



## **Disability Living Allowance reform – Department for Work and Pensions Public Consultation - 6 December 2010**

### **Joint response from Centre for Mental Health, Hafal, Mind, Rethink, the Royal College of Psychiatrists and the Scottish Association for Mental Health**

#### **About Us**

##### ***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.

### ***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 through 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***

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 *respectme* (Scotland's anti-bullying service) and 'see me' (Scotland's anti-stigma campaign).

## Introduction

We welcome the opportunity to respond to this consultation. Our organisations have a considerable body of expertise in mental health and connected issues and come into contact with a huge number of people with mental health problems many of whom are in receipt of Disability Living Allowance (DLA) in recognition of the additional costs they face as a result of their disability. Through our combined experience and expertise, we offer a comprehensive perspective on the importance of DLA for people with mental health problems and what issues need to be considered as the reform process progresses.

As part of the process of producing this consultation response, we have conducted a survey on the Mind website of people with mental health problems, which yielded 178 responses, mostly from people currently claiming DLA. We also collected case studies of DLA claimants and asked for input from mental health professionals. The findings from these consultations will be referred to throughout our response.

## Preliminary comments

Before responding to the specific questions posed in the consultation document we feel obliged to make clear our concerns with some of the assumptions and imperatives driving the reform process. We do see a need to simplify many of the complexities of welfare benefits and welcome some of the changes proposed for DLA, such as expanding and updating the definitions for care and mobility. Nevertheless, we believe that some of the cited drivers of reform are unfounded or unclear, and that some of the stated imperatives of the reform process are contradictory:

- Whilst we accept the Government has set an imperative of cutting the deficit and that departments have been set specific targets for savings, we do not support the current approach of reducing costs taken to DLA reform. We believe that the stated aim of saving 20 per cent on the future budget of DLA is incompatible with the concurrent objective of creating a new assessment that accurately and objectively identifies who needs additional support from DLA (or Personal Independence Payments). We do believe that savings can be made from DLA; but to aim for a specific percentage of saving fundamentally undermines the objectivity of the assessment process and the clear need to provide support for the disability costs of many people in the UK.
- Although the imperative of making a 20 per cent future saving has been made clear elsewhere, the likely impact of this is not discussed sufficiently in the consultation document. There has been insufficient account taken of the likely knock-on costs for social and health services of reducing access to DLA for those who do not have “the greatest need”, as will inevitably be the case if these savings are to be achieved.
- We do not think that the analysis of why so many people are in receipt of DLA is sufficiently robust to justify the step of looking to reduce the future budget of the benefit. The focus seems to be simply on the fact that more people than originally expected are claiming the benefit. It does not seem to have been considered that these original expectations may have been wrong; that the number of disabled people has increased with the

population; or that the proportion of disabled people in the population has increased, as suggested in recent research.<sup>1</sup> It is also possible that as time has passed that more eligible people have applied for the benefit

- The assertion that “the complexity and subjectivity of the benefit has led to a wider application than was originally intended” does not seem to be based on any cited evidence. We agree that this is a possible cause but it is far from clear that it is the principle cause. Anecdotal evidence from people working in this field and from mental health service users suggests that, in fact, there are a huge number of people not claiming DLA who are eligible.
- There is a legitimate argument for reassessing claimants in order to gauge whether their condition has improved or deteriorated. However, we believe that this would be possible to do within the current system and it is certainly not sufficient cause in itself for wholesale reform.
- We agree that often people are confused about how DLA relates to work. However, while stating that this means that DLA “can act as a barrier to work” it also needs to be recognised that, by maintaining people’s independence, it can also keep work as a viable possibility for many people.
- We are also disappointed that the consultation period did not meet the standard 12 weeks (as agreed in the Compact between the Government and the voluntary/charitable sector)<sup>2</sup> and that it ran over the Christmas period, effectively limiting the ability of people to contribute meaningfully to the consultation process.

## Summary of response

In our response to the consultation on Disability Living Allowance reform the Centre for Mental Health, Hafal, Mind, Rethink, the Royal College of Psychiatrists, and the Scottish Association for Mental Health would like to highlight the following:

- We do not support the objective of an overall reduction target for the basis of DLA reform – the reform should be based on supporting disabled people to lead fulfilling lives and not primarily concerned with reducing costs.
- People with mental health problems, particularly those with long-term problems, are among the most socially excluded groups of people in the UK and should not be further disadvantaged by the effects of benefits reform. The impact of these changes to DLA needs to be looked at in the context of cuts to Legal Aid and social care and changes in health provision.
- Receipt of DLA has been important for many people with mental health problems, allowing them to face the additional costs of their conditions. Nonetheless, DLA has not been given to many eligible people with mental health problems, either because they do not apply for it or that they have not been awarded it despite their considerable disability costs. Access to the new benefit must reflect the needs of people with mental health problems and must be fair and equitable.

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<sup>1</sup> Trends in the Employment of Disabled People in Britain, Institute for Social and Economic Research, Richard Berthoud, January 2011

<sup>2</sup> The Compact 2010, December 2010

<http://www.thecompact.org.uk/files/143051/FileName/TheCompact.pdf>

- We are concerned about the focus on those with ‘greatest need’ – this may be counterproductive and significantly disadvantage those eligible to lower rates of benefit, who may still have high disability costs. People with high levels of disability do not necessarily have the greatest disability costs
- There is a need to recognise the variability and complexity of disability, especially for those with mental health problems. This has implications for the range of disability costs and the type of essential items and activities on which the monies are spent.
- If a formal face-to-face assessment of disability is to be employed, then we must learn lessons from the Work Capability assessment. In particular the assessment should be reliable and valid, be as simple as possible, comprehensive and easy to administer and use clinicians who are adequately trained and accustomed to assessing people with mental health problems. The process must be subject to rigorous scrutiny and evaluation.

## Response to Specific Questions

Below are our responses to the questions in the consultation document which we feel are relevant to the people we represent and to which we have evidence or opinions to contribute.

### **1. What are the problems or barriers that prevent disabled people participating in society and leading independent, full and active lives?**

Mental health problems are recognised in statute as a disability but due to their nature they are often less visible than physical disabilities. However, it is the case that mental health problems are no less debilitating than physical health problems<sup>3</sup>.

Beyond the direct impact that mental health problems can have on a person’s ability to function day-to-day, the stigma and misconceptions associated with mental health problems mean that many people experiencing them are marginalised and ostracised from society. People with mental health problems, particularly those with long-term problems, are amongst the most socially excluded groups in the UK.<sup>4</sup> They are excluded from material resources, productive activity, social and neighbourhood relations, civic participation and health services, In common with other people with disabilities they are likely to live in poverty, having less income, more debt and financial hardship than those without mental health problems.<sup>2</sup>

Associated with these domains of exclusion, people with mental health problems face a myriad of barriers related to stigma and discrimination. For example, they may be discriminated against in the fields of employment, education and housing. Only about 20% of people with severe mental health problems and around 50% of those with less serious problems are in paid employment, yet 80% want to work.<sup>5</sup> The low rates of employment for people

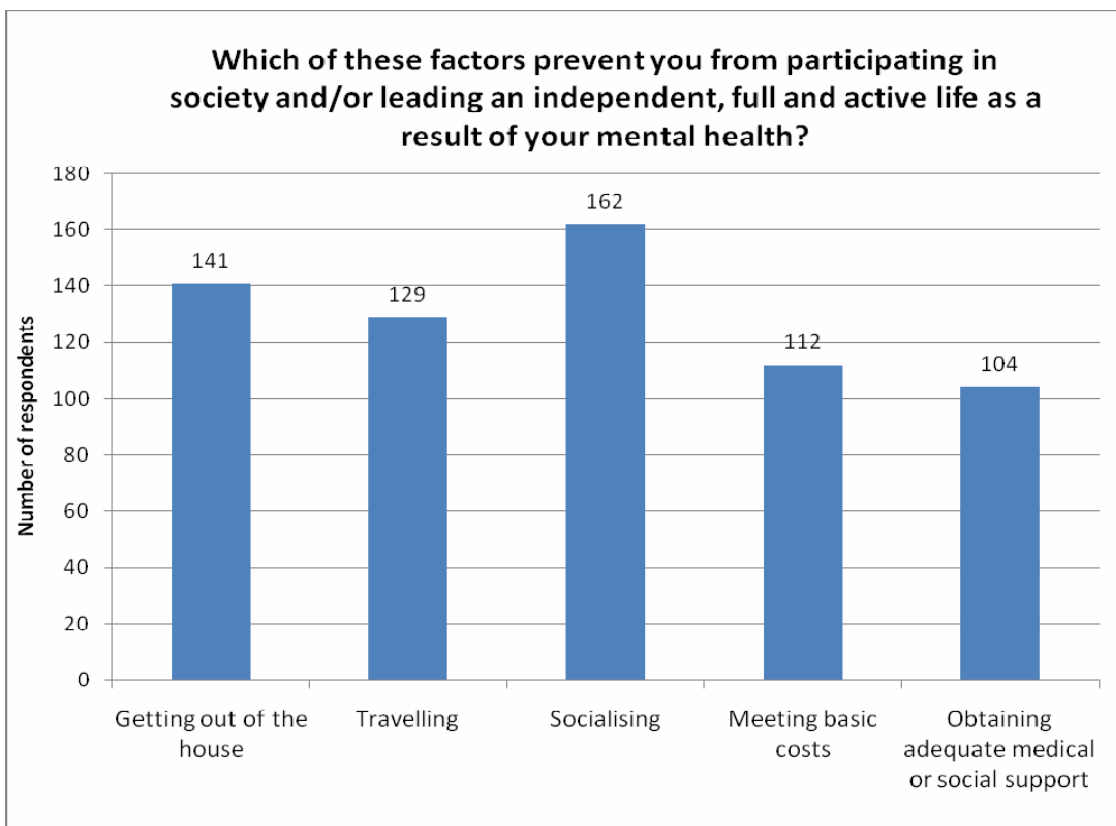
<sup>3</sup> Scott, K.M., Von Korff, M., Alonso, J. et al (2009) Mental-physical comorbidity and its relationship with disability: results from the World Mental Health Surveys, (2009), *Psychological Medicine*, 39, 33-43.

