



DWP Department for
Work and Pensions

Government's response to the consultation on Disability Living Allowance reform

Presented to Parliament by the Secretary of State
for Work and Pensions by Command of Her Majesty
April 2011

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Foreword by the Minister for Disabled People

Disability Living Allowance (DLA) has not been fundamentally changed or updated since it was introduced, and no longer provides the framework for supporting disabled people that is needed in the 21st Century. Over the last 18 years, DLA has failed to keep pace with the changing approach to disability in society, as successive governments have not seized the opportunity to review how this benefit works to support the aspirations of disabled people today. As it stands, DLA is complex to apply for and to administer, lacks consistency in the way it supports disabled people with similar needs, and has no systematic process for checking the ongoing accuracy of awards.

Now is the time to reform DLA and replace it with a new benefit for working-age disabled people. A benefit that better reflects the desire from disabled people to live independent lives, not to be labelled by a condition, but to be judged for what an individual can do not what they can't.

I would like to thank the impressive number of individuals and organisations who took the time to respond to our public consultation on DLA reform. During the consultation period I met many disabled people and their families, and disability organisations to discuss the reforms – I know how important the support is that DLA provides, and how much people value the fact that it is a cash payment, and can be spent to meet their own individual needs.

That is why Personal Independence Payment will remain a non-means-tested, non-taxable cash benefit that people can spend as they choose. It will also remain a benefit that is paid to people whether they are in or out of work. The priority is to support those facing the greatest challenges to living an independent life.

The importance of Personal Independence Payment means that it must remain sustainable for the future. Currently 3.2 million people receive DLA, an increase of around 30 per cent in the past 8 years. The announced reduction in projected working-age spend by 2015/16 will bring working-age expenditure back to 2009/10 levels.

Personal Independence Payment will be a more dynamic benefit that acknowledges that people's conditions change over time and that our understanding of how disability affects people changes too, so rather than having 70 per cent of people on indefinite awards, as is currently the case with DLA, we will introduce a new fairer, more transparent and objective assessment, and, in most cases, introduce fixed term awards. In doing so, we need to take account of the full range of disabilities and treat people as individuals, not labelling them by impairment type, creating a truly personalised benefit that evolves over time.

I am clear that as we design and develop how Personal Independence Payment will work in practice, we will need to continue to involve disabled people and their organisations. Their expertise will be essential and this document sets out in more detail how we plan to do this, so that their views are reflected in any changes we make.

Reform of DLA is long overdue. We have chosen at the first opportunity to legislate for a new benefit for disabled people that delivers support with integrity and a focus on personal independence – a benefit reform fit for the 21st Century.



Maria Miller MP

Parliamentary Under Secretary of State and Minister for Disabled People

Executive summary

1. The Coalition Government is committed to reforming Disability Living Allowance (DLA) to create a new benefit – Personal Independence Payment. We will create a benefit that is simpler to administer and easier to understand, is fair, and supports disabled people who face the greatest challenges to remaining independent and leading full, active lives.
2. On 6 December 2010, the Government published *Disability Living Allowance reform* (Cm 7984)¹ which set out our reform proposals and sought people's views. The consultation period closed on 18 February 2011.
3. This document outlines the responses received, from both individuals and organisations, and provides further information regarding the replacement of DLA and the introduction of Personal Independence Payment for people of working age (16-64) from 2013/14.
4. We received more than 5,500 responses to the consultation, including nearly 5,000 responses from individuals. Around half of responses from individuals were standard responses.² Over 500 organisations responded.

¹ <http://www.dwp.gov.uk/docs/dla-reform-consultation.pdf>

² A standard response was defined as two or more emails or letters that contained the same text, but were signed by different individuals.

The need for reform

5. DLA was introduced in 1992 and is no longer in step with the needs of the 21st Century welfare system. It lacks consistency in the way it supports disabled people with similar needs, and there is no straightforward way of reviewing people's entitlement to DLA on a regular basis, to ensure that they receive the right level of benefit. We know that people's conditions can change over time, but 70 per cent of DLA awards are indefinite, with no clear guidance to the individual on how they can report any changes in their circumstances to us.
6. It was clear from the responses received that some reform of DLA was welcomed. Both individuals and organisations pointed to the confusing nature of the benefit and inconsistent decision making. However, people are anxious to understand how these reforms will be carried out.
7. As many people recommended, we will continue to place disabled people at the heart of these reforms by involving them and their organisations in the design and testing of the new system.
8. Many responses we received expressed concern about how the reforms would achieve a reduction in projected working-age expenditure by 2015/16, although some respondents did accept the need to keep disability benefits affordable and sustainable for the future.
9. The Government is committed to ensuring that the new Personal Independence Payment remains affordable and sustainable for the long term. In just eight years, the number of people claiming DLA has risen from 2.5 million to 3.2 million – an increase of around 30 per cent.³
10. Reducing projected working-age expenditure by 20 per cent in 2015/16 means reducing working-age expenditure to 2009/10 levels in real terms – £11.8 billion.

The current system: What works?

11. We know there is a great deal that both individuals and disability organisations value about DLA.
12. Respondents strongly supported the Government's proposals for Personal Independence Payment to remain a non-means tested and non-taxable cash benefit that also acts as a passport to entitlement to other sources of help or support. Many people commented that it was important to them to have space on the claim form to describe the impact of their condition on their day-to-day life.

³ August 2010. http://83.244.183.180/100pc/dla_ent/tabtool_dla_ent.html

4 Executive summary

13. The Government will ensure that Personal Independence Payment remains a non-mean-tested and non-taxable cash benefit which people can spend in a way that best suits them. We also believe that disabled people are best placed to tell us themselves how their health condition or impairment affects them, and will ensure that individuals are able to do this.

Personal Independence Payment: Design of the benefit

14. Our aim, through the introduction of Personal Independence Payment, is to make the benefit fairer, more straightforward to administer, and for it to be easier and clearer to understand.
15. There will be two components of Personal Independence Payment; a daily living component and a mobility component, each with a standard and enhanced rate.
16. There was no consensus in the responses we received on whether people with certain impairments or health conditions should have an automatic entitlement to Personal Independence Payment. Many do not think it is right that we should judge people purely on the type of health condition or impairment they may have, and are committed to a more individualised approach to assessing an individual's claim, and we agree.
17. Extending the Qualifying Period to six months will bring our definition of a long-term disability in line with the Equality Act 2010 and align the benefit more closely with the qualifying rules for Attendance Allowance.

The assessment and review process

18. We are developing the assessment for Personal Independence Payment in collaboration with a group of independent specialists. It is being designed to enable support to be targeted at individuals who require the most assistance to live full, active and independent lives. It is intended to be a simpler, fairer, more objective and more transparent assessment of individual need.
19. The assessment will consider an individual's ability to carry out key everyday activities. The greatest priority in awarding the benefit will be that it goes to those individuals who are least able to carry them out. There was considerable support in the consultation for the activities that we are proposing to include in the assessment.
20. More than 70 per cent of the current DLA caseload has an indefinite award.⁴ Although we are able to reassess the level of award of any customer at any time, there is not currently any systematic way of ensuring that awards remain correct. This leaves disabled people more vulnerable to incorrect claims.

⁴ August 2010. http://research.dwp.gov.uk/asd/asd1/adhoc_analysis/2011/analysis_of_disability_living_allowance_DLA_awards.pdf

21. Under Personal Independence Payment, other than in exceptional circumstances, awards will be for a fixed period. We will take a personalised approach to award lengths, based on the individual's needs and the likelihood of their health condition or impairment changing.
22. Most individuals and organisations said that, for people who had a high level of need or an impairment or health condition which would not improve or change over time, a longer award with a less intensive assessment process would be appropriate. We will consider how the review process can be designed to ensure that it is proportionate and appropriate.

How Personal Independence Payment will be administered

23. We received many suggestions for ways to make the administration of Personal Independence Payment more straightforward and easier for disabled people, their families and carers to understand.
24. The Government is committed to streamlining the application process and ensuring that it is more transparent and less complex. This includes ensuring that we are receiving the right types of supporting evidence at the appropriate part of the claim process.
25. We have listened to respondents' concerns and suggestions and, where they are relevant, we will reflect the recommendations of Professor Harrington's review⁵ of the Work Capability Assessment (WCA) in the design and development of the Personal Independence Payment assessment and claims processes.
26. We will work with disabled people, their organisations and carers as we develop Personal Independence Payment to make the application and administration process as straightforward as possible. Annex 1 sets out how we plan to do this in more detail.

Children and people aged over 65

27. We do not plan to extend Personal Independence Payment to new or existing claims for children from 2013/14. The needs of children are very different to those of adults and we would want to build on our experience of developing the objective assessment for claimants of working age before applying it to children. We would also consult before extending any objective assessment to children.
28. Individuals already in receipt of Personal Independence Payment will continue to receive the benefit past the upper age limit of 65, provided they continue to meet the eligibility criteria. We will use the experience of reassessing the working-age caseload to inform any future decisions on the treatment of this customer group.

⁵ Harrington M, 2010, *An Independent Review of the Work Capability Assessment*, TSO.

Mobility in care homes

29. The Government has listened to the strong concerns raised by individuals and organisations about the Spending Review proposal to withdraw the DLA mobility component from people in residential care. The Government will not now introduce this measure as planned in October 2012. We are both reviewing existing and gathering further evidence to inform how best to proceed. Meeting the mobility needs of people in residential care will now be considered as part of the wider reform of DLA. The Government is committed to ensuring that residents of care homes are able to get out and about, and is therefore looking to remove overlaps in funding, not mobility.

The consultation

1. On 6 December 2010, the Government published *Disability Living Allowance reform* (Cm 7984)⁶, a public consultation that set out reform proposals and sought views about ways in which the benefit could be improved.
2. To make our proposals as accessible as possible, the consultation document was produced in a wide range of formats. These included Easy Read, Audio CD and cassette, Large Print, and Braille. A translation of the executive summary was made available in Welsh. A summary version, including consultation questions, was produced in British Sign Language (BSL) on DVD. PDF versions of the main paper and Easy Read versions, the BSL version and the Welsh executive summary were also made available online at www.dwp.gov.uk/dla-reform or by request to the Department.
3. The consultation closed on 18 February this year. During the consultation period, the website was visited more than 90,000 times and the PDF version of the document was viewed more than 35,000 times. We received nearly 5,000 responses from individuals, of which around 50 per cent were standard responses⁷, and more than 500 responses from organisations.

⁶ <http://www.dwp.gov.uk/docs/dla-reform-consultation.pdf>

⁷ A standard response was defined as two or more emails or letters that contained the same text, but were signed by different individuals.

