Personal Independence Payment: assessment thresholds and consultation

Comments from the Centre for Mental Health, Hafal, Mental Health Foundation, Mind, Rethink Mental Illness, the Royal College of Psychiatrists and the Scottish Association for Mental Health

Introduction

We welcome the opportunity to feed back on the second draft assessment criteria and proposed thresholds for the new Personal Independence Payment (PIP). As individual organisations we have engaged with the development work around the new assessment at a number of stages. Our response is informed by this engagement and our experience of the challenges people with mental health problems face in benefits assessment processes. We also ran a survey among people currently receiving Disability Living Allowance. This was designed to ascertain whether the activities and descriptors reflected the experiences of people affected by mental illness.

Our organisations are pleased that changes have been made to the initial draft criteria. Some of these changes reflect the concerns we raised in our response to the consultation last summer. However we still have outstanding concerns about the assessment activities and weightings.

Key recommendations

1. Consider measures of frequency, severity and duration to assess the impact of fluctuating conditions**.**
2. 'Managing therapy or monitoring a health condition' needs to be further developed to adequately reflect the experiences of people with a mental health condition.
3. Reference to familiarity should be made within 'Engaging socially' and the threshold of overwhelming psychological distress should be reconsidered.
4. The 'Making financial decisions' activity needs a higher weighting within the assessment. It also needs to reference the assistance people might need to make these decisions**.**
5. The assessment for the mobility component is not comprehensive enough to identify the barriers people with mental health problems face.
6. Anyone scoring 4 points for Activity 10 should have these points transferred to their daily living score if they do not qualify for the lowest rate of mobility.
7. More overt reference could also be made to the impact of disinhibition or lack of insight on a person's ability to undertake a journey safely and reliably.

8. Simplify the process for assessing fluctuating conditions to mitigate problems of self-reporting.

Consultation response

1. Survey findings

1.1 In order to inform our response to this consultation, we ran a survey among people currently receiving Disability Living Allowance (DLA). The survey asked people to choose descriptors that reflected their experience of the relevant activity. People were also given a chance to comment on the activities and some comments are included throughout our response. 520 people responded to the survey, of whom 322 were claiming solely for a mental health condition. 198 were claiming for both physical and mental health conditions.

1.2 Results from our survey show that while some people may see an increase in their entitlement, a significant number are likely to lose out. For the daily living component, about 23% of current claimants claiming solely for mental health will see a reduction in entitlement. For 14% of respondents this means receiving no daily living component at all, where they currently receive the care component. A further 9% would see a reduction from high or middle rate care to standard rate daily living. This is based on the assumption that the new standard rate will be lower than the current middle rate. We are naturally worried about the large numbers set to lose out on daily living. This is particularly important given our concerns about the mobility component, outlined later in the response. The survey shows that approximately 20% of respondents currently claiming the mobility component of DLA look set to entirely lose this entitlement.

1.3 The survey also flagged up where people were struggling to understand the scope or relevance of the activity. It is useful to consider people's comments about problems they had with understanding and applying the descriptors. Some of this feedback is included at relevant points through this response. These points are also important to consider when designing any application form or assessor guidance for PIP. In identifying where people struggle to self-report, steps can be taken to make sure people are supported to respond as fully as possible.

2. Fluctuating conditions

2.1 We are concerned that the proposals for fluctuating conditions are overly complex and still do not adequately address the impact of fluctuations. While we welcome the effort to address fluctuation, and the 'majority of days' rather than 'majority of time' approach, this will still be difficult to assess. This is particularly true when two or more descriptors apply at various points in someone's condition. It is common for individuals affected by mental illness to under-report the severity or

impact of their condition.[1] We are concerned that it will therefore be even more difficult for claimants to accurately report the impact of their condition in light of this complexity. As outlined in our response to the previous draft of the PIP criteria, we propose that the applicants should be asked about frequency, severity and duration to assess impact of fluctuations.

