs that disabled people have to pay *precisely because they are disabled*. Whether they are classified as AB, C1, C2 or DE; what income bracket they are in, or whether they are able to save or not is not relevant as disability-related costs are costs that in principle disabled people should not have to incur. No one should have to pay £40 to change a light-bulb solely because they are disabled and live alone and so are unable to change it themselves or have anyone to help them. DLA and PIP are designed to serve as contributions towards extra costs. However, many of these extra costs are dependent on whether people have others around them to help provide them with support. Research commissioned by Scope and carried out by the independent think tank Demos shows that the extent to which an individual has a network of informal support has a strong influence on their disability-related

costs;²¹ having someone around to help has a big impact on whether or not a disabled person can overcome the barriers preventing them from participating. It is therefore important to take this factor into account for doing so will help the Government achieve its objective of ensuring that “support is focussed on those with the greatest barriers”.²²

Conclusion

In recent meetings and correspondence with the DWP it is clear that they are committed to pursuing this medical model assessment. We are very disappointed by this decision and, as a result, are extremely concerned as to the effects this will have on disabled people – particularly those with low impact of impairment but who face high barriers and incur significant costs – and their families. We do not believe there to be much value now in debating detail in an assessment that, we believe, will prove unfit for purpose. However, we do place great value on the open conversations and positive relationship we have with the Department – particularly with its staff on both the assessment development and implementation teams. In this spirit, we would be more than happy to discuss in detail with the department where – in terms of the design and development of the assessment – we think they are going wrong, where they need to be and how to get there.

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²¹ Wood, C and Grant, E *Counting the Cost* (London: Demos, 2011)

²² DWP *Disability Living Allowance Reform – impact assessment – October 2011* (London: DWP, 2011)