Breakdown of responses

4. The responses gave the Government an overview of what works well with Disability Living Allowance (DLA), as well as what needs to change. There was a wide variety of views on what reform of DLA could achieve – including some differences between the views of individuals and larger disability organisations. Pages 13–43 provide a summary of the views expressed by individuals and organisations.
5. Responses to the consultation were received via telephone, post, fax, email and through our online consultation site.

| Table 1 Breakdown of consultation responses | |
|--|----------------------------|
| Origin of response | Number of responses |
| Individuals | 2,448 |
| Organisations ⁸ | 523 |
| Department for Work and Pensions staff | 85 |
| Standard Responses | 2,449 |
| Total | 5,505 |

6. To supplement the consultation document we held a series of meetings with disability organisations at Ministerial and official level, and attended events with disabled people and their organisations, as well as with our own staff, to discuss their views. Pages 46–56 list the organisations that submitted a response to the consultation.
7. DLA reform applies to England, Wales and Scotland. Social Security is a devolved matter in Northern Ireland. The Government will continue to work closely with the devolved administration in Northern Ireland to seek to maintain a single system across the United Kingdom. Consequently, responses received from individuals and organisations in Northern Ireland were considered during this process.

Structure of this document

8. This publication summarises the main points made by respondents and provides the Government’s response to them. We have made it clear where we have made a decision as a result of the consultation, and where we will provide more information during the passage of the Welfare Reform Bill. Annex 1 summarises our next steps as a result of recommendations made from the responses we received.

⁸ These include joint responses to the consultation from more than one organisation.

9. Not all respondents chose to answer the specific questions asked; many people preferred to provide their views on the reforms in general. Where possible, we have tried to include these responses in the appropriate sections. Responses that did not fall easily under the specific questions have been summarised under Question 22: 'Is there anything else you would like to tell us about the proposals in this public consultation?'
10. In this response, we have grouped the questions and responses received into key themes. For that reason, questions will not necessarily be dealt with in the order that they were originally asked:
 - The need for reform
 - The current system: What works?
 - Personal Independence Payment: Design of the benefit
 - The assessment and review process
 - How Personal Independence Payment will be administered
 - Additional comments on our proposed reforms
11. Both the *Disability Living Allowance reform* (Cm 7984) consultation and this response are available at www.dwp.gov.uk/dla-reform.
12. If you would like to receive this response in a particular format, for example, Large Print, Braille, Audio, or Easy Read, please contact:

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The need for reform

“I would like to end in saying that a reform of DLA is long overdue. Decisions are currently made by people who often seem to have little or no understanding of a lot of medical conditions and how they can impact on everyday life for someone with a disability. The forms rely on the person filling them out being clear and precise in their answers and basically saying the right thing.”

(Email response from a member of the public)

1. The Coalition Government is committed to supporting disabled people to exercise choice and control, and lead active, independent lives. We recognise the important role that cash benefits such as Disability Living Allowance (DLA) play in achieving this, and are committed to maintaining an extra-costs benefit for disabled people.
2. However, DLA is no longer meeting the needs of a 21st Century welfare system and is not sustainable in the long term. In just eight years, the number of people receiving DLA has risen from 2.5 million to 3.2 million – an increase of around 30 per cent.⁹ People are unclear about who qualifies for the benefit, and awards can be inconsistent and subjective.

⁹ August 2010. http://83.244.183.180/100pc/dla_ent/tabtool_dla_ent.html

3. We know that people's circumstances can change over time, but 70 per cent of the current DLA caseload have indefinite awards¹⁰ with little clear guidance to the individual on how and when they should report any changes in their circumstances. Under the current system, there is no systematic process for checking the ongoing accuracy of awards, which means individuals can carry on receiving an incorrect award for a significant period of time. For example, 24 per cent of working age DLA claimants have either not had a change to their award, or their award looked at, for a decade.¹¹ This can mean that, over time, support is not always targeted at those who face the biggest challenges in living independent lives.
4. Over the last few years, we have been told by many individuals and disability organisations that the benefit needs to be updated, made easier for disabled people to understand, and for the Department for Work and Pensions (DWP) to administer.

“We recognise that DLA is a system of support for disabled people that is in need of reform.” **(Essex Coalition of Disabled People)**

5. In their responses to the consultation, most organisations agreed that DLA needed modernising. Particular areas identified for improvement included simplifying the claim process, recognising the barriers faced by people with learning disabilities or mental health conditions, developing a more robust system for assessing individual need and reducing inconsistent decision making.

“Decision Makers need more evidence from a wider range of professionals in order to make a properly informed decision.” **(Macmillan)**

“[There] is an unacceptable inequality of access to the benefit, disempowerment of claimants and a waste of public funds through groundless and avoidable appeals.” **(Cambridge & District Citizens Advice Bureau)**

6. Individual respondents commented that the complex claim process and design of the claim form needed to be improved. A few individuals commented that the name ‘Disability Living Allowance’ had negative connotations.

“I love the new name seems more dignified than being given an ‘allowance’ for being disabled.” **(Written response from a member of the public)**

¹⁰ August 2010. http://research.dwp.gov.uk/asd/asd1/adhoc_analysis/2011/analysis_of_disability_living_allowance_DLA_awards.pdf

¹¹ Ibid.

12 The need for reform

7. Some DWP staff commented on the large amount of case law that had grown up around the benefit – for example, around definitions of being ‘virtually unable to walk’, which could lead to inconsistent awards. Others said that there was no clear guidance on what evidence individuals should produce in support of their claim, leading to delays in awarding the benefit. At present, around 50 per cent of decisions are made without any additional medical evidence.¹²
8. Using the responses we received to the consultation, and with continued input from disabled people and their organisations, we will design a benefit that is easier to understand, has a simpler claim process, and is more straightforward to administer. Personal Independence Payment will reflect the needs of disabled people today, recognise that people’s conditions can change over time, and treat people fairly, improving choice, control and the ability to lead an independent life.

¹² Source: Pension, Disability and Carers Service Operational Management Information.
http://research.dwp.gov.uk/asd/asd1/adhoc_analysis/2011/analysis_of_disability_living_allowance_DLA_awards.pdf

Summary of responses to consultation questions

The current system: What works?

Question 1

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

Question 3

What are the main extra costs that disabled people face?

1. Responses to these questions, from both individuals and organisations, illustrated the individualised nature of disability. Respondents said that disabled people face social, physical and economic barriers. Examples of social and physical barriers included access to transport and getting to work; getting around more generally; a lack of medical and social support; difficulties in socialising and social exclusion; as well as the stigma faced by disabled people in society. Economic barriers that were cited included reduced employment opportunities for disabled people, which lead to lower incomes.
2. In their responses, many individuals said they incurred extra costs as a result of these barriers. For example, in order to get around, people reported that they incurred additional costs which included increased taxi usage and the purchase of mobility aids.

14 Summary of responses to consultation questions

“One of the main barriers is the inability to get around on their own. It is true to say that white canes and guide dogs are invaluable aids, however, they do not replace the eye sight. Using Public transport is also a problem for people with a sight loss. Firstly timetables can be difficult to read and if the person has decided to travel by public transport it is a case that they are not able to get to either the bus or train station thus often requiring the use of a taxi thus extra costs are incurred. Most people with a sight loss often find it difficult to navigate their way round shops and supermarkets meaning that they either have to rely on friends or relatives to help them or use local council help which they have to pay for.” **(Fife Society for the Blind)**

3. Many individuals also said that they incurred extra costs as a direct result of their condition or impairment. For example, respondents cited the fact that they might need to buy certain foods or follow a specialised diet, or they had higher than average utilities bills and had to supplement the ongoing costs of aids and adaptations.

“My condition also has dietary implications (gluten and lactose intolerance) which mean that I cannot use most ready meals and as I can no longer cook for myself this means extra costs in terms of food and food preparation.”
(Email response from a member of the public)

“Heating/electric – as usually at home for greater part of the day than those that work full time, physically disabled individuals consume more energy costs. Individual often requires more heat etc due to nature of condition. Specialised equipment usually needs electric to run it (eg bath hoist, electric aids etc) and charging of medical aids.” **(Email response from a member of the public)**

“Nearly everything I use is speech adapted so if my microwave breaks down for example, it’s not a case of simply buying a new one I have to order it from specialist suppliers.” **(Quote from an individual taken from Leonard Cheshire Disability Response)**

4. Many respondents felt that barriers and costs such as these reduced employment opportunities, leading to a further reduction in income. Social stigma was also felt to be a significant barrier.

“The greatest barrier to disabled people participating in society is often caused by the attitudes of able bodied people making instant assumptions about disabled people. These instant assumptions usually betray a lack of awareness of the full nature of a particular person’s disability. Moreover the consequence of this is that the behaviour of an able bodied person may be, albeit unintentionally, patronising. Other barriers are often physical. There are still many workplaces and public facilities which are still not disability friendly.”
(Email response from a member of the public)

5. Organisations also provided a wide range of information about the extra costs that disabled people face. In their response, Scope cited their research carried out in conjunction with the think-tank Demos, recommending that an assessment for an extra-cost benefit should be “multi-dimensional and personalised”, taking into account factors such as housing and transport in addition to the ability to carry out activities.¹³

Government response

6. Government is working across all departments to ensure that potential barriers to inclusion are identified at as early a stage as possible and, wherever possible, removed. Personalisation has a key role to play in this, together with choice and control. So the Government has made a commitment to extend the greater roll-out of personal budgets to give people and their carers more control and purchasing power, and to use direct payments to carers and better community-based provision to improve access to respite care. It has reformed Access to Work, so disabled people can apply for jobs with funding already secured for any adaptations and equipment they will need.
7. The principle of improving outcomes and giving people more choice and control over the services they receive also underpins all the health and social care reforms. The Government will also continue to help disabled students with talent and ability to access higher education through appropriate, targeted funding support and is establishing a new framework, with increased responsibility on universities to widen participation in higher education.
8. However, we know that disabled people face additional costs to enable them to lead full and active lives, and DLA provides a contribution to those as a non-means-tested and non-taxable cash benefit. That is why Personal Independence Payment will continue to provide a cash contribution towards these costs. The consultation responses clearly showed the lack of consensus over what these costs are and how they could be calculated. This supports the academic research on the subject.
9. We do not think it practical to base eligibility for Personal Independence Payment on a calculation of actual costs incurred. Such an approach would be expensive and difficult to administer and would lead to inconsistent outcomes for individuals. DLA measures care and mobility needs as a proxy for the extra costs disabled people face. We will introduce a new assessment for Personal Independence Payment, taking fuller account of the impact of impairments and reflecting the 21st Century view of disability.
10. The assessment will be a simpler, fairer, more objective and more transparent assessment of individual need. It will take account of physical, sensory, mental, intellectual and cognitive impairments, and will focus on an individual's ability to carry out key day-to-day activities. Mobility and the extent to which individuals need care and support in their everyday lives will remain central to this.

¹³ Wood C and Grant E, 2010, *Counting the cost*, DEMOS.

16 Summary of responses to consultation questions

11. We believe that this approach will allow us to focus resources on those individuals who are least able to live independent lives. We believe that incorporating external factors such as transport and housing to the new assessment would, in addition to being administratively difficult, lead to even more subjective and inconsistent decision making, which is one of the criticisms of the current system. As we implement the reforms, we will assess the extent to which the new assessment accurately meets the aims of prioritising support to individuals who face the greatest challenges and expense.