<sup>4</sup> Boardman, J., Currie, A., Killaspy, H., Mezey, G. (2010) *Social Inclusion and Mental Health*. London: RCPsych Publications.

<sup>5</sup> Fit for Purpose: The Reform of Incapacity Benefit IPPR, Stanley K & Maxwell D, 2004.

with mental health problems could be the result of a number of factors, including a combination of stigma and discrimination, low expectations, and a lack of appropriate supports. It could also be the result of inflexible or inadequate organisational procedures and practices; recent research has revealed that 72% of workplaces still have no formal mental health policy.<sup>6</sup> The Government has recognised these issues through its funding for the Time to Change campaign and through its Mental Health Strategy.

As part of our survey for this consultation, we asked which of a selection of factors prevented the respondents from participating in society and leading independent, full and active lives as a result of their mental health. For each of the five areas we identified, well over half the respondents agreed that these areas were problematic for them. Some specific issues, such as difficulties socialising, were identified by almost all the respondents as a problem.



These data reinforce other findings on the social exclusion of people with mental health problems, showing that they face a whole array of barriers that prevent them from participating in society and living independently as a direct consequence. In addition, external factors such as stigma and discrimination can further limit people’s ability to participate meaningfully.

**2. Is there anything else about Disability Living Allowance (DLA) that should stay the same?**

We welcome the commitment to maintain with PIP some of the most important features of DLA: a non-means-tested benefit that can be used as the individual

<sup>6</sup> Mental Health: Still The Last Workplace Taboo?, Shaw Trust, December 2010

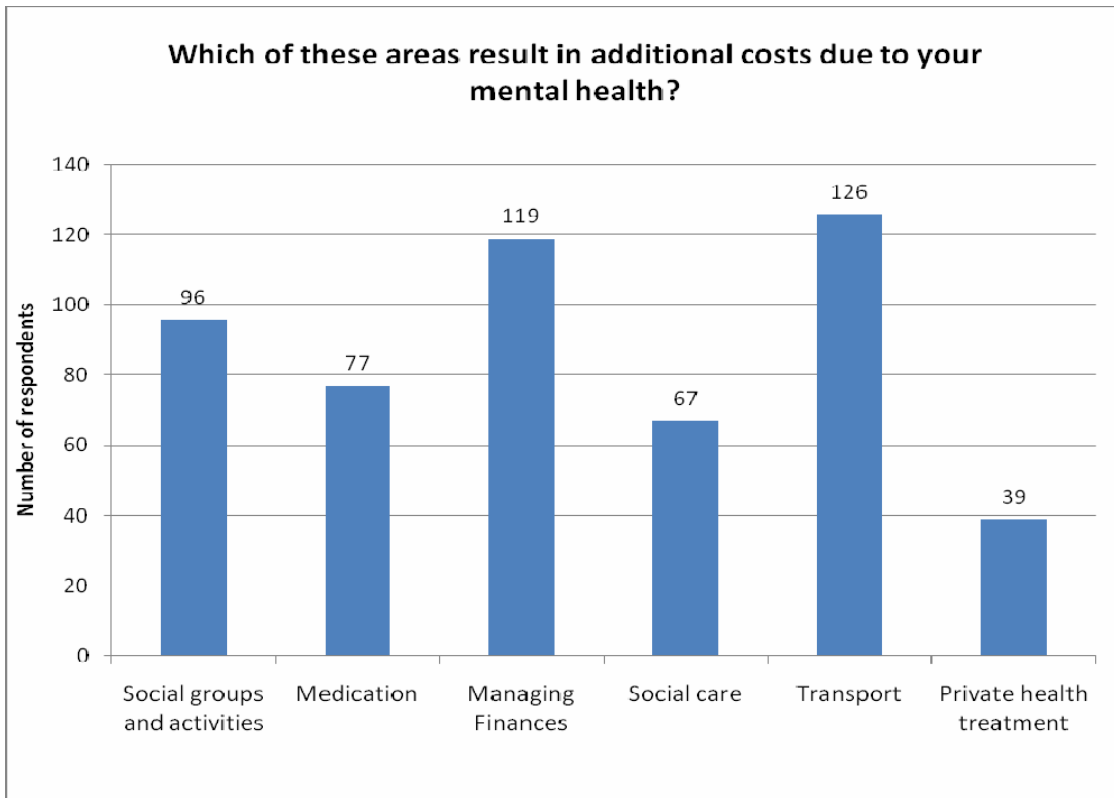
chooses, in recognition of the extra costs incurred by disabled people due to their disability.

The importance of DLA for people with mental health problems is reflected in this statement from a person with bipolar affective disorder:

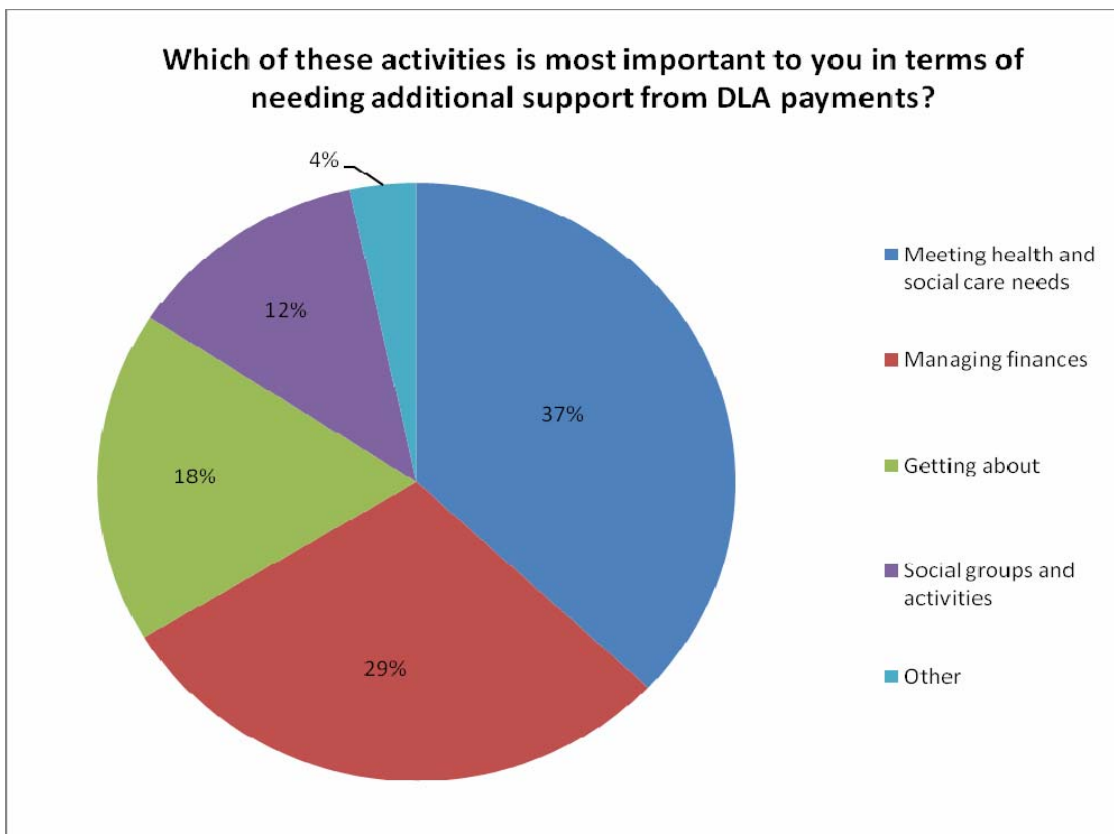
*“I suffer from bipolar disorder and often become very paranoid and sometimes suicidally depressed. I spend a lot of my DLA on my phone and Internet bills because I need a lot of reassurance from family and friends who can't be there in person. Without those long phonecalls I would be at much greater risk of harm. Having DLA also means that when I am well enough I have money which allows me to go out for coffee with friends who are earning, or to take small courses. Doing this boosts my mood and helps keep me out of hospital. DLA is also a cushion for me because when I am hypomanic I tend to overspend and I can't always return the unwanted items. I spend more time than most people in my home because I am not fit to work most of the time, so DLA is useful for extra heating costs. Also, when I am very paranoid, I am unable to use public transport. DLA pays for taxis to appointments or to get shopping. If I did not get DLA, I would live in fear of getting into financial difficulty, which would make my illness worse. I spent two years in hospital. I have now managed to stay out of inpatient services for most of the past 18 months, but I am sure that without the boost DLA gives me, I would have cost the NHS much more during that time. If I lose it - which I fear I will - I have no doubt that my mental health will deteriorate.”*