2.2 The method proposed in the draft criteria of assessing fluctuation also does not adequately reflect the episodic, acute nature of some people's experience of mental illness. In this case people can be severely unwell for less than 50% of days but then with support and self-management can manage their condition well for the remainder of the time. While this was captured well by the 'at worst' criterion in the Disability Living Allowance assessment, this has been lost in the new proposals. Again our recommendation to focus on frequency, severity and duration might better reflect this.

2.3 The proposed approach does not take into account the cumulative impact of fluctuations across a number of activities, which can result in significant barriers to independent living. There is also little flexibility in the criteria to take adequate account of interaction effects, where barriers for one activity may impact on ability to carry out another.

Recommendations:
Simplify the process for assessing fluctuating conditions to mitigate problems of self-reporting.

Consider measures of frequency, severity and duration to assess the impact of fluctuating conditions.

3. Managing therapy or monitoring a health condition

3.1 From our survey, it is clear that this activity is still not well understood despite the changes that were made. It also does not seem to reflect the experience of people affected by mental health conditions. Some comments from our survey respondents on this activity are below.

I don't need support to manage therapy, I need support to get me to have therapy. If I had someone with me, I'd go to therapy, but on my own, I just can't get it together.

I find this question difficult to answer as regards monitoring mental health condition it is difficult to define absolute frequency monitoring is required - for reason that level of monitoring fluctuates over time dependent on stability of mental health condition

Again, can't tick a box to answer it- if really manic I "don't need meds....."

[1] Slade, M., Phelan, M., Thornicroft, G. Parkman, S (1996) The Camberwell Assessment of Need (CAN): comparison of assessments by staff and patients of the needs of the severely mentally ill. *Social Psychiatry and Psychiatric Epidemiology*31, 109-113

My episodes can occur without warning, and rapidly escalate to a full blown psychosis over 2-4 days so I need supervision from friends, neighbours and mental health professionals to look for signs.

Again, it just isn't that straight forward. Both depression and hypomania can result in me forgetting to take medication. Or I can decide I'm fine and don't need it.

3.2 Another example may be seen in people who do not accept, or have a low awareness that, they have a mental health condition (sometimes referred to as lack of 'insight'). In these instances this might result in someone not managing therapy or monitoring their condition. This is not because it is not necessary, but because they believe they do not need it. Currently, they would not score any points for this activity. However they are clearly in a position where their health could deteriorate as a result of their inability to effectively manage their therapy or monitor their condition. Also, although the notes for this activity explain that supervision to avoid the risk of accidental or deliberate harm is accounted for, it is unclear how this will work. While supervision to manage therapy is addressed, people might not consider the supervision they need to prevent harm falling into this category. This activity also does not make reference to other interventions such as befriending,[2] peer support and self-management tools. The inclusion of these and other forms of support would ensure this activity better captured the needs of people affected by mental illness.

Recommendations:
The descriptors and notes for this activity need to be further developed to adequately reflect the experiences of people with a mental health condition.

Further consultation on this descriptor should be carried out with people affected by mental illness.

4. Engaging socially

4.1 We welcome the removal of a prescribed time period over which distress must take place for communication activities before it can be scored. However, we still have concerns that 'overwhelming psychological distress' is a high threshold at which to start considering the impact of an activity. This could exclude many people who face significant barriers to participation as a result of the stress and anxiety it can cause. This in turn could further isolate people from sources of support.

4.2 Many responses to our survey also commented on the difference between a familiar and unfamiliar social situation and the difference this can make on their ability to manage. This is a comparable distinction to that in the 'Planning and following a journey' activity. By introducing it into the scoring for this activity, a better range of experiences could be assessed as familiarity has a significant impact on levels of anxiety.

I am fine with people I already know but meeting new people causes too much anxiety.

[2] Recommended in NICE Guidelines for Bipolar Disorder (CG38) and Depression (CG90)

I tend to only go to places where I already know the people. I'm very wary of strangers.

Recommendation:
Reference to familiarity should be made in this activity and the threshold of overwhelming psychological distress should be reconsidered.