Question 2

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

12. Respondents to the consultation stated how important the money they receive for DLA is in allowing them to lead independent lives.

“Currently the DLA allows me to be able to afford to keep an emergency phone, to enable contact whenever necessary with my doctor/parents which is massively important at time of acute mental distress, and to afford to run a car which means I can take a more active role in social activities as due to my mental health I am prone to extreme agoraphobia and a tendency to avoid leaving the house after dark.” **(Email response from a member of the public)**

13. It was clear that people value the fact that DLA is non means tested, non taxable and is paid as a cash benefit that is not linked to employment status. People also valued that receipt of the benefit provided a passport to entitlement to other sources of help or support.
14. The majority of respondents said that the special rules currently in place for people that are terminally ill¹⁴ worked well and should remain the same.
15. A lot of individuals and many organisations commented that having space on the claim form to describe the impact on the individual of their health condition or impairment was important and should be kept in the design of the new claim form.

¹⁴ A person is 'terminally ill' at any time if, at that time, he suffers from a progressive disease and death in consequence of that disease can reasonably be expected within six months; Social Security Contributions and Benefits Act 1992, Section 66, Subsection 2(a).

Government response

16. We agree that Personal Independence Payment should remain a non-means-tested, non-taxable benefit that is paid to disabled people whether they are in or out of work. Payment will not depend on having paid National Insurance contributions. It will continue to provide universal cash support and enable disabled people to spend the benefit in the way which best meets their individual needs. We will retain the special rules for individuals who are terminally ill, providing a fast track service to the enhanced rate of the daily living component, and removing the requirement for them to undergo assessment or meet the required Qualifying Period.
17. We believe that disabled people are best placed to tell us themselves how their health condition or impairment affects them, and recognise the importance of this for many disabled people. Individuals will still be able to provide information about their health condition and its impact on their daily lives. We will work with disabled people and their organisations as we design Personal Independence Payment to ensure this information is captured effectively.

Personal Independence Payment: Design of the benefit

Question 4

The new benefit will have two rates for each component:

- a. Will having two rates per component make the benefit easier to understand and administer, while ensuring appropriate levels of support?**
- b. What, if any, disadvantages or problems could having two rates per component cause?**
18. The majority of organisations welcomed the move to the new, broader definitions of the daily living and mobility components as being a better reflection of the real experience of disabled people's daily lives.

“We support the introduction of a ‘daily living’ component in place of the ‘care’ component, in order to reflect the breadth of needs among individuals with the same disability and condition, as well as across these groups.”

(National AIDS Trust)

19. Department for Work and Pensions (DWP) staff also welcomed the move to two rates within each component as they felt it would be more straightforward to administer.

18 Summary of responses to consultation questions

20. However, many individual respondents to this question were concerned that, by moving to two rates of benefit per component, we planned to remove the lowest rate of the care component of DLA. Some organisations commented that, by raising the threshold at which an individual would qualify for benefit, those with some, but not significant, support needs would be disproportionately affected and could end up using other government services at greater cost to the state.

“Until these rates, and their scope are defined, it is not possible to comment in detail on this. However, it is likely that a two band arrangement will be too broad and the parameters too coarse.” **(Limbless Association)**

Government response

21. We believe that having two components of Personal Independence Payment, each with a standard and enhanced rate of payment and with more clearly defined criteria, will enable us to better reflect in awards the impact of impairments on individuals’ ability to participate in everyday life.
22. At present, the higher and lower rates of the DLA mobility component are based on different criteria. With the exception of some automatic entitlements, higher rate mobility is generally awarded for physical health conditions or impairments, whereas lower rate mobility is linked to the need for supervision or guidance when outdoors. This means that there is some overlap between lower rate mobility and the care component, as the care component is largely based on the need for supervision or attention. In the new assessment, there will be separate criteria for each component, based on an individual’s ability to carry out certain everyday activities. These criteria will determine entitlement to both the standard and enhanced rates of the component, depending on the impact of a health condition or impairment.
23. Our aim, through these changes, is to make Personal Independence Payment fairer, more straightforward to administer, and easier and clearer for individuals to understand.
24. All current recipients of DLA of working age (16-64) will be assessed against the new criteria for Personal Independence Payment, starting from 2013/14.
25. We will make a decision about the monetary value of the different rates at a later stage. However, our intention is to pay the enhanced rate for both components at no less than the higher rate of DLA mobility and highest rate of DLA care components.

Question 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?

26. Respondents were split on whether some health conditions or impairments should receive an automatic entitlement to the benefit. Many individuals cited their personal circumstances and suggested that these should automatically qualify them for Personal Independence Payment.
27. Around half of organisations agreed that it was necessary to consider the impact of a health condition or impairment on an individual basis. However, they recommended that for disabled people who need more support, we might want to consider an alternative to the face-to-face consultation.

“We don’t believe that certain impairments should mean an automatic entitlement to PIP.” **(Scope)**

28. However, the majority of impairment-specific organisations argued in favour of automatic entitlement for members who need more support, citing the administrative efficiencies that this could bring.

“This would be a retrograde step [to remove automatic entitlement] which would not only introduce uncertainty for claimants, but would remove an administratively straightforward process from a small number of well-defined groups. This runs counter to wider efforts to streamline benefit administration.” **(Joint response from the visual impairment sector)**

Government response

29. We acknowledge that there is a difference of opinion on this issue. However, we do not think it right that we should judge people purely on the type of health condition or impairment they have, labelling individuals in this way, and making blanket decisions about benefit entitlement. We recognise that people lead varied and often complex lives, with differing circumstances and needs – they do not fit neatly into boxes. We believe that Personal Independence Payment should reflect this, providing support tailored to these personal circumstances. We are designing an assessment that will treat people as individuals and consider the impact of health condition or impairments on their everyday lives. The assessment will take account of the fact that many people have complex support needs and more than one health condition or impairment.

20 Summary of responses to consultation questions

30. We recognise the importance of ensuring that the assessment process is appropriate to individuals' circumstances and that there may be administrative efficiencies in introducing a more streamlined assessment for some individuals. For example, we accept that face-to-face consultations may not be appropriate in every case. We are still considering the delivery model for the Personal Independence Payment assessment and no conclusions have yet been reached on this.
31. As we develop the assessment and the administration of Personal Independence Payment in more detail, we will continue to work with disabled people and their organisations in the design and delivery of the benefit.

Extension of Qualifying Period

32. Some organisations were in favour of our proposal to extend the Qualifying Period¹⁵ from three months to six months, before benefit would be paid. This, when combined with the Prospective Test, which would remain at six months, would mean that, to be eligible for Personal Independence Payment, an individual's health condition or impairment must be expected to last a minimum of 12 months. This brings Personal Independence Payment in line with the definition of long-term disability for the purposes of the Equality Act 2010 and in guidance to that Act recently published.¹⁶

“This can be viewed as a positive because it reflects the definition of disability contained in the Equality Act 2010 and takes account of individuals with long term impairments that are likely to have a greater impact on the individual's ability to carry out day to day activities.” **(Redbridge Disability Association)**

33. However, many organisations and some individuals were not in favour of this proposal, and argued that some health conditions and impairments, such as cancer, have a sudden onset and individuals incur extra costs very soon after diagnosis.

“[We are] concerned by the introduction of a six months qualifying period for PIPs. This will mean that newly disabled people – those most in need of support are left without the appropriate funding to meet their needs.” **(Spinal Injuries Association)**

¹⁵ The period of time an individual must meet the eligibility criteria.

¹⁶ Office for Disability Issues, 2010, *Equality Act 2010 Guidance: Guidance on matters to be taken into account in determining questions relating to the definition of disability.*

Government response

34. Personal Independence Payment is intended to support people with long-term health conditions or disabilities. A Qualifying Period of six months helps us achieve this. It allows time for a clearer and more informed understanding of an individual's ongoing need and prognosis. This will enable us to ensure that the benefit is targeted most appropriately. The change brings our definition of long-term disability in line with that from the Equality Act 2010 and aligns the benefit more closely with the qualifying rules for Attendance Allowance.
35. As now, people will not always have to wait six months before being paid Personal Independence Payment if some, or all of the Qualifying Period has been satisfied by the time they submit their claim.
36. The first six months of a disability may well attract additional costs but those may be met through other mechanisms such as NHS travel costs, free prescriptions, aids and adaptations provided by the NHS or the Local Authority, and through a range of social security benefits depending on their circumstances during this period, including access to Employment and Support Allowance (ESA).
37. The process for terminally ill people, known as 'special rules', will remain the same as now. People who are terminally ill will continue to be exempt from the Qualifying Period and Prospective Test.

The assessment and review process

The assessment

Question 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?

38. We received a lot of comments from individuals and disability organisations on which activities were most essential for everyday life. Social interaction or communication, ability to get around and maintaining a life outside the home were mentioned most, but other activities described included:
- self care – bathing, dressing, toileting
 - safety – whether in or out of the home
 - eating and drinking
 - managing one’s financial and daily affairs
 - cooking
 - condition management
 - social support networks
 - getting around inside – up/down stairs, in/out of bed
 - meeting everyday family responsibilities
 - shopping
 - maintaining living standards at home
 - work
39. Many people felt that more information about how the assessment will operate and the detail of the criteria would help them better judge how support could be prioritised to individuals least able to live full and active lives. Some organisations linked comments in this question with their answers to Question 1 and 3, about the extra costs that disabled people face.

Government response

40. We are developing the assessment for Personal Independence Payment to enable support to be targeted at individuals who require the most assistance to live full, active and independent lives. As part of this, we want it to reflect a more complete and structured consideration of the impact of an individual's health condition or impairment, whether physical or mental, on everyday activities. The detail of the assessment is being developed in collaboration with a group of independent specialists in health, social care and disability, including disabled people themselves.
41. It would not be practical to consider all everyday activities, so we propose that the assessment should focus on those key everyday activities which are essential to enabling participation and independence. It is positive that the activities we are proposing featured strongly in the consultation responses, both from individuals and from organisations. The assessment will consider an individual's ability to carry out all of the activities, although some activities will relate to the daily living component and others to the mobility component. At this stage, we believe that the activities should be:

Daily living component

- planning and buying food
- preparing and cooking food
- feeding and drinking
- managing medication and monitoring health conditions
- managing prescribed treatment other than medication
- washing and grooming
- toileting and managing incontinence
- dressing and undressing
- communicating with others

Mobility component

- planning and following a journey
- moving around

42. We know how important it is to get this right, and full comment and discussion on the detail of our plans will be an essential part of the development process. To enable this, we plan to publish more detail of the assessment, including the criteria against which people will be assessed, before the Personal Independence Payment proposals in the Welfare Reform Bill are debated at Commons Committee Stage. We are keen to work with disabled people and their organisations to hear their views on these initial proposals. We will then carry out formal testing of the criteria over the summer to enable us to refine the criteria further.