### **3. What are the main extra costs that disabled people face?**

There are a number of ways for people with mental health problems to address the barriers to involvement and independence identified earlier. However, particularly in terms of increasing independence, direct payments which allow the individual to overcome these barriers themselves are hugely important. In looking to overcome these barriers, people with mental health problems can face substantial additional costs. We asked respondents to our survey which particular areas led to increased costs and the response once again showed that people often face multiple issues. Of particular significance were meeting transportation costs, taking part in social groups and activities and being able to manage finances independently. People can face additional transportation costs due to issues such as anxiety or agoraphobia; can need additional support to engage socially such as through attending groups; and can have difficulties managing their finances as a result of the mental health problems or face extra costs not directly linked to condition or impairment such as higher electricity bills due to spending more time at home.



We also asked which activities were most important in terms of needing additional support from DLA. Again, the response was very mixed, highlighting the variability of people's needs. This also suggests that a wide array of areas need to be covered by the new assessment in terms of gauging where and how an individual might face difficulties or barriers which DLA (or PIP) could help them to overcome.



One respondent noted the importance of DLA for getting around and the costs of some specific aspects of her disorder:

*“I use my DLA to help me get around in my car as I am unable to use public transport. It also enables me to communicate via the internet with the council, utility companies etc and to use the internet to buy things I need as I find it hard to talk to people on the phone, face to face or to go to shops. I am unable to wash my clothes as I cannot touch wet clothing so the money helps me to be able to get my clothes cleaned. I have to be able to buy first aid equipment to deal with my self harm but prefer to deal with the injuries myself rather than seek help. DLA gives me a lot of independence that I wouldn't have without it. It is an essential aspect of my income and ability to cope. Without it I have no doubt that my mental health would deteriorate to a level that would leave me either totally dependent on other people or would leave me hospitalised.”*

Another reinforced this and also pointed to its importance for keeping well:

*“My DLA enables me to go out when I am too unwell to use public transport on my own. It pays for the fare of someone to accompany me or for a taxi. It also enables me to attend activities that help to keep me well/balanced and pay for courses that I hope will eventually help me get back to work in some capacity. If I need someone to go somewhere with me I can pay for that/towards that. Without DLA I would be stuck inside in my own and have more frequent relapses which are a danger to my life & ends up in a lengthy hospital stay. The less frequent serious relapses the better the chance of me living a life. I have bipolar affective disorder/manic depression. Also, I do not qualify for free prescriptions so it helps towards the cost of my annual prescription card as I have 3 types of meds for mental health & some meds for physical health.”*

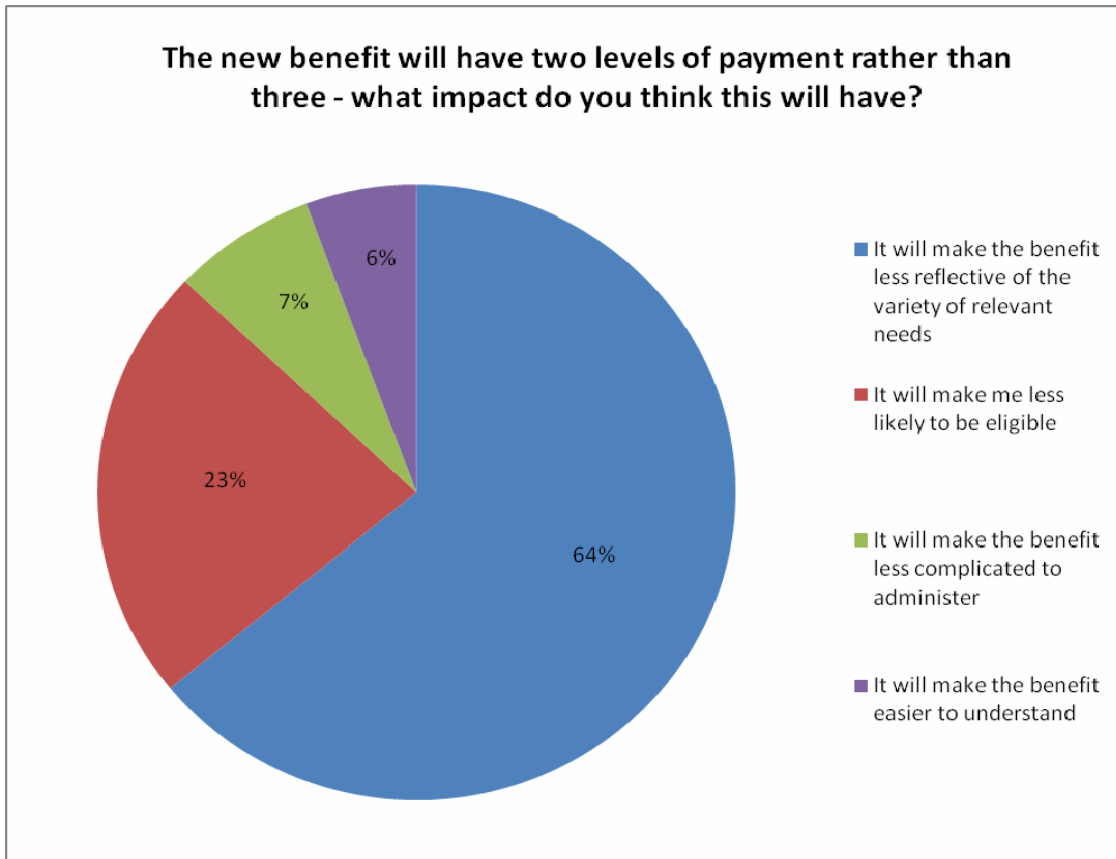
#### **4. The new benefit will have two rates for each component:**

- **Will having two rates per component make the benefit easier to understand and administer, while ensuring appropriate levels of support?**
- **What, if any, disadvantages or problems could having two rates per component cause?**

We welcome moves to help simplify the benefits system but, at the same time, the system does need to recognise the variety and complexity of disability and particularly mental health problems. Considering previous Government announcements regarding the intention to cut the future budget of DLA (or PIP) by 20 per cent, it must be assumed that it will be those on the lower rates of DLA that will lose out in this restructuring.

Discussion with mental health professionals has also revealed that a common experience is that people using mental health services are often not receiving DLA despite being eligible for the benefit. The increased presence of Welfare or Benefits Advisors working in, or alongside, Mental Health Teams has allowed more people to successfully apply for DLA and to improve their access to community or other opportunities. This applies to all levels of the existing benefit.

When we asked our survey respondents what they thought the impact of a reduction in the number of rates would have, the majority of respondents thought that the most significant impacts would be that it would render the benefit less reflective of the variety of relevant needs and that it would make them less likely to be eligible. Only 6% of claimants thought that the primary impact would be to make the benefit less complicated.



We are very concerned that people with mental health problems currently receiving lower rates of DLA may not qualify for PIP. We believe that this would be not just deeply damaging to those people concerned but also a mistake in terms of looking to reduce expenditure. Although such claimants may be receiving relatively small amounts of DLA, our experience suggests that this money can be instrumental in helping them to remain involved in their local community and staying well and out of hospital. Activities such as attending a class or travelling to a community group may seem relatively inconsequential but can have an immensely positive impact on people’s lives. For this reason, it should also be recognised that removing this support may well lead to deterioration in many people’s conditions, the knock-on cost of which, for health and social care services, would eclipse the savings made within the welfare budget.

The dangers of equating the levels of disability and the costs of disability may have been seen in the recent Scope survey of over 800 disabled people (including some with mental health problems) which showed no correlation between the need for care and support and disability-related costs and there was no single factor identified that could act as an appropriate proxy for total disability cost.<sup>7</sup>

<sup>7</sup> Wood, C. & Grant, E. (2010) *Counting the Cost*. London: DEMOS.

Importantly, those with the highest disability spending were those who were likely to be the most deprived and socially excluded (e.g. unemployed, living in poor accommodation, having no transport, savings or bank account, being in debt). It is therefore likely that those with a low functional impact of their disability, but who experience high costs, will miss out if the proposed assessment focuses solely on the level of disability.