5. Financial decision making

5.1 We welcome the inclusion of this activity but have concerns about the weighting of it and the wording of the descriptors themselves. This activity is currently the only one of the daily living activities where scoring the highest descriptor does not result in a PIP award. This is in spite of the very vulnerable situation not being able to make financial decisions would place people in. The case study below illustrates this in regards to appointeeship.

Mrs A is an appointee for her son. She has made applications for ESA, DLA and HB on his behalf - filling in the forms, getting medical evidence and receiving the money on his behalf. Her son has a diagnosis of schizophrenia but has no insight into his condition. He therefore does not feel the need to seek medical help, is not taking medication and doesn't feel the need to claim welfare benefits for illness or disability. He is well presented and intelligent. However he has no concept of money and is unable to hold down a job because of his illness. Before Mrs A got appointeeship, her son was facing eviction as rent arrears were building up as he wasn't claiming housing benefit. She was having to support both herself and him financially out of her pension. Without her acting as appointee it is likely that her son would be street homeless with no income at all, therefore no ability to buy food etc.

5.2 As this case study demonstrates, it is unlikely this person would pick up points in other activities but there is clearly a high level of need. We believe that this activity needs to be weighted so that the higher levels of need result in a PIP award. We also believe that there should be an additional descriptor that addresses situations where people have appointeeship or power of attorney in place, which would score 8 or 10 points. It is important that both this high level of need and the challenges people face at a lower level are adequately addressed by this activity.

5.3 We also believe that assistance from another person needs to be taken into account within this activity. This is relevant for both simple and complex decisions and would better reflect the support someone might need. Prompting on its own does not seem appropriate for this activity as this will often not be enough for people. A number of respondents to our survey also mentioned issues around impulsiveness, disinhibition and motivation having an impact on their ability to manage finances. In these cases, for example, prompting might not be adequate and the intervention of another person might be necessary.

Recommendations:
The weighting for this activity needs to be increased so that scoring for the higher descriptors results in a PIP award. The scale needs to be increased with

higher descriptors referencing arrangements for appointeeship and power of attorney.

Assistance from another person should be taken into consideration when carrying out this activity.

Issues around motivation and impulsive, uninhibited behaviour will have a large impact on someone's decision making ability and should be considered.

6. Mobility component

6.1 We are very concerned that new PIP assessment will negatively impact people currently receiving the DLA mobility component because of mental health problems. We believe it could also disadvantage people who do not currently receive DLA but could benefit from this support. Over 80% of the current working age claimants of DLA for mental health receive the lower rate of the mobility component. Approximately 5% receive the higher rate.[3] An assessment that fails to recognise the mobility needs of people with mental health problems could disadvantage a large number of people. Our survey results suggest that 20% of people with mental health problems currently receiving DLA mobility will not receive the PIP mobility component.

6.2 We have a number of key concerns about the mobility component of the new assessment. There is only one descriptor (descriptor D, Activity 10) with an overt reference to mental health scores enough points to be awarded the mobility component. We recognise that having only one activity for the mobility component where mental health is considered is in line with Disability Living Allowance. However the points structure and descriptors for this activity reduce people's chances of scoring points for mental health. For the daily living component there are a number of activities where people can score points towards the proposed thresholds. We recognise that the daily living component encompasses a wider variety of activities than the mobility component. However there is a danger that people with mental health problems whose problems with getting around are not properly captured by the proposed descriptors will lose out.

6.3 We believe a more comprehensive definition of mobility should be introduced. There should be explicit reference to difficulties people face with using public transport. The time it might take for someone to prepare and feel able to leave the house is not taken into consideration in this activity. The stress and anxiety caused by travelling should be recognised as well as 'overwhelming psychological distress', which is again a high threshold at which to start considering the impact of an activity. We welcome the removal of a prescribed duration for this distress but are still concerned about the threshold. More overt reference should also be made to the impact of disinhibition or lack of insight on a person's ability to undertake a journey safely and reliably.