Question 7

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

43. Many individuals and organisations welcomed the recognition that variable and fluctuating conditions will be reflected in the design of the assessment. Many people commented that a one-off assessment made it more difficult to capture the changes people can experience in their condition, and that using assessors who fully understood, or had experience of working with people with fluctuating conditions would be valuable.
44. Many individuals suggested types of additional evidence, from a support worker or other healthcare professional, which could be sought alongside a face-to-face consultation during the assessment process. Some people recommended that the claim form needed to be designed in a way that enabled people with fluctuating conditions to capture the particular ways they were affected by this.

“You need to treat everybody as if the worst days, not the best, are the standard. The person should have enough support to cover them if every day was a bad day otherwise they could end up in trouble.” **(Email response from a member of the public)**

“It is essential that the assessors, who we would not expect to be experts, do take on board the information given to them by the person’s specialist medical team who will have a much fuller understanding of what capacity or ability the person with C[ystic] F[ibrosis] has, and the treatment burden they endure.” **(Cystic Fibrosis Trust)**

Government response

45. We know that it is essential that the assessment for Personal Independence Payment accurately captures variable and fluctuating conditions. The assessment will not be a ‘snapshot’ of any one day but will consider an individual’s ability to carry out activities over a period of time, and whether these can be carried out reliably, repeatedly, safely and in a timely manner. We intend to publish more detail on the assessment criteria before the proposals in the Welfare Reform Bill are debated at Commons Committee Stage.
46. High-quality training and guidance to assessors and decision makers will be a vital part of this, and we will develop these with input from disabled people and their organisations. We also recognise that it can be vital in these cases to seek and consider evidence from the individual, their carer where appropriate, and the health and social care professionals who support them on a regular basis. Ensuring that the individual is able to advise on which professionals are best placed to provide supporting evidence will form a core part of this approach.

47. Although ESA and Personal Independence Payment are different benefits paid for very different reasons, we recognise that many of the recommendations of Professor Harrington's review of the Work Capability Assessment (WCA)¹⁷ will help the development of the Personal Independence Payment assessment. For example, we will consider whether Personal Independence Payment could use a similar approach to Professor Harrington's recommendation for mental, intellectual and cognitive champions, and whether this approach could be widened to capture other prevalent variable and fluctuating conditions.

Question 8

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

a. What aids and adaptations should be included?

b. 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?

48. The responses received from both individuals and organisations confirm that this is a very important area to get right. There were some individuals and organisations, particularly health and medical professional organisations, who thought that aids and adaptations should be taken into account in the assessment if they have enabled an individual to live more independently. As part of this, there was also recognition that the ongoing cost of aids and adaptations should be considered, along with whether an individual's equipment needs might change over time.

"Any aid or adaptation which raises a person's ability to carry out daily life should be considered. It's about levelling the playing field and equality of opportunity to take part in life!" **(Email response from a member of the public)**

"It is reasonable to take into account equipment and adaptations where there is evidence that they have maximised a person's independence or wellbeing and there are no associated additional costs." **(College of Occupational Therapists)**

49. Certain aids and adaptations are currently taken into account when assessing entitlement for DLA. For example, cooking aids and adaptations may be considered if they are readily obtainable, such as a perching stool as part of the 'main meal' test; whilst ability to walk is considered alongside aids which are habitually worn or used, such as a prosthetic leg. Concerns were raised that, under DLA reform proposals, benefit awards would be removed from people who have made successful use of aids or adaptations and that this might encourage disabled people not to improve their independence. The importance of DLA in enabling individuals to purchase their own equipment rather than relying on local provision was also highlighted.

¹⁷ Harrington M, 2010, *An Independent Review of the Work Capability Assessment*, TSO.

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50. There was a strong feeling that the use of aids or adaptations does not entirely remove the extra costs incurred by disabled people, or the barriers they face. Both individuals and organisations were particularly concerned about ongoing costs such as maintenance, repairs and replacements, which the individual may fund through their DLA.

“There is a real concern that under the current proposals an individual will jeopardise entitlement to PIP if they have made an effort to improve their quality of life.” **(Joint Response from Breakthrough UK, Greater Manchester Coalition and Manchester Disabled People’s Access Group)**

“On the well-established principle that ‘a met need is still a need’, on balance we think that aids and adaptations should be discounted in the assessment for PIP.” **(Foundation for People with Learning Disabilities)**

Government response

51. Disabled people receive a diverse range of support from Government, including aids and adaptations which can make a real difference to people’s lives. For example, Local Authorities spent over £230 million on aids in 2009-10. Through Personal Independence Payment, we wish to target support to those disabled people who are least able to participate and to live independently. We therefore believe it is right and fair for the assessment to take some account of the successful use of aids and adaptations where they help individuals carry out activities. We will do so in a way that is proportionate and appropriate.
52. We accept that there are costs associated with some aids and adaptations, that availability can vary, and that disabled people should have choice and control over their lives. As such, when Personal Independence Payment is implemented we are clear that aids and adaptations that are available and are successfully used by an individual will be considered.
53. If we are to enable disabled people to maximise their ability to live full, active and independent lives, it is vital to ensure that all areas of government provision join up appropriately. We will consider further how best to bring together all avenues of support available to disabled people and ensure that they are able to maximise their ability to be independent. We will continue to work with disabled people and their organisations on this issue.

Question 11

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

a. What benefits or difficulties might this bring?

b. 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?

54. Responses highlighted a number of positive elements to this approach. Many felt that a face-to-face consultation could enable a more human approach, providing an opportunity for disabled people to clarify the impact of their health condition or impairment, and for an assessor to ask questions and gain a much deeper understanding. It was also suggested that this approach would be likely to produce more realistic and consistent outcomes, although high quality guidance and training for assessors would be essential – many individuals in particular felt that consultations should be undertaken by specialists.

“There are potentially many benefits of having a face-to-face discussion with healthcare professionals. They enable the disabled person to clarify and provide any additional information to support their case. However, it should be recognised that for some people the experience could be stressful.”

(British Medical Association)

“Good idea. They will be able to inform the Department about the day to day life of the person. Maybe better than the applicant again particularly if there is learning difficulty. Sometimes the problems experienced each day are glossed over by the applicant as they have become “normal” over the weeks/months/years. I completed a form for a lady once and asked her if she could get up and down the stairs unaided. She said yes. It was only after talking further it was revealed she could only do it on her bottom and it sometimes took 30 mins each way.” **(Email response from a member of the public)**

55. Conversely, other responses questioned what value would be added by the use of an independent assessor, particularly for variable and fluctuating conditions, and highlighted the expense of face-to-face consultations. A common concern was extra stress for the individual and that this might exacerbate health conditions or impairments. Several responses raised the issue of accessibility and said it was vital that advocates and interpreters should be able to attend with the disabled person. Many organisations expressed concern that the assessment might be akin to the WCA in ESA and felt that the proposal would result in a medical approach to determining Personal Independence Payment entitlement.

“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.” **(Joint response from Centre for Mental Health, Hafal, Mind, Rethink, the Royal College of Psychiatrists and the Scottish Association for Mental Health)**

56. There was a general consensus that disabled people who face the greatest barriers should not have to attend a face-to-face consultation and entitlement should be decided by a paper-based assessment. Several disability-specific organisations also suggested that individuals with the particular health conditions or impairments that they represented should be exempted.

Government response

57. The Personal Independence Payment objective assessment will be very different to the WCA, as it will focus on ability to carry out key everyday activities, rather than capability to work and direct measures of associated functions. However, we are looking closely at the WCA experience and taking account of the recommendations of the first independent review carried out by Professor Harrington¹⁸ where these are helpful for the design of Personal Independence Payment. We fully recognise the need to ensure that the benefit has an effective, transparent and empathetic assessment process.
58. We are still in the process of developing the new claims and assessment process for Personal Independence Payment and no decisions have yet been made. A key part of ensuring the successful delivery of the benefit will be providing effective communication and support to individuals throughout the claims process. We are keen to work with disability and welfare rights organisations to ensure that we get the approach right.
59. We believe that, for the great majority of people, a face-to-face consultation between the individual and a trained independent assessor will play a key role in creating a fairer, objective and more transparent assessment for Personal Independence Payment than that which currently exists under DLA. In particular, a face-to-face consultation will give individuals the opportunity to put across their own views of the impact of their impairment on their everyday lives and ensure that decisions reflect the best evidence. We do accept, however, that face-to-face consultations may not be appropriate in every case – particularly for those individuals with the most severe impairments. No decisions have been taken yet on the delivery model for the new assessment and we are still developing the new claims and assessment processes. It will, of course, be essential to ensure that we get the process right. We are keen to continue working with disabled people, their organisations and carers as we further develop these.

60. Also essential will be ensuring that assessors and decision makers have appropriate training and guidance to carry out their roles effectively. We will again seek to work with disability organisations on the development of this. We will also consider how we can ensure that, where possible, specialist expertise is available – for example, whether Professor Harrington's recommendation for mental, intellectual and cognitive champions would be appropriate within Personal Independence Payment, to enable expert knowledge and best practice to be shared.
61. If an individual wants to bring a family member, carer or advocate with them to their face-to-face consultation, they will be encouraged to do so. We will also continue to consider the circumstances where individuals may not need to take part in any face-to-face process, to ensure that the assessment is appropriate to individual circumstances. If a face-to-face consultation is part of an individual's assessment, we will ensure that it takes place in the most appropriate setting and that any assessment facilities are fully accessible.

Question 10

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

62. We received lots of useful feedback on this issue and clear themes emerged. There was a strong consensus on the need for professional input from those who support the individual on a regular basis. It was recognised that the most appropriate professionals could differ, with the main options being an individual's GP, a consultant or specialist, or social or healthcare professionals. Some responses suggested that existing formal evidence should be used where appropriate, such as community care plans, occupational therapy assessments and medical certificates.

"I believe there needs to be a combination of medical and social evidence to adequately attempt to identify a disabled person's needs. I believe medical statements particularly from GP's and OT's of use but also information from community centres, friends and supporters / carers / PA's is equally important."

(Email response from a member of the public)

"Few people with disabilities are likely to have regular home visits from their GPs, and their main day-to-day contact may be with a physiotherapist, a C[ommunity] P[sychiatric] N[urse], a support worker or keyworker, a social worker, or a family carer; or they may manage unsupported, other than by their GP, who sees them in their surgery. Therefore, we consider that GPs are not always best placed to provide supporting evidence. In most cases, the claimant should be asked to nominate the most relevant health or social care professional." **(Social Security Advisory Committee)**

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63. Most responses said that the individual's self assessment of the impact of their health condition or impairment on their daily life was vital. Several organisations proposed that the disabled person should be at the centre of the evidence gathering process, to enable them to nominate the most relevant professional to seek supporting evidence from. Seeking evidence from non-professionals who know the individual well, such as family members and carers, was also suggested.