The proposed assessment of eligibility will need to consider how impaired the claimant is; the cost of reducing the impact of that impairment measured in terms of the individual's ability to participate; and how effective this intervention will be. When doing so it will be important to recognise that people with less severe impairments can often derive huge benefit from relatively minor financial assistance. Focusing resources only on those with the most substantial and tangible impairments may seem intuitively acceptable, but the risk is that many with less obvious or severe impairments will lose benefits which have allowed them to access resources essential to maintain their functioning and to prevent relapse or social deterioration. High costs are particularly incurred during a relapse or acute episode and these costs have high impact on the individual and their family or carers, as well as on health and social services (especially if an inpatient admission is necessary). The costs of this to the person, to services and to society need to be borne in mind when considering the savings to the benefits budget.

#### **5. Should some health conditions or impairments mean an automatic entitlement to the benefit, or should all claims be based on the needs and circumstances of the individual applying?**

Although we understand the motivation for assessing people based on their specific circumstances, in-keeping with the social model of disability, we are concerned about the impact of the assessment process on people with severe mental health problems. This may not mean that someone with a diagnosis of, for example, schizophrenia should necessarily be automatically entitled. However, it is important that the initial stages of the assessment process, prior to the proposed face-to-face assessment are able to identify someone with severe need and make an award based on existing evidence rather than requiring the individual to go through a process that may well be very stressful and detrimental to their health. The existing automatic entitlements to higher rate DLA seem to be an efficient and effective way to decide upon entitlement in these cases and it would not be efficient to ask people to go through the assessment process when there is a clear entitlement to the benefit.

#### **6. How do we prioritise support to those people least able to live full and active lives? Which activities are most essential for everyday life?**

We welcome the move to reclassify the 'Care' component as 'Daily Living', in recognition of the variety of activities that can help someone achieve independence and inclusion. We also welcome the recognition that the 'Mobility' component shouldn't simply apply to those with physical difficulties with getting around and needs to also look at other factors that may prevent

someone from being able to get around, such as anxiety, disorientation or social withdrawal.

It is sensible that levels of support be reflective of the impact that disabilities have on day-to-day living and the associated costs. However, the question of which activities are most essential for everyday life is subjective, and the answer will be unique to the person concerned. It is, therefore, not possible to quantify the value or necessity of any particular activity; for example, one person may hold visiting family as being 'essential' while another person may not.

In deciding which activities are 'essential', we would refer to International human rights standards and instruments, such as the UN Convention on the Rights of Persons with Disabilities. This Convention builds on existing international human rights instruments in order to explicitly reaffirm the human rights of disabled people. The Convention encompasses civil and political, as well as economic, social and cultural rights. These rights cover all areas of life including: personal mobility; health; education; work; recreation; and provision for equal recognition of disabled people before the law.

People have a right to social security which supports an adequate standard of living. To be human rights compatible, the welfare benefits system cannot be administered arbitrarily or on a discriminatory basis. While amounts of support may vary, any person who is identified as having a disability should be entitled to receive support appropriate to their needs.

A DWP review<sup>8</sup> comments that the costs to a disabled person of maintaining the same standard of living as an otherwise 'similar', non-disabled person depends on three factors:

- The amount of additional need they have as a result of their disability;
- The level of provision of free/subsidised services, by statutory or voluntary organisations;
- The effect of their disability on income, for example, disabled people generally have lower incomes than non-disabled people (as they are less likely to be employed).

This highlights the need for investment in mental health services and the voluntary sector, as well as meaningful action to address the barriers to employment for disabled people. It also indicates that testing the functional impact of a person's disability will not account for disability related costs driven by factors such as employment status and housing, and will leave some people without support.

## **7. How can we best ensure that the new assessment appropriately takes account of variable and fluctuating conditions?**

We are deeply concerned that the new assessment could replicate some of the problems seen in the Work Capability Assessment (WCA) – namely, that it may be insensitive to mental health needs and/or inaccurately

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<sup>8</sup> Review of the existing research on the extra costs of disability, 2005, DWP Working Paper 21.

reflect the impact that mental health problems can have on daily living. The WCA (and its predecessor) have been criticised for their inaccuracy and the poor quality of the interview process and Professor Harrington's Independent Review<sup>9</sup> recommended that the descriptors should be examined, in particular how they account for other fluctuating conditions.

It is likely that there is no single way of taking account of variable and fluctuating conditions and that several methods should be considered:

- a. The assessment should be sufficiently robust to deal with either the variation of the conditions, or the variability of symptoms. For example, a person with a mental health problem may find that 30% of the time their mood is low and at other times they cannot concentrate or at other times they are irritable or have to withdraw to deal with their auditory hallucinations. Perhaps none of these factors, on their own, may be severely incapacitating, but together they are sufficient to affect their overall functioning. The same may apply to the variation of these individual symptoms.
- b. Any assessment of functioning should ask about severity, duration and frequency rather than simply trying to gauge an impairment based on simple and one-dimensional proxy measures
- c. For those with variable conditions they may be less incapacitated on their better days, but on their bad days they may function poorly. Symptoms may be so severe on the minority of days that they need to be given greater weighting.
- d. The assessment should be able to evaluate variability in several ways and use these methods to develop a judgement as to the combined effects of these fluctuations. These multiple ways could include not only the assessment of a 'typical day', but also a 'typical week'. A judgement should also be made of the claimant's functioning at its worst, which should include what they are like during an acute episode of their illness. Whatever ratings are used could be assessed as to how often they apply, and the worst case scenario could be used to provide a reliable rating. The subjective components of their problems could be assessed in a similar way – subjective experiences potentially include: overall distress experienced; chaotic thinking, difficulty organizing self or routine; feeling overwhelmed; tolerance for frustration; self confidence; fear of others' expectations; debilitating side effects of medication; and difficulty coping with stress. The use of a semi-structured format to the interview as outlined above would also facilitate this process.
- e. The assessment should reflect the nature and severity of variations in mental health conditions. At the very least, we would like individuals to be provided with a greater explanation of how the effect of fluctuating conditions is assessed in the new assessment. This would allow individuals to be clear in explaining how their condition does vary.
- f. To account for fluctuating conditions, equal weight must be given to evidence supplied by the professionals who are providing ongoing treatment and support to claimants. A person's medical history should also be taken into consideration; for example, information about recent hospital

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<sup>9</sup> Harrington, M. (2010) An Independent Review of the Work Capability Assessment. London: The Stationery Office.

admissions could be useful in capturing the true impact of a fluctuating mental health problem.

- g. The final decision makers must have a full understanding of people's individual circumstances. Evidence should be sought from specialists, such as community psychiatric nurses, who might see a claimant on a regular basis and who could provide information about what additional needs that person had day-to-day.
- h. The 'independent healthcare professionals' conducting face-to-face interviews must have adequate mental health expertise. It is also important that people are able to explain what it is like when they are both well and unwell, and how frequently each occurs. Some people may find it difficult to articulate exactly how a particular mental health problem affects them, which can be made more challenging when providing details on complex forms or when people are unsure as to what information is important. For many people, particularly those with a severe and enduring condition, being encouraged to have an advocate or someone with them for support at face to face meetings would be welcome.
- i. It is important that assumptions are not made about applicants based on appearance and behaviour on the day of the assessment. People's conditions can vary dramatically and our experience suggests that they are far more likely to act positively in an assessment than to 'play-up' their impairments.
- j. The assessment must also be adapted for people who have physical problems as well as mental health problems. The additive effect of these should be considered and steps should be taken to ensure that the mental health problem is not ignored.

Given the findings on the lack of a clear relationship between level of disability and disability costs<sup>7</sup>, the assessment should consider not only the level of functioning but its costs. It may also need to take into consideration the circumstances of the applicant which affect disability costs. Overall, the assessment must be both valid (correctly measuring what it is intended to measure) and reliable (provides consistent and reproducible results). It should also be as simple as possible, comprehensive and easy to administer. It must be a fair and just process and be subject to a thorough and scientifically rigorous evaluation.