[3] DWP Tabulation Tool (August 2011) *Disability Living Allowance - all entitled cases Caseload (Thousands) : Main Disabling Condition by Mobility Award Type*

6.4 There is also a false divide between the components. For people with physical disabilities, there is a fairly clear distinction between barriers related to care (or daily living) and mobility. For people with mental health problems, we believe this distinction is less clear. Someone with a mental health problem may struggle to get around as a result of factors that currently fall with the daily living component. These include engaging socially, managing therapy or monitoring a health condition, making financial decisions. Similarly, problems someone with a mental health problem may face in getting around will have a significant impact on their daily living activities. We therefore believe that anyone scoring on descriptor B on Activity 10 should have these four points transferred to their daily living score if they do not qualify for the lowest rate of mobility. Otherwise, this substantial impairment/barrier will not be recognised in the PIP award simply on the basis that they experience a condition that does not clearly conform to the mobility-daily living divide that is built into the structure of the new benefit.

Recommendations:
A more comprehensive definition of mobility is needed to better reflect the experiences of people with mental health conditions.

The 4 points from 'Planning and following a journey' should be transferrable if someone is not eligible for the mobility component.

More overt reference could also be made to the impact of disinhibition or lack of insight on a person's ability to undertake a journey safely and reliably.

Who we are

Centre for Mental Health
Centre for Mental Health is an independent, national charity that aims to help to create a society in which people with mental health problems enjoy equal chances in life to those without. We aim to find practical and effective ways of overcoming barriers to a fulfilling life so that people with mental health problems can make their own lives better with good quality support from the services they need to achieve their aspirations. Through focused research, development and analysis, we identify the barriers to equality for people with mental health problems, we explore ways to overcome those and we advocate for change across the UK.

Hafal
Hafal is run by its 1,000 members - people with a serious mental illness and their families and carers. Every day our 160 staff and 150 volunteers provide help to over 1,000 people affected by serious mental illness across all the 22 counties of Wales. The charity is founded on the belief that people who have direct experience of mental illness know best how services can be delivered. In practice this means that at every project our clients meet to make decisions about how the service will move forward and the charity itself is led by a board of elected Trustees, most of whom either have serious mental illness themselves or are carers of a person with a mental illness. 'Hafal' means equal. Our mission is to empower people with serious mental

illness and their families to enjoy equal access to health and social care, housing, income, education, and employment, and to achieve a better quality of life, fulfil their ambitions for recovery, and fight discrimination.

Mental Health Foundation
The Mental Health Foundation is the UK's leading mental health research, policy and service improvement charity. We are committed to reducing the suffering caused by mental ill health and to help us all lead mentally healthier lives. We help people to survive, recover from and prevent mental health problems. We do this by carrying out research, developing practical solutions for better mental health services, campaigning to reduce stigma and discrimination and promoting better mental health for us all.

Mind
Mind is the leading mental health charity in England and Wales. We work to create a better life for everyone with experience of mental distress by:

- Campaigning for people's rights
- Challenging poor practice in mental health
- Informing and supporting thousands of people on a daily basis

A fundamental part of Mind's work is provided though our network of over 180 local Mind associations who last year worked with over 220,000 people running around 1,600 services locally. Services on offer include supported housing, crisis help lines, drop-in centres, counselling, befriending, advocacy, and employment and training schemes. Over 30,000 people are supported by our national telephone help lines. Welfare reform is a key issue for many of the people Mind has contact with.

Rethink Mental Illness
Rethink Mental Illness, the leading national mental health membership charity, works to help everyone affected by severe mental illness recover a better quality of life. We help over 52,000 people each year through our services and support groups and by providing information on mental health problems. Our website receives over 600,000 visitors every year. Rethink's Advice and Information Service helps almost 8,000 people each year and advises people daily with benefit claims.

Royal College of Psychiatrists
The Royal College of Psychiatrists is the leading medical authority on mental health in the United Kingdom and is the professional and educational organisation for doctors specialising in psychiatry.

The Scottish Association for Mental Health
SAMH is a Scottish mental health charity which provides an independent voice on all matters of relevance to people with mental health and related problems and delivers direct support to around 3000 people through over 80 services across Scotland. SAMH provides direct line-management to respect*me* (Scotland's anti-bullying service) and 'see me' (Scotland's anti-stigma campaign).