“An individual's clinical ability to hear is not always an indicator of their ability to communicate effectively without support, and the individual him/herself must continue to have a role to play in contributing to their own assessment.” **(RNID)**

64. Several organisations felt that evidence from different sources should be weighted equally and highlighted the importance of training and guidance for assessors and Decision Makers to enable them to weight conflicting evidence appropriately.

“Consistency will only be achieved with any welfare payment if the people who make the decisions are consistently uniform in their approach.”
(Lowestoft & North Suffolk Branch of the National Autistic Society)

Government response

65. We agree that the individual needs to be at the centre of the information gathering process to ensure that the assessment accurately determines the impact of their health condition or impairment. We recognise the importance of getting evidence from the individual and also working with them to identify the most appropriate additional sources of information, particularly professionals who support them on a regular basis. The wide variety of suggestions that were made on this issue will be considered further as we continue to develop the Personal Independence Payment assessment process. We will, of course, also consider where it may be helpful to incorporate recommendations from Professor Harrington's first review of the WCA into this design work.

The review process

Question 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?

66. Many organisations responded on this issue with recommendations on how we could set the frequency of reviews, and how they could be carried out. Most, but not all, of these responses were specific to certain conditions or impairments and some organisations made more general comments on how often people with, for example, mental health conditions should be assessed.
67. There was consensus from individuals and organisations that for people who have a high level of need, or a health condition or impairment that will not improve or change over time, a longer award with a less intensive assessment process would be appropriate.

“People felt in many cases where claimants had impairments which were very unlikely to improve then you should be able to give them longer awards.”
(Disability Action in Islington)

68. Individual respondents who were in receipt of indefinite awards were not in favour of reviews. Many said that their health condition or impairment had not changed in several years and that undergoing regular reviews would be stressful for them.

Government response

69. More than 70 per cent of the current DLA caseload have an indefinite award.¹⁹ Although we are able to reassess the level of award of any customer at any time, we do not currently have any systematic way of ensuring that awards remain correct. Individuals' conditions and needs may increase or decrease over time – sometimes so gradually that the individual themselves may not notice. Even where impairments and conditions themselves do not change, the impact of them might – as people manage their condition more effectively, for example.

¹⁹ August 2010. http://research.dwp.gov.uk/asd/asd1/adhoc_analysis/2011/analysis_of_disability_living_allowance_DLA_awards.pdf

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70. The 2004/05 *DLA National Benefit Review*²⁰ identified cases where the change in customers' needs had been so gradual that it would be unreasonable to expect them to know at which point their entitlement to DLA might have changed. These cases do not result in a recoverable overpayment as we cannot identify when the change occurred. It found that £630 million (or 11.2 per cent of cases) was overpaid because of these changes in customer circumstances. It also found that £190 million (or 6.3 per cent of cases) was underpaid to individuals for the same reason.
71. It cannot be right that individuals receive incorrect awards for long periods. Under Personal Independence Payment, other than in exceptional circumstances, awards will be for a fixed period, allowing us to ensure awards remain correct. We will take a personalised approach to setting the length of awards, varying the frequency and format of awards and reviews depending on the individual's needs and the likelihood of their health condition or impairment changing.
72. We know that for some conditions, longer fixed-term awards with regular reviews will be most appropriate, but these reviews might not necessarily always involve a face-to-face consultation. We recognise that it will be important to ensure that the review process is applied sensitively and appropriately and we are considering this as we develop the operational processes.

How Personal Independence Payment will be administered

Question 9

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

a. How could we make the claim form easier to fill in?

b. 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?

73. Both individuals and organisations had views on how we could make the administration of Personal Independence Payment more straightforward and easier for disabled people, their families and carers to understand.
74. Many individuals and organisations made suggestions about how we could make the claim form more accessible and easier to use. These included: making it available in a range of accessible formats, enabling people to claim online or having a combination of set answers to questions and a section of the claim form that enables the individual to describe the effect of their health condition or impairment on their everyday life.

²⁰ *Fraud, error and other incorrectness in Disability Living Allowance: The results of the Benefit Review of Disability Living Allowance, 2005.*

“Form design can be crucial for easy use. Elements such as layout (size of font, type of font, colour contrast, use of graphics) language and format (“read aloud” audio option) can impact on the ease of use for people, especially those with any visual/sensory impairment.” **(Dyspraxia Foundation)**

75. Other suggestions we received in terms of helping people apply for the benefit included providing telephone helplines and increasing advocacy and support for User-Led Organisations which often help disabled people through the claim process.

Government response

76. We have worked with disability and welfare rights organisations to improve the DLA claim form and we will continue this approach as we design and test the operating model for Personal Independence Payment. We recognise that the form remains too long and complicated, and will seek to simplify the process for individuals wherever possible. The introduction of face-to-face consultations will provide individuals with the opportunity to explain the details of their circumstances, put across their views directly and allow assessors to clarify points with them. This should reduce the amount of information we need to gather through the claim form. We are also committed to offering disabled people the option of claiming Personal Independence Payment online, in addition to the paper claim form.
77. We will work with disabled people, their organisations and carers as we develop how Personal Independence Payment will be administered to make the application process as straightforward as possible. At each stage of our development process we will consider the opportunities for simplification and engage relevant customer groups accordingly. We expect initial engagement to take place from April 2011 onwards.

Question 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?

78. Many individuals suggested that a clear statement on what was meant by a change in circumstances from the Department, sent out when people receive Personal Independence Payment, would help people understand what is required of them. Others suggested that we could encourage people to report significant changes in their circumstances by sending out annual reminders to individuals.

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79. Some people requested that, where possible, this statement be tailored to the individual's health condition or impairment.
80. Organisations also commented that at present, there was a lot of confusion about what changes in circumstances individuals should report, and that the current wording in the DLA up-rating letter could be improved.

“Write to people on an annual basis asking them to report any changes and ask them to attend a medical check up every three years.” **(Online response from an individual)**

“Information around the review process and individual responsibilities must be clear, succinct and clearly communicated in a timely fashion.” **(Arthritis Care)**

Government response

81. In order to keep payment of Personal Independence Payment targeted at the right people, it is important that customers are clear on when and how they should report a change in their circumstances, and we want to support people to do that.
82. As we develop the design of Personal Independence Payment, we will work with disabled people, their organisations and carers to ensure that all customer information is clear and easy to understand. If an individual is found to have knowingly withheld information about a change in circumstance which would have resulted in a reduction in benefit, they will have to repay the amount claimed. In addition, a penalty or a prosecution may result.

Question 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?

Question 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?

83. Individuals and organisations who responded to these questions felt that some guidance on accessing support or advice would be helpful – particularly if the individual had recently become disabled. There was a strong preference for people to be made aware of local services and support which could be tailored to their individual circumstances.

“Information and advice in relation to benefit entitlement, income maximisation, aids and adaptations, community care assessment processes, employment support and respective community activities and resources should be included as part of the process.” **(Cornerstone)**

“It is always better to do this in a positive way, encouraging disabled people to see how they could improve their lives, rather than in a negative way that could be perceived as intrusive and even threatening. Disabled people meet enough discouragement and barriers in their everyday lives already.” **(Online response from an individual)**

84. However, some people commented that this measure could appear to introduce conditionality into Personal Independence Payment, and that this would not be appropriate for a benefit designed to contribute towards the extra costs of disability. In addition, others said that spending money on leaflets would not be the most effective or targeted use of government funds.

Government response

85. We will explore whether the objective assessment process could provide an opportunity to give people advice, signpost them to further support and potentially encourage both take-up of aids and adaptations and, where appropriate, use of services to improve their condition or support the management of their condition.
86. We want Personal Independence Payment to be a more active and enabling benefit, so we are keen to develop ways to help encourage individuals to make use of services and support. We will consider further how this could work in practice. We do not intend to make Personal Independence Payment conditional on taking up certain activities or support, although we will keep this under review. For example, we might reconsider this if it became clear that a proportion of people were failing to access available aids, adaptations or services that would significantly help them.

Additional comments on our proposed reforms

Question 16

How do disabled people currently fund their aids and adaptations? Should there be an option to use Personal Independence Payment to meet a one-off cost?

87. We received a great deal of feedback to this question from individuals who purchase aids and adaptations in many different ways including using their DLA, their own savings, loans, hire purchase agreements and help from family and friends.

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“Many disabled people currently fund their aids and adaptations through fundraising, grants, help from relatives and charities. Yes it should be an option to Personal Independence payment to meet one off costs.” **(Online response from an individual)**

88. Some respondents were interested in the possibility of being provided with a lump sum or one-off cost to fund more expensive aids and adaptations, but were keen to learn more about how this would work in practice.

“Personal Independence Payments may well prove useful for one-off costs but building an individual’s capacity should still be the first consideration rather than presuming a lifetime’s dependence on aids and adaptations.” **(Social Work Resources, South Lanarkshire Council)**

Government response

89. We are interested in exploring how we might better support disabled people with the cost of aids and adaptations. We will consider how these ideas might be taken forward, but recognise that legal and operational issues mean that these may need to be introduced in the longer term, beyond 2013.

Question 17

What are the key differences that we should take into account when assessing children?

90. Many people suggested that we collect evidence from schools and other organisations involved in the support of disabled children. Most respondents said that the experience of parents and other carers of children should be taken into account when assessing children, and some people said that children themselves should play a central role in their assessment.
91. However, many organisations and individuals expressed significant concern about introducing a new assessment for children without additional testing and consultation. Many organisations advised that, before an assessment suitable for children is developed, the Government should consult again in more detail, and involve parents and organisations representing disabled children.

“We would urge the Government not to introduce any changes without proper assessment of potential impact it will have on the life chances of disabled children, their ability to exercise their rights under the UNCRC and Convention on the Rights of People with Disabilities and without proper consultation with disabled children themselves.” **(The Children's Society)**

Government response

92. Personal Independence Payment will be introduced for working-age adults from 2013/14.
93. We will not extend Personal Independence Payment to new or existing claims for children from 2013/14. The needs of children are different from those of adults and may vary at key stages of development. Their needs may also change as they approach adulthood and seek greater independence. We are clear that, before we could apply the new Personal Independence Payment to children, we would need to develop a specific assessment to ensure that the needs of children with long-term health conditions or impairments are properly considered. We will build on the experience of developing the objective assessment for claimants of working age to inform our decisions about the future arrangements for children.
94. To inform our decisions on the arrangements for children we will also work with disability organisations, families with disabled children and relevant specialists. Clearly, extending Personal Independence Payment to children would be the right thing to do when we can demonstrate it provides a fairer, more objective and more transparent alternative to the current arrangements. However, before taking such a decision we would need to consult and this would also need to be subject to Parliamentary scrutiny.
95. In developing the arrangements for children on DLA, we also want to take account of ongoing work across Government. The Department for Education's Green Paper *Support and aspiration: A new approach to special educational needs and disability*,²¹ published on 9 March, sets out the Government's aspiration to move towards a single assessment process for a child's social care, health and special educational needs. The Department for Education plans to test the approach, starting this year, and we will look at the findings of the pathfinders to explore whether the single assessment process might also be used to support claims for Disability Living Allowance and Personal Independence Payment.