#### **8. Should the assessment of a disabled person's ability take into account any aids and adaptations they use?**

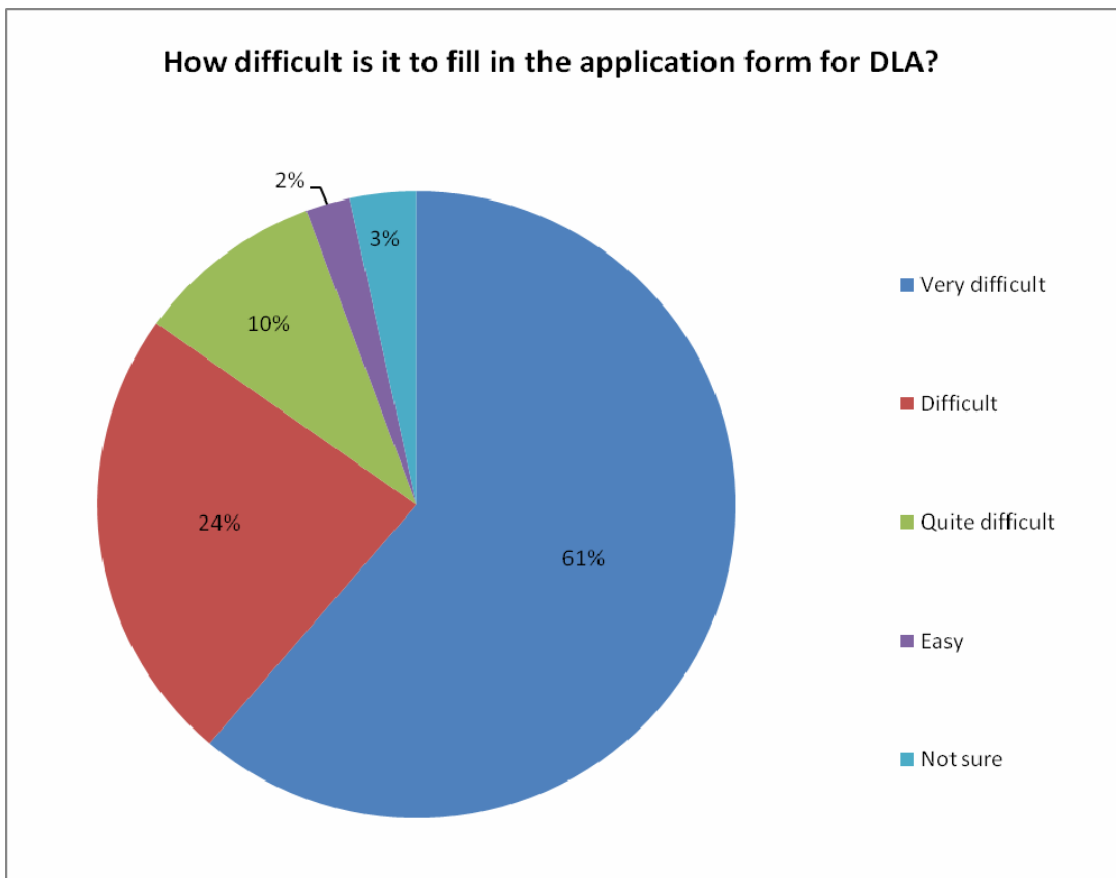
- **What aids and adaptations should be included?**
- **Should the assessment only take into account aids and adaptations where the person already has them or should we consider those that the person might be eligible for and can easily obtain?**

Since aids and adaptations are more likely to be of relevance to people with physical disabilities, we do not have significant input to contribute on this issue. However, this may well be an issue for people with multiple disabilities and we do believe that it is important that a situation is not created where there is a disincentive to take on such changes due to the possible impact on eligibility for the benefit.

**9. How could we improve the process of applying for the benefit for individuals and make it a more positive experience? For example:**

- **How could we make the claim form easier to fill in?**
- **How can we improve information about the new benefit so that people are clear about what it is for and who is likely to qualify?**

We have heard from many people that the application form for DLA is complex and that it often does not seem relevant to their condition and the barriers and impairments they face. This is also captured in a previous report from the Citizens Advice Bureau.<sup>10</sup> We asked our survey respondents how difficult they found the application to fill in and the vast majority stated that it was either difficult or very difficult.



It is vital that a redesign of the form takes the needs of people with mental health problems into full consideration, including through thorough and meaningful consultation of people with mental health problems.

In addition to the evidence referred to earlier that DLA is under-claimed, the fact that only around 16% of those claiming DLA due to mental health problems (compared to, for example, 46% of Incapacity Benefit claimants)<sup>11</sup> suggests either that the benefit is not designed adequately to support these people or that there is a lack of communication to them that they may be eligible. This mirrors issues, for example, with Access to Work and Personal Budgets where there is low uptake amongst people with mental health

<sup>10</sup> Citizens Advice Bureau (2006) *What the doctor ordered? CAB evidence on medical assessments for incapacity and disability benefits*. London: CAB.

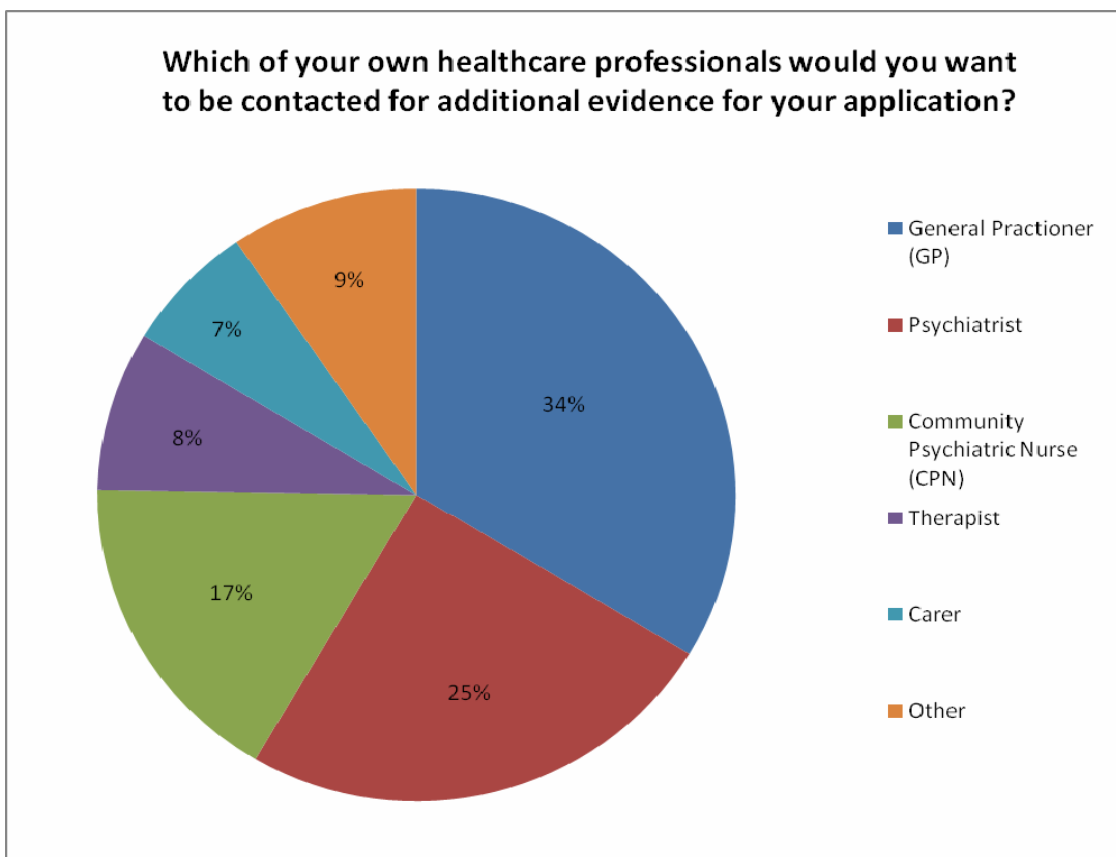
<sup>11</sup> DWP Statistics Tabulation tool

problems as it is not always clear that the assistance is relevant to them; even though it can be hugely beneficial to those who do claim.

We would therefore also recommend greater efforts to make clear that this is a benefit suitable for people with mental health problems both directly to potential claimants and to those who deal directly with them, such as health and social care staff and DWP staff within Jobcentre Plus.

### 10. What supporting evidence will help provide a clear assessment of ability and who is best placed to provide this?

Another recommendation of the Harrington review was that the use of other healthcare professionals in the assessment process be explored. In the case of mental health problems, it takes a great deal of time, contact, experience and expertise to get anywhere near fully understanding the impact that a mental health problem can have on any particular individual. It is therefore vital that evidence is collected routinely from relevant health or social care professionals who have had substantial contact with the applicant.



As the chart above shows, the response to our survey question on who people would want to be contacted to provide additional evidence shows that there is no one type of professional who is best placed to do so. The most relevant and knowledgeable professional depends very much on the personal relationships, experience and care pathway of the individual concerned. It is therefore vital that applicants are asked which professional is contacted to provide additional evidence and that this request is followed.

## **11. An important part of the new process is likely to be a face-to-face discussion with a healthcare professional.**

- **What benefits or difficulties might this bring?**

People experiencing mental distress have reported, to all of our organisations, experiencing face-to-face Work Capability Assessments where they were treated with a lack of dignity and respect; where their answers were inaccurately recorded; and where assessors demonstrated little to no understanding of mental health. Many also felt that they were not given the opportunity to explain the impact that their mental health problem had on their daily lives, instead being asked a series of closed questions. These reports echo those witnessed by the Citizens Advice Bureau.<sup>12</sup>

Although we are aware that Ministers and civil servants have looked to distance the new PIP assessment from the WCA, it is hard to avoid the reality that it does seem to closely resemble aspects of this heavily-criticised assessment. The use of a face-to-face 'discussion' with a healthcare professional does mean that the assessment will have a medical feel to it, and the likely use of Atos or a similar organisation as contractors will provoke concerns for many service users and their representative organisations. A recent Disability Benefits Consortium survey shows that 76% respondents with mental health problems strongly agreed that the stress and anxiety of a medical assessment made their health worse and a further 22% agreed with this statement.