21 <http://www.education.gov.uk/publications/eOrderingDownload/Green-Paper-SEN.pdf>

Question 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?

Question 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?

96. We received many responses from individuals that stated how important DLA is for getting them access to other benefits, entitlements or services. Organisations who responded said that this passporting arrangement was important as it saved administrative costs from people applying for services separately.
97. Some of the services and entitlements outlined in people's responses included the Blue Badge scheme, the warm front scheme, bus passes, special educational needs assessments, benefit entitlement, and travel and leisure activities.
98. Many people said that if this passporting was stopped, disabled people would be affected in a variety of ways including reduced mobility, greater social isolation and that fewer people would be able to remain in work. Others said that there would be a financial impact if these arrangements ceased.

“If the Personal Independence Payment was not able to be used as a passport to other benefits and services it is quite possible that the disabled person would not be able to access these in any other way as they would not have enough money to do so and no other means of getting it. This could have a profound influence on their quality of life.” **(Email response from a member of the public)**

“Greater poverty is potentially the biggest effect if DLA (PIP) was not used as a passport to other services and benefits. Claimants will also lack the opportunity to access a holistic package of entitlements and services to support them in all areas of their lives.” **(The Association for Spina Bifida and Hydrocephalus)**

Government response

99. We acknowledge the importance of the passporting arrangements that currently exist for those on DLA. We will ensure that organisations and other government departments are aware of the introduction of Personal Independence Payment from 2013/14 so they can amend their systems and information accordingly. We will want to ensure that, as now, people with the greatest barriers to participation are able to access other services and support as easily as possible.
100. Our intention is that individuals will receive an award letter, as now, which would continue to act as confirmation that they were in receipt of particular component(s) of Personal Independence Payment at a particular rate. We will continue to work with colleagues across government to identify further opportunities for streamlining this process.

Question 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?

101. Some respondents to this question suggested that if the individual agreed, their information should be made as widely available as possible to other agencies and organisations. They highlighted the administrative savings this approach would make. Others preferred that their personal details be kept confidential and pointed to potential data protection issues.
102. Organisations who responded pointed to the different eligibility criteria in place for different benefits and services, and while there was some support for streamlining, others were concerned that this would lead to Personal Independence Payment being localised as part of Local Authority Adult Social Care Services.

Government response

103. While Personal Independence Payment will remain a separate cash benefit paid to individuals, we are committed to streamlining assessments where possible to provide a better, more cost-effective service to individuals. As we develop Personal Independence Payment, we will consider how we can work with other government departments, including Department of Health, to consider how we could do this.
104. The Government has set up the independent Commission on the Funding of Care and Support, chaired by Andrew Dilnot, to consider how we ensure affordable and sustainable funding for care and support for all adults in England, both in the home and other settings, in the face of growing demand. We will consider carefully the recommendations of the Dilnot Commission and the interaction between Personal Independence Payment and the social care system, to ensure people receive the support they need, when they need it, in a way that best meets their needs.

Question 21

What impact could our proposals have on the different equality groups (our initial assessment of which is on page 28 of Cm 7984) and what else should be considered in developing the policy?

105. Not many individuals or organisations responded to this question, although those that did strongly recommended that a full equality impact assessment be carried out as more detail of Personal Independence Payment is developed.

“An equality impact assessment would enable any adverse impact on any group or groups to be identified and mitigated before the policy is implemented, and supports policy makers to consider any opportunities to promote equality that have previously been missed or could be better used.” **(Equality and Human Rights Commission)**

Government response

106. An Equality Impact Assessment of the proposals was published on 8 March 2011 and can be found at: www.dwp.gov.uk/policy/welfare-reform/legislation-and-key-documents/welfare-reform-bill-2011/index.shtml. It will continue to be updated as we further develop how the reforms will work in practice.

Question 22

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

Mobility in care homes

107. Strong concerns have been raised by individuals and organisations about the Spending Review proposal to cease payment of the DLA mobility component from people in residential care after 28 days.
108. Charities including Mencap, Sense and the UK Disabled People’s Council have expressed concerns that the removal of the payment would leave disabled people confined to their care homes.

“We are opposed to the removal of the mobility component of DLA for people living in residential care. This is a regressive step which will deny 80,000 people their independence and limit their participation in community life, and undermines the government’s commitment to promoting social justice for disabled people.” **(Mencap)**

109. A coalition of disability charities produced two reports on this issue, 'Don't Limit Mobility' and 'DLA Mobility: sorting the facts from the fiction'.²²
110. We have also received several responses from individuals worrying about how they or their family members will cope without this payment.

"My brother is in a care home. The fees (paid by the Local Authority with a contribution from him) do not cover transport. He pays some of DLA Mobility towards the cost of the home van. When he uses public transport he has to have one or two people with him because of his condition and he has to pay their fares as well as his own. So the DLA Mobility is vital for him to be involved in an 'ordinary' life as well as attend medical appointments etc."
(Email response from an individual)

111. Further concerns have been raised about the damaging impact of removing this payment for children and young people at residential schools and colleges, particularly on how individuals would get home and out and about during school holidays.

Government response

112. The Government has listened to charities and other stakeholders and will no longer remove this payment from October 2012. Instead, the Government is both reviewing existing and gathering further evidence. This has been welcomed by disability groups.
113. Our work has so far revealed that the current support for the mobility needs of disabled people in residential care is inconsistent. There is a lack of clarity about funding leading to confusion about who should provide what, leaving the most vulnerable people at the risk of variable provision.
114. Meeting the mobility needs of people in residential care will now be considered as part of the introduction of Personal Independence Payment. Any subsequent changes to the mobility component of the Disability Living Allowance for people in residential care will be included in the design of Personal Independence Payment. It has never been the intention of this policy to remove disabled people's mobility, only to remove any overlaps in public funds.
115. Many respondents commented on the importance of the Motability scheme. The Department will work closely with Motability under the reformed system of Personal Independence Payment. We are still considering how Personal Independence Payment will provide access to the Motability scheme. However, it will continue to play an important role going forward in supporting the mobility of severely disabled people.

²² Don't Limit Mobility, <http://www.mencap.org.uk/displaypagedoc.asp?id=20622>

Appeals

116. Many people expressed concern that the introduction of Personal Independence Payment could increase the rate of appeals and questioned whether the Tribunals Service would be able to cope with the increased numbers.

Government response

117. We will be working closely with the Ministry of Justice to understand and minimize the impact that Personal Independence Payment will have upon appeals that go on to the Social Security Tribunal. As part of this work we will be looking to streamline and simplify processes and carefully plan so that the Tribunals Service can cope with the future level of appeals.
118. We recognise that there are already a large number of appeals within the appeals system which has been mainly caused by the introduction of ESA. The Tribunals Service has reacted strongly to these additional pressures and has been increasing its capacity through the recruitment of additional staff, judiciary and medical tribunal members, as well as a range of judicial and business process improvements. Meanwhile, within the DWP we have been working to improve the quality of original decision making, and arrangements for reconsidering cases, so that only appropriate appeals filter through to the Tribunals Service.
119. As a consequence the Tribunals Service will, by the end of the 2010/11 business year, have completed a third more Social Security cases than in 2009/10, and 50 per cent more than it did in 2008/09.
120. Individuals who believe the decision made is incorrect will be able to ask the Department to reconsider their case. If the individual believes the reconsidered decision to be incorrect they will have the right of appeal. In addition, we intend to encourage individuals to contact the Department to discuss their case, before entering the formal dispute process.
121. Professor Harrington's Independent Review of the WCA noted the high rate of appeals following the introduction of ESA and made recommendations for reducing the appeal rate.²³ We are considering whether these recommendations can be applied to Personal Independence Payment. We want to make the system as simple as possible to understand and operate; ensure that decisions are right first time; and where errors are made correct them as quickly as possible.

²³ Harrington M, 2010, *An Independent Review of the Work Capability Assessment*, TSO.

Over 65s

122. It is our intention to allow individuals already in receipt of Personal Independence Payment to continue receiving the benefit past the upper age limit, provided they continue to meet the eligibility criteria. We will use the experience of reassessing the working-age caseload to inform our decisions on the reassessment of over 65s.

Carers

“Health and social care services would collapse without the support provided by the UK’s carers. It is essential, as the Government plans the biggest reforms to disability benefits since the creation of DLA, that they give far greater prominence to analysis of the impact on families. Without this, there is the risk that reforms could have unexpected and perverse impacts upon family care – putting greater pressure on families and on health and social care services.”
(Carers UK)

123. The Government announced at the introduction of the Welfare Reform Bill that Carer’s Allowance (CA) will continue to exist as a universal benefit providing an independent income for carers and recognition of the important role they play. We are considering how the introduction of Personal Independence Payment will interact with CA, and how it can best support carers alongside the support provided through the Health and Social Care System as set out in *Recognised, valued and supported: the next steps for the Carers Strategy*, published in November 2010.²⁴

²⁴ Department of Health, 2010, http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_122077

Annex 1

Action taken

Many individuals and organisations suggested ways in which we could develop the benefit, ensuring that we put the disabled person at the heart of the development and claim process. The table below sets out our next steps.

| You suggested | Our next steps |
|---|--|
| That we put disabled people at the heart of these reforms by involving them and their organisations in the design and testing of the new system | <ul style="list-style-type: none"> • Disabled people are experts in their own lives and we will continue to work with them, their organisations and their representatives as we work towards the introduction of Personal Independence Payment in 2013/14 and beyond. • At each stage of our development process we will consider the opportunities for joint working and expect the next stage of our engagement to take place from April 2011 onwards. • This will include the development of the claim form and the claim process as well as training and guidance for staff and assessors of Personal Independence Payment. |
| Disabled people are the best people to advise about their needs during the assessment process | <ul style="list-style-type: none"> • We will continue to work with disabled people and their organisations in the development and testing of the assessment. • Individuals will continue to be able to provide information themselves on their personal circumstances and the impact of their impairment(s) on their everyday lives. • The individual will be able to provide and suggest, ahead of the assessment, what they consider to be the best and most appropriate sources for their supporting evidence. • The face-to-face consultation will include an opportunity for the individual to provide information on the impact of their health condition or impairment. |

| You suggested | Our next steps |
|--|--|
| That the claim process and assessment take proper account of fluctuating conditions | <ul style="list-style-type: none"> • We will work with disabled people to develop the assessment and claim process to ensure it takes account of an individual's ability to carry out activities over a period of time and the impact of a fluctuating condition. |
| That we involve disabled people and their representatives in the writing of guidance and training of staff and assessors | <ul style="list-style-type: none"> • We will work with disabled people and their organisations as we develop the training and guidance for staff and assessors. |
| That the roles of advocates within the claim process remain very important | <ul style="list-style-type: none"> • We recognise the importance of claimants being able to have advice and support from advocates during the claim process. • A carer, family member, advocate or other person requested by the disabled person will be able to attend the consultation if they wish. • There will be space on the claim form for the disabled person's carer, family member or advocate to provide additional or supporting information if this is appropriate. |
| We take account of the recommendations from Professor Harrington's review of the WCA | <ul style="list-style-type: none"> • We will ensure that Professor Harrington's recommendations from the Independent Review of the Work Capability Assessment are reflected in the design and delivery of Personal Independence Payment where they are relevant. |
| The current DLA claim form is too long and repetitive | <ul style="list-style-type: none"> • We are committed to introducing a more transparent and less complex claim process for Personal Independence Payment. • We will develop an improved claim form which we will design and test with disabled people and their organisations. |
| Claim forms must be available in accessible formats | <ul style="list-style-type: none"> • We are committed to ensuring that the Personal Independence Payment claim form is accessible. • We received lots of feedback on ways in which we could improve the claim form by making it available in particular formats, such as Easy Read and Large Print, as well as being placed online. We will continue to explore the options suggested. |
| It should be easier to report changes in circumstance | <ul style="list-style-type: none"> • We will work with disabled people to ensure that claimants know when and how to keep the Department informed of any changes in their circumstances. • We will continue to work with disabled people, their representatives and our staff to ensure straightforward processes are in place to make reporting changes as simple as possible. |
| That Personal Independence Payment should remain a 'passport' to other benefits and services | <ul style="list-style-type: none"> • We will ensure that organisations and other government departments are aware of the introduction of Personal Independence Payment from 2013/14 so they can amend their systems and information accordingly. |