It is important that the problems of the WCA are not repeated in the new assessment. These include:

- a. Poor quality assessments carried out by the clinical assessors. These do not give sufficient consideration to mental health problems, were often hurried, that many clients reported encountering rude or insensitive examining doctors, and that reports were inaccurate and took answers out of context.<sup>10</sup> The CAB also found repeated evidence of people with severe mental health problems being found fit for work, that the impact of mental health problems was being underestimated in the presence of coexisting physical problems, and that people's mental health difficulties were downplayed.<sup>12</sup>
- b. Factors contributing to the poor quality of assessments include<sup>9</sup>: the accuracy of the medical history in the clinician's report; distortions of what they were told in the interview; poor questioning by the clinician; inadequate recording of claimants' responses; a failure to observe accurately; a lack of understanding of the criteria; poor recording of variable conditions; the downplaying of the severity of conditions; and overuse of referral for repeated medicals.<sup>12</sup>
- c. Clinical assessors often had a poor awareness of mental health problems. People attending consultation events facilitated by Mind and Rethink, during the development of the original WCA in 2007, highlighted that assessors tend to make judgements on a person's capability based on their

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<sup>12</sup> Citizens Advice Bureau (2010) *Not working. CAB evidence on the ESA work capability assessment.* London: CAB.

- appearance or ability to articulate their problems rather than on their capability to work as measured by the WCA.
- d. There are reports of claimants who are assessed being frequently confused about the purpose of the medical assessment and not understanding why the doctors performing the assessment reach a different conclusion to their own doctor. Communication about the assessment needs to be more accessible and provide a clear explanation of the purpose of the assessment should be provided.

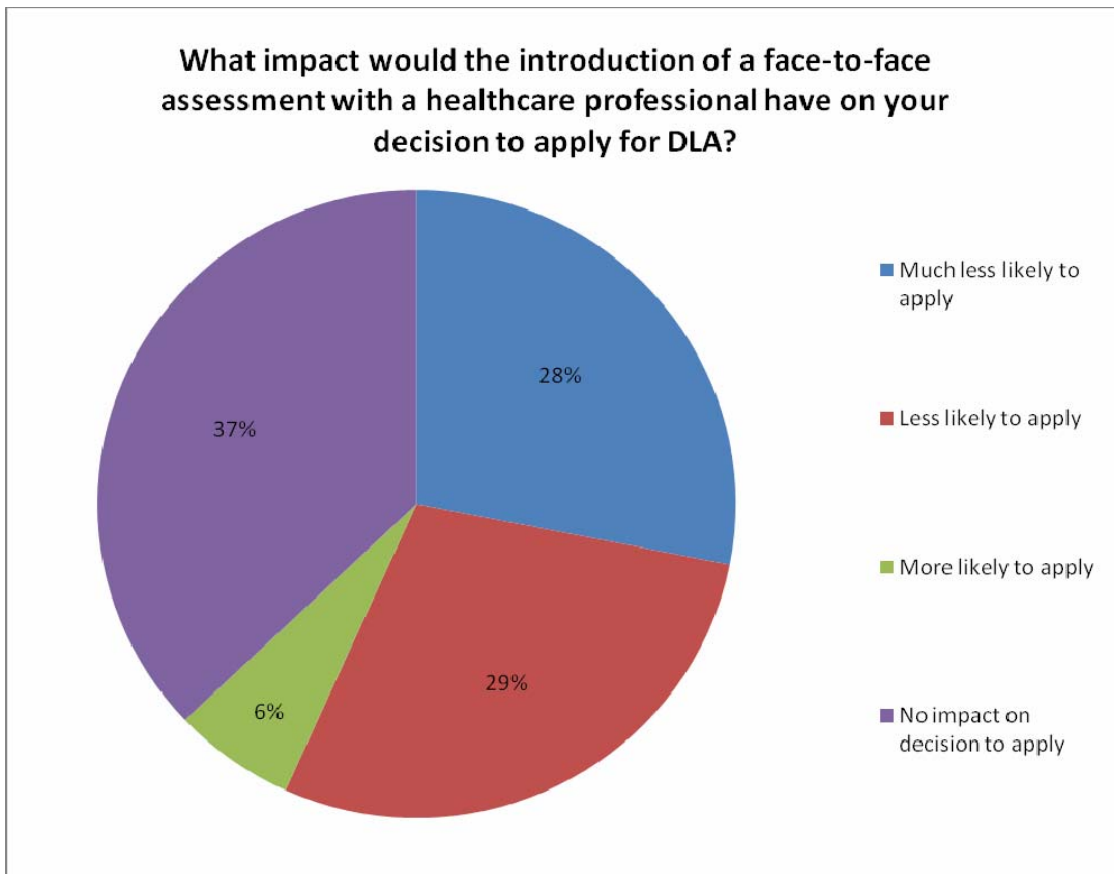
The evidence gathered on the WCA assessments over the years points to the need to provide good quality training to clinical assessors and to properly evaluate the ability of the medical assessors to accurately assess the functioning of the claimants. It also suggests that there may be systematic problems in relation to those with mental health problems. Some of this may be addressed by improvements in the clarity of the assessment. The assessment interview could be made into a semi-structured interview which would aid the systematic collection of data (as with many research interviews) and may also help improve the interaction of the assessing clinician and claimant. Such an interview design would also allow for improved training of the assessors and a ready means of evaluating the quality of their interviews and rating. We recommend that a thorough evaluation of the competence and training of the assessors is undertaken.

Some people with mental illness are not able to manage their own benefit claims. This might be because they lack insight and do not accept that they have a mental illness. It might be because they are too ill to organise the claim, or their life has become chaotic. For example:

*Mr A is a retired person, widower, with a son in his 40s who has a long standing history of schizophrenia. He spent many years in and out of hospital and had problems engaging with mental health services when in the community. He had no insight into the fact that he was mentally ill. He became homeless in 2006 and moved in with his father because he had nowhere to live and no benefit. After this, the pair lived on the father's retirement pension alone for 9 months.*

In these circumstances, a face to face interview is not appropriate. Instead, appointeeship should be promoted as an option to family members. The appointeeship system should be reformed to ensure that people like Mr A's son receive the financial support they need. JCP literature states that it is necessary for the beneficiary to be interviewed face to face to apply for appointeeship. In many cases, this is not possible, for the same reasons that they are not claiming benefit in the first place. This stops carers from applying and families from receiving vital financial support.

The majority of respondents to our survey, when asked what impact the introduction of a face-to-face assessment would have on their decision to apply for DLA, stated that it would make them less or much less likely to apply. This is a deeply concerning response and suggests that serious thought needs to be given about whether this is the most appropriate format of assessment; who is contracted to provide this service; and how the new assessment is communicated to current and potential applicants.



Careful consideration needs to be given as to whether face-to-face interviews are the most cost-effective means of assessment for PIP applicants. These interviews are costly and can be inaccurate if the training and skills of the assessors is not thoroughly addressed. They also cause considerable distress to applicants. If other methods (eg paper assessments) are as accurate then they should be carefully considered.

- **Are there any circumstances in which it may be inappropriate to require a face-to-face meeting with a healthcare professional – either in an individual’s own home or another location?**

We would strongly recommend that people who are not able to get to any interview/assessment centre (e.g. those with severe anxiety, agoraphobia, social withdrawal or similar conditions) should be offered a meeting at home.

## **12. How should the reviews be carried out? For example:**

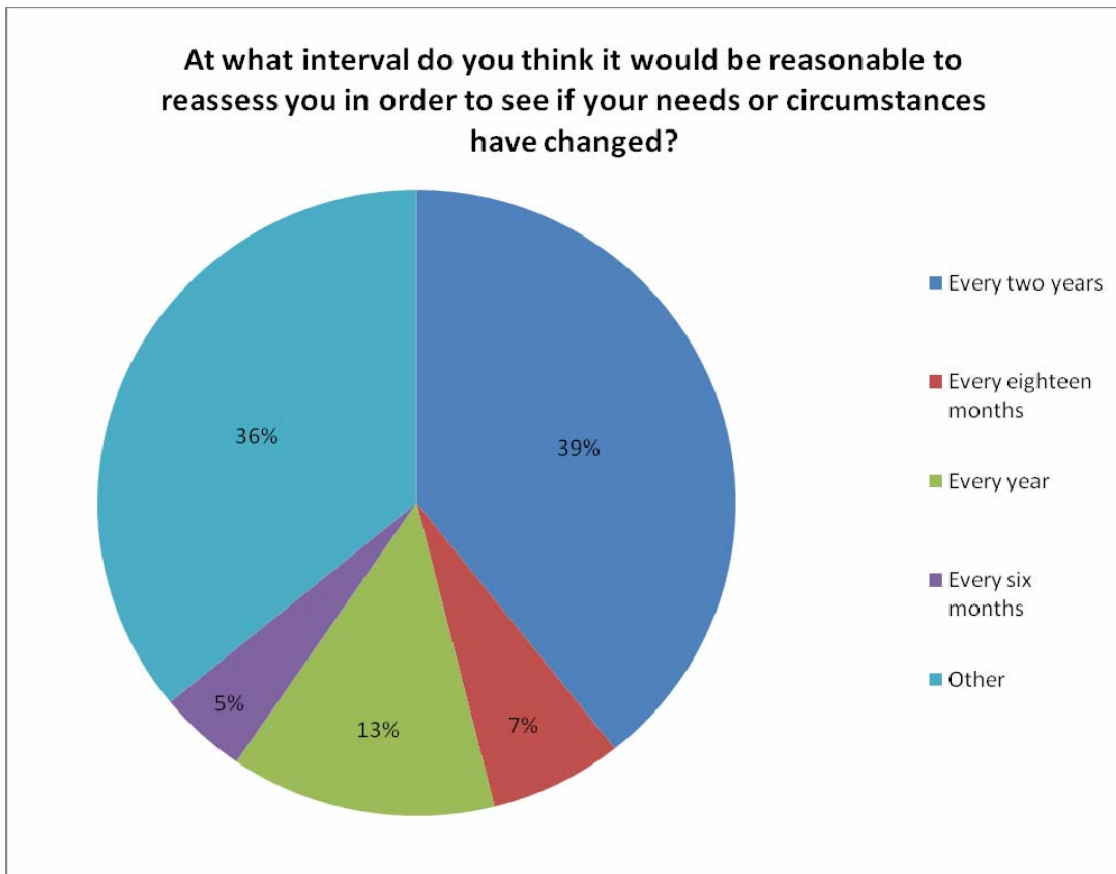
- **What evidence and/or criteria should be used to set the frequency of reviews?**
- **Should there be different types of review depending on the needs of the individual and their impairment/condition?**

We recommend that, wherever possible, claimants are reassessed through evidence submitted by health and social care professionals rather than going through another face-to-face assessment, which may be expensive, stressful and counterproductive. If the initial face-to-face assessment, in combination

with the original additional evidence provided, is sufficient to establish the needs and barriers of the applicant, then updates from relevant health and social care professionals should be adequate to gauge whether these needs and barriers have changed substantially. If this additional evidence suggests that there has been a substantial change in the individual's condition, then it may be worth considering whether their PIP award needs to change. However, if the report is that there has been little change in their condition then it is unlikely that there needs to be a change in their award level.

As discussed in question 13, people's conditions can vary dramatically and so it makes little sense to try and reassess the impact of these conditions on a very frequent basis. The recovery process from a mental health problem can be long and difficult, with relapses along the way. It is therefore important that people are given the time to fully recover and that, if DLA is helping with this process, the benefit is not removed at the first sign of improvement. There also needs to be consideration of how stressful the process of reassessment could be for people and how this might impact on their mental health.

Our survey results on this issue support these suggestions, with most people supporting the option of reassessment every two years (though many more selected the 'other' option and suggested longer periods of around five years).

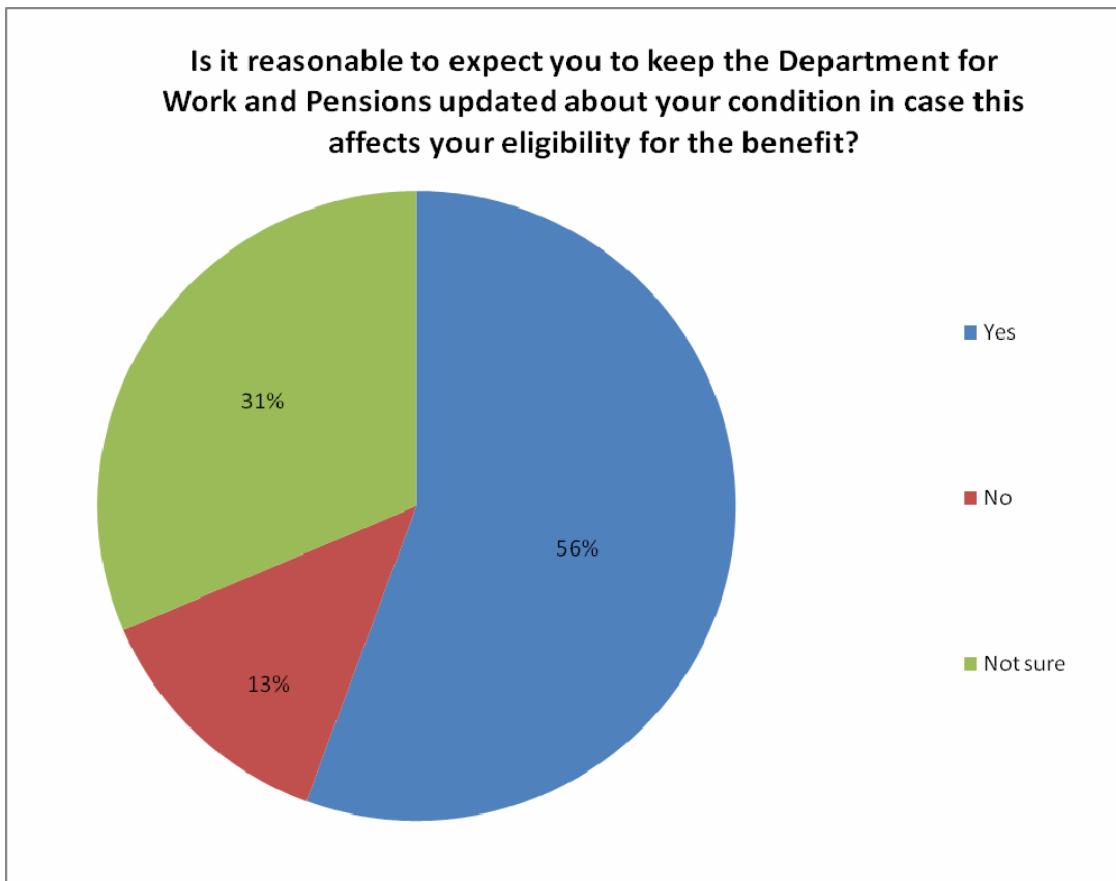


We would suggest that evidence from relevant health and social care professionals will be vital in deciding how frequent reviews should be based on the prognosis for the individual concerned and how beneficial PIP will be in terms of their ongoing recovery.

**13. The system for Personal Independence Payment will be easier for individuals to understand, so we expect people to be able to identify and report changes in their needs. However, we know that some people do not currently keep the Department informed. How can we encourage people to report changes in circumstances?**

It is important to highlight that people with mental health problems experience ongoing interruptions in their daily lives and disengagement from dealing with documentation or finances is not uncommon. We are concerned that the application of a penalty could cause extra stress, financial hardship, fear of stigma with regard to breaking rules/laws, and ultimately exacerbate mental health problems.

Vulnerable claimants may not always understand what is required of them; without robust investigation into the reasons why claimants fail to meet their responsibilities and without sufficient mental health training for the staff involved, there is a serious risk that penalties will be wrongly applied to the most vulnerable people.



The majority of respondents to our survey agreed that it was reasonable to be expected to keep the DWP updated about changes in their condition and very few believed it wasn't. Those who were not sure were presumably unclear about what this would actually entail and how often they would be expected to report changes.

Since people's mental health problems can vary dramatically, it would be unhelpful and unrealistic to expect updates on every fluctuation. In order for someone to have a realistic understanding of how substantially their condition

had improved, it would make more sense to request a regular but infrequent update. As such, this could simply be tied into the reassessment process discussed above, so long as this does not lead to excessive reassessment.

**14. What types of advice and information are people applying for Personal Independence Payment likely to need and would it be helpful to provide this as part of the benefit claiming process?**

People require much more support to understand the welfare system as a whole but increasingly organisations providing independent advice are having their funding cut, meaning that help is unavailable for people who do not have the ability to pay.

People must be able to access support without having to navigate complex processes and forms, as well as different layers of national and local government. Allowing people to make a single application for all major entitlements would be a welcome and much needed improvement to the current system, although this should not entail a single, combined assessment process (see question 20).

**15. Could some form of requirement to access advice and support, where appropriate, help encourage the minority of claimants who might otherwise not take action? If so, what would be the key features of such a system, and what would need to be avoided?**

It could be beneficial to signpost people to support in order to help them better manage their condition and/or access help. However, we would oppose making this a 'requirement of the benefit'.

Conditionality is inappropriate for extra-costs benefits. Furthermore, people must have the right to access appropriate care and treatment at the right time for them. Access to different types of treatment and care is an important requirement for people with mental health problems, yet existing systems do not always have safeguards to prevent mismatches between service user needs and service availability. Mental health care can also sometimes focus too narrowly on diagnosis rather than the needs of an individual. Requiring a person to comply with a particular course of treatment or support could have very serious implications for their mental health and wellbeing.

It would be better to put the onus on social and health services (including mental health teams and General Practice) to offer people with mental health problems access to Benefits Advisors and to fund these appropriately.