Annex 2

Organisations responding to Disability Living Allowance reform consultation

| | |
|--|--|
| A2B Access to Benefits | Age Cymru |
| ABCD Cymru | Age Discrimination Task Group of the Vale Older People's Strategy Forum |
| Aberdeen Action on Disability | Age NI |
| Access in Dudley | Age UK |
| Accessible Wrexham Group | All-Party Parliamentary Group (APPG) for Sickle Cell and Thalassaemia |
| ACT NOW Autism Campaigners Together | All Wales Forum of Parents and Carers of People with Learning Disabilities |
| Action Disability Kensington & Chelsea (ADKC) | Alzheimer Scotland |
| Action for ME and Association of Young People with ME | Alzheimer's Society |
| Adapt (North East), Northumberland LINK and the Northumberland Disability & Deaf Network | AME (Access Made Easy) |
| Administrative Justice and Tribunals Council (AJTC) | AME Disability Consultants |
| Advice in Rotherham | Andover and District Mencap |
| Advice Network & Advice Centres for Avon | AOHNP – Association of Occupational Health Nurse Practitioners (UK) |
| Advice NI | ARChive |
| Afasic | Arfon Access Group |
| Age Concern Dacorum | |

Organisations responding to Disability Living Allowance reform consultation

| | |
|---|--|
| Arthritis Care | Blue Badge Modernisation Team – Welsh Assembly |
| Arthritis Research UK | Blue Badge Team – Wigan Council |
| Asbestos Victims Support Groups Forum UK | Blue Badge Unit – Hampshire County Council |
| Aspire | Blue Ribbon for the Awareness of Myalgic Encephalomyelitis (BRAME) |
| Assert (Brighton and Hove) | Body & Soul |
| Assist UK | Bournemouth Community Care Services |
| Association for Spina Bifida and Hydrocephalus (ASBAH) | Bournemouth Borough Council |
| Association of Directors of Adult Social Services (ADASS) | Bracknell Forest Council |
| Association of Disabled Professionals | Bradford People First |
| Association of Train Operating Companies (ATOC) Ltd | Bradford Strategic Disability Partnership |
| Ataxia UK | Bradnet |
| Atos Healthcare | Brain Tumour Action |
| Autism in Scotland and Lothian Autism Network | Breakthrough UK, Greater Manchester Coalition of Disabled People and Manchester Disabled People's Access Group (joint response with BADGE, Body Positive, Disability Stockport, Disabled Tenants from Harvest Housing Group, International Society of Disabled People, Our Independence, Prosthetic User Group, Salford Deaf Blind Group, Salford Disability Forum, Tameside People First, Trafford Centre for Independent Living, and Wigan and Leigh People First) |
| Autism Rights | Breast Cancer Care |
| Autism West Midlands | Brighton & Hove Federation of Disabled People |
| Autism-in-Mind (AIM) | Brigstowe Project |
| Barnet Carers Centre | Bristol City Council |
| Barnsley Metropolitan Borough Council | Bristol Disability Equality Forum |
| Bentley Community Support Service | Bristol LINK |
| Betterdays | British Lung Foundation |
| Birmingham Carers Association | British Medical Association (BMA) |
| Birmingham Disability Resource Centre | |
| Birmingham Disability Resource Centre working with Birmingham LINK/Gateway Family Services CIC (joint response) | |
| Blackpool Council | |
| BLESMA | |

| Organisations responding to Disability Living Allowance reform consultation | |
|--|---|
| British Society of Rehabilitation Medicine (BSRM) | Charterhouse Counselling Ltd |
| Brixton Advice Centre | Cheshire Centre for Independent Living (CCIL) |
| Bromley Parent Voice | Chesterfield Community Mental Health Services |
| Buckinghamshire County Council | Chichester Access Group |
| Calderdale Parent and Carers Council | Child Poverty Action Group (CPAG) |
| Calico Disability Forum | Children and Young People HIV Network |
| Camberley Aspergers Group | Children in Wales (CIW) |
| Cambridge & District Citizens Advice Bureau | Choices and Rights Disability Coalition |
| Camden Citizens Advice Bureau | Citizens Advice |
| Camphill Scotland | Citizens Advice & Rights Fife |
| Capability Scotland | Citizens Advice Scotland |
| Capital Project Trust | City of Edinburgh Council's Department of Health and Social Care |
| Cardiff and Vale Coalition of Disabled People | City of York Council Benefits Service |
| Care Forum Wales (CFW) | Civil Service Pensioners' Alliance |
| Carers Gloucestershire Advice & Advocacy Team | CLASP - Leicester, Leicestershire and Rutland Carers Centre |
| Carers In Hertfordshire | CLIC Sargent |
| Carers Northern Ireland | Clwyd Alyn Housing Association |
| Carers Outreach Service | Coalfield Communities Federation |
| Carers UK | Colchester Prosthetic User Group |
| Carers UK Birmingham | College of Occupational Therapists (COT) |
| Carers UK Hounslow | Commission for Victims and Survivors for Northern Ireland |
| Carers Services – Hounslow | Community Union (including National League of the Blind and Disabled) |
| Carerwatch and The Broken of Britain (joint response) | Consumer Credit Counselling Service (CCCS) |
| Cartrefi Cymru | Consumer Focus Wales |
| Centre for Mental Health, Hafal, Mind, Rethink, the Royal College of Psychiatrists and the Scottish Association for Mental Health (joint response) | Contact a Family |
| Ceredigion People First | Contact a Family and The Children's Trust, Tadworth (joint response) |
| Certitude Support | |

Organisations responding to Disability Living Allowance reform consultation

| | |
|---|---|
| Contact a Family NI | Disability Benefits Consortium (DBC) |
| Convention of Scottish Local Authorities (COSLA) | Disability Equality (nw) Ltd |
| Conwy County Borough Council | Disability Information Service Huntingdonshire (DISH) |
| Cornerstone | Disability Rights Partnership (Disability Alliance, National Centre for Independent Living and Radar) |
| Cornwall Community Volunteer Service (CCVS) | Disability Wales |
| Coventry Citizens Advice Bureau | Disabled People Against Cuts |
| Crohn's and Colitis UK | Disabled Persons Transport Advisory Committee (DPTAC) |
| Cross Keys Homes | DISC (Disabled Information and Support in the Cotswolds) |
| Cued Speech Association UK | DLA Help Group |
| Cumbria Mental Health Group | Down's Syndrome Association (DSA) |
| Cymorth Cymru | Down's Syndrome Scotland |
| Cystic Fibrosis Trust | Downright Excellent |
| DAGLA (Disabled Advisory Group on Leisure Activities) | Drive |
| DARD Disability Forum | Dudley Metropolitan Borough Council |
| Dawlish Voices | Dundee City Council (Social Work Department) |
| Deaf Access | Dundee Visually Impaired Ladies' Club |
| Deaf Connections | Durham County Council |
| Deaf Ex-Mainstreamers Group Ltd | Durham Dales Action for Carers |
| Deaf Links | Durham Learning Disability Service User Parliament |
| Deafblind Scotland | Dyspraxia Foundation |
| Depression Alliance Scotland | East Dunbartonshire Council |
| Diabetes UK | East Dunbartonshire Visually Impaired Peoples Forum |
| Different Strokes | East Renfrewshire Disability Action (ERDA) |
| Disabilities Forum | East Riding of Yorkshire Council |
| Disability Action | |
| Disability Action in Islington (DAII) | |
| Disability Advice Service (East Suffolk) | |
| Disability Advice St Helens | |

| Organisations responding to Disability Living Allowance reform consultation | |
|--|--|
| East Surrey Aspergers Group | Foundation for People with Learning Disabilities |
| Ecas | Fragile X Society |
| Eddystone Trust Service Users | Gateshead Advocacy and Information Network (GAIN) |
| Edinburgh University Feminists | Gateshead's Physical Disability and Sensory Impairment Partnership |
| Elcena Jeffers Foundation (EJF) | Get Together Group |
| ENABLE ACE Annan Self Advocacy Group | Glasgow Homelessness Occupational Therapy Service |
| Enable Care and Home Support | Glasgow Housing Association |
| ENABLE Scotland | Gloucestershire Community and Adult Care Directorate |
| Enabling Radio Drama West Yorkshire | Great Yarmouth Borough Disability Forum |
| Enfield Disability Action | Greater Manchester Passenger Transport Executive (GMPTEx) |
| English Community Care Association (ECCA) | Greater Manchester Welfare Rights Advisers Group (GMWRAG) |
| Enham | Green Party of England & Wales |
| Epilepsy Action | Greenwich Association of Disabled People's Centre for Independent Living |
| Epilepsy Connections | Guildford Group |
| Epilepsy Scotland | Habinteg Housing Association |
| Equality and Human Rights Commission | Hackney Citizens Advice Bureau |
| Equality Network | Hackney Independent Forum for Parents/Carers of Children with Disabilities (HiP) |
| Essex Coalition of Disabled People (ECDP) | Halton LINK & the Halton Carers' Centre (joint response) |
| Every Disabled Child Matters (EDCM) | Hampshire County Council |
| FACT Bucks | Hampshire Personalisation Expert Panel (PEP) |
| Family Action | Haringey Disability First Consortium |
| Family Advice & Information Resource (FAIR) | Harlow Advocacy |
| Family Voice Norfolk | Harrow Association of Disabled People |
| Femauro | |
| Fibromyalgia Support Group for Surrey and Sussex | |
| Fife Society for the Blind | |
| Flourish House | |
| Footprint Down Syndrome Foundation | |