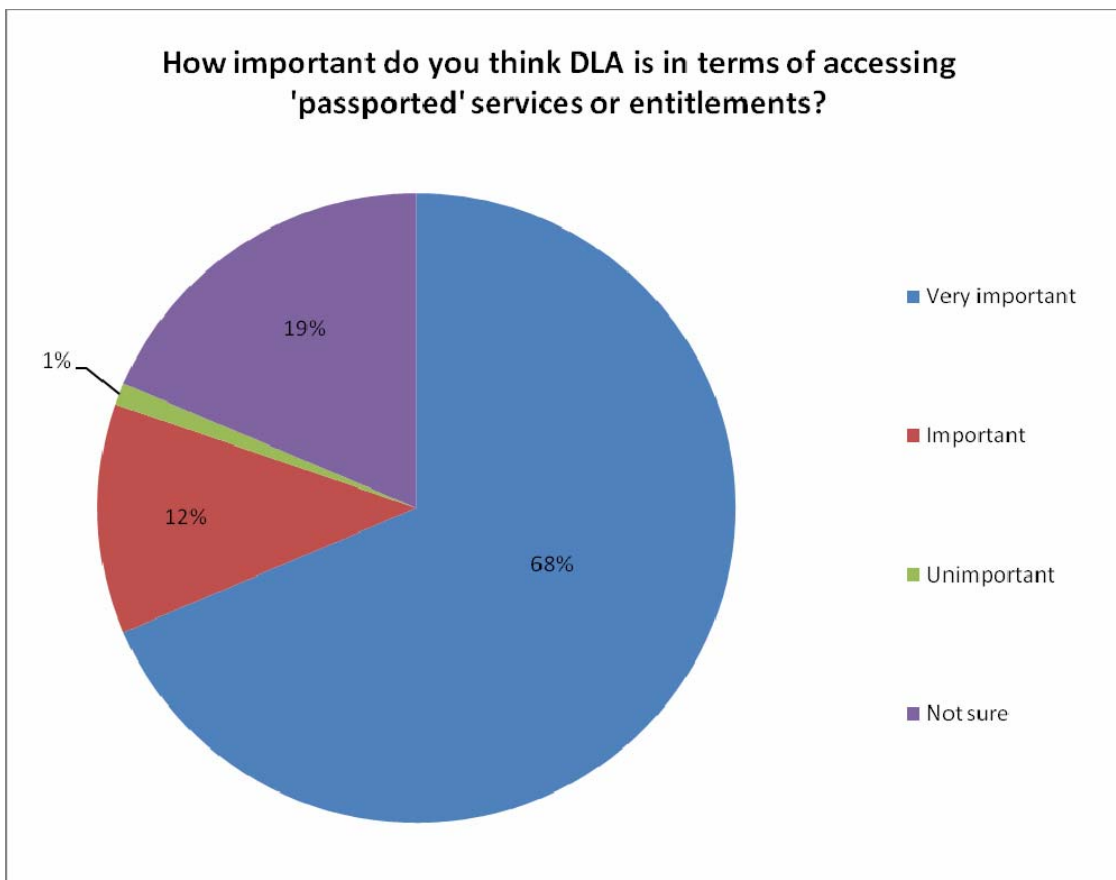
**18. How important or useful has DLA been at getting disabled people access to other services or entitlements? Are there things we can do to improve these passporting arrangements?**

*and*

**19. What would be the implications for disabled people and service providers if it was not possible for Personal Independence Payment to be used as a passport to other benefits and services?**

As the data below shows, our survey respondents stated that DLA was very important to them in terms of accessing passported services and entitlements.

In response to a subsequent open question on the implications of losing these passporting arrangements, people stated that this would be detrimental to their independence and damaging financially: for example losing free transport or prescriptions which would either present a significant rise in costs or an inability to access vital services. Many of the responses we received suggested that there were whole networks of entitlements and support attached to people's DLA that would be at risk of collapsing if they were no longer eligible or if these passporting arrangements disappeared. In addition, many people with long-term mental health problems live around the poverty threshold and loss of many of these entitlements would risk them falling below this level<sup>4</sup>. This suggests that the knock-on effect of such a change could be devastating.



**20. What different assessments for disability benefits or services could be combined and what information about the disabled person could be shared to minimise bureaucracy and duplication?**

We appreciate that there may be scope for investigating how information-gathering processes for many different benefit decisions could be better aligned. We are aware that the current systems create real stress and difficulties for claimants and families, both through the substantial amount of time filling in complicated forms and through travelling times to various assessments. We would support an investigation into how these processes could be brought together to make the system easier for claimants, less costly for families in terms of time spent off work supporting claimants and to reduce the costs of administrative processes. Such an investigation should look at international practice and should consider health and social care as well as welfare assessments. This kind of investigation should not be rushed, but should be done in consultation with everyone involved in the system: claimants, past and present, healthcare professionals, administrators and decision-makers.

However, it needs to be borne in mind that different benefits have clearly distinct purposes and are hence awarded on the basis of different criteria. We would be very concerned that the integration of different benefits assessments may lead to a blurring of the lines between benefits and a compromise in the integrity of the gauging of eligibility for each. Furthermore, given the substantial concerns we have expressed about the WCA, the majority of which were validated by the Harrington review, we would be deeply concerned about the use of a flawed assessment to gauge eligibility for an entirely separate benefit. We have already heard anecdotal evidence of people losing access to DLA as an indirect result of being declared 'fit for work' on their WCA and we believe that such practice is totally unacceptable.

In summary, we would welcome further investigation into how information can be gathered more effectively to better inform the benefits assessment process and avoid duplication of efforts on the part of the claimant and the Department. But we do not believe that eligibility for one benefit should be used to pre-judge or eligibility for a benefit of a different purpose, particularly when the assessment-of-eligibility for certain benefits has been shown to be so unreliable.

**21. What impact could our proposals have on the different equality groups (our initial assessment of which is on page 28) and what else should be considered in developing the policy?**

It is important that people with mental health problems are not disadvantaged in the new assessment. We believe that, particularly for those claimants with mental health problems that result in lower-level needs who may miss out under a reassessed benefit, DLA payments can play a hugely important preventative role. By keeping people engaged, involved and independent within their community, they can be helped to recover from their mental health problems and avoid relapsing.

As such, there needs to be a detailed assessment of the possible impact of removing DLA from these lower-rate claimants, as is likely within any effort to reduce the future budget. This assessment needs to include the potential knock-on costs for health and social care services if people's conditions worsen as a result of losing access to DLA. We believe that these costs could far outweigh any potential short-term savings from DLA and could be hugely damaging for the people concerned.

## **22. Is there anything else you would like to tell us about the proposals in this public consultation?**

We are concerned about the move to extend the qualifying period for DLA from three months to six months. Mental health problems can have a rapid onset and early support is vital in terms of the chances of recovery. As such, receiving DLA while someone's mental health problem is in its early stages could save significant sums in terms of avoiding more expensive care further down the line. As with the broader impact assessment discussed above, we feel it would be short-sighted to look to make quick savings through changes like this without considering what the longer-term health and cost implications may be.

It is important that the changes to DLA are considered as part of a wider set of reforms that will impact significantly on people with mental health problems, rather than in isolation. As well as the other welfare reforms being taken forward by the DWP, there will also be substantial cuts to legal aid and social care and radical reorganisation of how healthcare is delivered. We are deeply concerned about the potential cumulative impact of these changes: firstly because they could be hugely damaging to people with mental health problems who may find it much harder to access the care and support that they need; and secondly because we believe that, in many cases, attempts to make short-term savings, if not fully considered, may simply prove to be false economies due to the knock-on costs of increased levels of mental health problems. We believe that the best way to make savings in this area is to ensure that people are properly supported so that they can recover effectively, require less health and social care support, and possibly move back into work.

We also received several comments about the important knock-on effects for carers of receiving DLA:

*"My DLA pays for my husband, who is self employed, to take time off when I am ill and if he has had to stay with me to keep me from harm. I need supervision when cooking etc and he takes time out to help out. It also pays for transport as I am too ill to drive. If I didn't have DLA I would lose a lot of my independence and my mental health would definitely decline. I am so scared about having a review and am constantly waiting for the letter to come through for interview. I just could not manage without it."*

*"My son has Asperger's, suffers from OCD and severe anxiety. We were refused DLA to begin with then with the help of a local Welfare Rights unit his claim was allowed. I do all his paper work but worry that this benefit will be taken away. After years of wasting time with mental health services he has*

*now been properly diagnosed and is at a specialist college. They close on alternate week ends and he has to take the train home. Without his DLA we could not afford all the train fares and he could not be reasonably independent. At 21 a young man needs to feel he is not dependent on his parents but is getting an income in his own right. After college we hope he will be able to work or even go to uni. Everybody needs a chance of a life. Until a year ago our son was not having his chance.”*

If a substantial number of DLA claimants have their benefits reduced or removed as a result of the new proposals, this could have a significant impact on Carer's Allowance and other passported benefits, particularly disability premiums. We would like to see the Government publish an urgent analysis of the knock-on impacts of the DLA proposals on family incomes. Any reduction in these incomes could have serious consequences for families as they lose disability and carers benefits.

The consultation paper does not examine where eligibility for Carer's Allowance would be established within the new Personal Independence Payment. As a result, it is impossible to assess the impact of these changes on carers and the ability of families to care for ill or disabled friends and relatives.

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