Organisations responding to Disability Living Allowance reform consultation

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|---|--|
| Hastings and Rother Disability Forum | Knightstone Housing Association |
| Hastings & Bexhill Mencap Society | Lambeth Pan Disability Forum |
| Headway – the Brain Injury Association | Langleys Solicitors |
| Headway East Lothian | Law Centre (NI) |
| Headway Glasgow | Learning Disability Alliance Scotland |
| Hear Here/Voice Glasgow | Learning Disability Coalition |
| Hertfordshire County Council | Learning Disability Wales |
| Hft (joint response with Speak Out North Oxford, Leeds and Kent groups) | Leicester City Council Welfare Rights Service |
| HOPE for Autism | Leicester City Learning Disability Partnership Board – Carers Action Group |
| HUG Action for Mental Health | Leicestershire AIDS Support Services (LASS) |
| Hypermobility Syndrome Association (HMSA) | Leicestershire County Council |
| Ideal for All (Sandwell) | Leicestershire Partnership NHS Trust |
| Inclusion London | Leonard Cheshire Disability |
| Inclusion Scotland | Limbless Association |
| Inclusive Mobility and Transport Advisory Committee (Imtac) | Livability |
| IncomeMAX | Liverpool Central Citizens Advice Bureau |
| Independent Living Fund | Liverpool Mental Health Consortium Service User Group |
| Inspire Community Trust | Living Well Borders Project |
| Interface | London Borough of Barnet Adult Social Services |
| Isledon Mental Health Resource Centre users' group | London Borough of Hounslow Welfare Benefits and Money Advice Unit |
| Isos Housing Group | London Welfare Rights Officers Group |
| James Rennie School – Specialist Communication & Interaction College | Long Term Conditions Alliance Scotland (LTCAS) |
| Joint Committee on Mobility for Disabled People (JCMD) | Lothian Centre for Inclusive Living (LCiL) |
| Kingsbridge Speaking Up group | Low Incomes Tax Reform Group (LITRG) |
| Kingston Centre for Independent Living | Lowe & Co Solicitors |
| Kingwood | Lowestoft & North Suffolk Branch of the National Autistic Society |

| Organisations responding to Disability Living Allowance reform consultation | |
|--|--|
| Lymphoma Association | National Association of Deafened People (NADP) |
| Macmillan Cancer Support | National Association of Independent Schools (NAIS) and Non-Maintained Special Schools (NASS) |
| Maidstone & Malling Carers Project | National Association of Laryngectomee Clubs (NALC) |
| Mantell Gwynedd County Voluntary Council | National Association of Welfare Rights Advisers (NAWRA) |
| Martha Trust | National Autistic Society (NAS) |
| Mayor of London | National Council on Inland Transport |
| MDF The Bipolar Organisation | National Deaf Children's Society (NDCS) |
| Mencap | National Kidney Federation |
| Mental Health Action Group (MHAG) | National Network of Parent Carer Forums Task Group |
| Merton and Lambeth Citizens Advice Bureaux | National Pensioners Convention |
| Merton People First Disability Support Group | National Rheumatoid Arthritis Society (NRAS) |
| Midland Heart | National Union of Students (NUS) |
| Milton Keynes Deaf Community | NAVCA (National Association for Voluntary and Community Action) |
| Mind in Croydon | Neath Port Talbot Disability Network |
| Mind Monmouthshire | Neurological Alliance of Scotland |
| Mobilise | Newcastle City Council Adult and Cultural Services Directorate Sensory Support Team |
| Momentum Scotland | Newcastle City Council Physical Disability Team (social work) |
| Motability | Newcastle Learning Disability Partnership Board |
| Motor Neurone Disease Association (MND) | Newcastle-upon-Tyne City Council Blue Badge team |
| MS Therapy Centres (Scotland) | Newham People First and Newham Coalition |
| Multiple Sclerosis Society | Newlife Foundation for Disabled Children |
| Muscular Dystrophy Campaign (MDC) and Trailblazers | NHS Lothian |
| Myalgic Encephalopathy (ME) Association | NHS Rotherham Occupational Health Advice Service (ROHAS) |
| Myeloma UK | |
| Myotonic Dystrophy Support Group (MDSG) | |
| National Advisory Council to The Thalidomide Trust | |
| National AIDS Trust | |

Organisations responding to Disability Living Allowance reform consultation

| | |
|--|--|
| Norfolk Coalition of Disabled People | Nottinghamshire Deaf Society |
| Norfolk County Council | Nystagmus Network |
| Norfolk Disabled Parents Alliance | One Voice 4 Parents |
| North Bank Forum | One Voice Parents Group in Coventry |
| North East Lincolnshire Down's Syndrome Support Group | Options for Life |
| North East Lincolnshire Local Involvement Network (NEL LINK) | Optua (East Anglia) |
| North East Sensory Services | Organisation of Blind African Caribbeans (OBAC) |
| North Lanarkshire Council: Housing and Social Work Services | PAMIS |
| North Lanarkshire Disability Access Panel | Papworth Trust |
| North Lanarkshire Disability Forum | Parent Carer Involvement Board and Hertfordshire Parent Partnership Service (joint response) |
| North Staffordshire Healthwatch | Parkinson's UK |
| North Tyneside LINK | Partners for Inclusion (Sheffield partnership board for people with physical, sensory & cognitive impairments) and Sheffield Centre for Independent Living |
| North Wales Brain Injury Service | Pembrokeshire Association of Voluntary Services (PAVS) and Disabilities Special Interest Network (DSIN) |
| North West Mental Health Welfare Rights Group | Pembrokeshire People First |
| North Yorkshire County Council Adult and Community Services Directorate | People First |
| Northamptonshire County Council | People First (Scotland) |
| Northern Ireland Assembly Committee for Social Development | Plymouth Area Disability Action Network (PADAN) |
| Northern Ireland Association for the Care and Resettlement of Offenders | Portsmouth Carers Centre |
| Northern Ireland Council for Voluntary Action (NICVA) | Portsmouth Disability Forum |
| Northern Ireland Human Rights Commission | Positive East |
| Northumberland County Council's Care and Wellbeing Overview and Scrutiny Committee | Powys People First (Brecon, Llandrindod Wells, Newtown, Welshpool and Machynlleth groups) |
| Nottinghamshire County Council | Preston DISC |
| Nottinghamshire County LINK Consultation Co-ordination Panel | Public and Commercial Services (PCS) Union |

| Organisations responding to Disability Living Allowance reform consultation | |
|---|--|
| Quarriers | Scarborough and Ryedale Carers Resource |
| RCT People First Rhondda | Scope |
| ReACH Forth Valley | Scottish Accessible Transport Alliance (SATA) |
| Redbridge Concern For Mental Health and RUN-Up (joint response) | Scottish Campaign on Welfare Reform (SCoWR) |
| Redbridge Disability Association | Scottish Consortium for Learning Disability |
| Redbridge LINK | Scottish Council on Deafness |
| Regional Disability Network West Midlands | Scottish Disability Equality Forum (SDEF) |
| Renfrewshire Access Panel and Renfrewshire Disability Network (joint response) | Scottish Independent Advocacy Alliance (SIAA) |
| Renfrewshire Council | Scottish National Federation for the Welfare of the Blind |
| Renfrewshire Link | Scottish Spina Bifida Association |
| Rescare – the Society for Children and Adults with Learning Disabilities and their Families | Scottish Trades Union Congress (STUC) |
| Restricted Growth Association | Scotts Project Trust |
| Ricability (Research Institute for Consumer Affairs) | Sense |
| Richmond Advice and Information for Disabled People (Richmond AID) | Sense Scotland |
| Richmond and Kingston ME Group | SHARE Community |
| Rights Advice Scotland | Sheffield City Council’s Adult Social Care Mobility Strategy Project Team |
| Ripon Physical and Sensory Impairment Group (RipPSI) | Sheffield Law Centre |
| RNIB Northern Ireland | Sheffield Mental Health Citizens Advice Bureau |
| Rotherham Occupational Health Advice Service | Shout Out: self advocacy group for adults with learning disabilities in Medway, Kent |
| Royal Borough of Kensington and Chelsea | Shropshire Parent and Carer Council |
| Royal British Legion | Sickle Cell Society |
| Royal College of Nursing | Sight sector response Wales (joint response – RNIB Cymru, Wales Council for the Blind, Vision Support, Sight Support, Vision Impaired West Glamorgan (VIWG) and Cardiff Vales and Valleys Institute For The Blind (CVV)) |
| Royal National Institute for Deaf People (RNID) | Skill: National Bureau for Students with Disabilities |
| Salford City Council | Skills for Care & Development (SfC&D) |
| Sandwell Council ASSIST | |

Organisations responding to Disability Living Allowance reform consultation

| | |
|---|---|
| SNAP Cymru | Suffolk County Council's Financial Inclusion & Advice Service |
| Social Care Institute for Excellence (SCIE) | Sunderland City Council, Health, Housing & Adult Services Directorate |
| Social Firms UK | Support in Mind Scotland |
| Social Inclusion Unit – City and County of Swansea | Surrey Coalition of Disabled People and Action for Carers Surrey (joint response) |
| Social Policy Research Unit, The University of York | Sussex Oakleaf Mental Health Day Care service users |
| Social Security Advisory Committee (SSAC) | Sandwell Visually Impaired (SVI) |
| South and Vale Carers Centre | Swansea Council for Voluntary Service |
| South Copeland Disability Group (SCDG) | SW Veterans Advisory & Pension Committee |
| South East London Aphasia Hub | Tai Pawb |
| South Hams Citizens Advice Bureau | Tameside Metropolitan Borough Council |
| South Lanarkshire Council Social Work Resources | Tayside Deaf Association Forum |
| South Norfolk Equalities Group | T Cell |
| South Wilts Mencap | Teignbridge Speaking Up group |
| South Yorkshire Centre for Inclusive Living | Tenovus |
| South Yorkshire Deaf community | Terrence Higgins Trust (THT) |
| Southampton City Council Adult Health and Social Care | The Access Group – Tunbridge Wells Borough Area |
| Speak Out in Hounslow | The Action Group |
| Spelthorne Home Improvement Agency | The Children's Society |
| Spinal Injuries Association (SIA) | The Dystonia Society |
| Spinal Injuries Scotland | The Federation of Private Residents' Associations (FPRA) |
| Spoke | The Forgotten Heroes |
| St Albans and Region Scope (Star Scope) | The Forum |
| St. Saviour's Centre for Deaf People | The Grace Charity for M.E |
| Standing Commission on Carers (SCOC) | The Haemophilia Society |
| STEPS | The Northern Ireland Welfare Reform Group |
| Stockport Libraries and Information Service (Welfare Rights team) | |

| Organisations responding to Disability Living Allowance reform consultation | |
|---|---|
| The Omnibus Partnership | The National League of the Blind and Disabled, |
| The Poverty Alliance | The Royal National Institute of Blind People, |
| The Rainbow Group | SeeAbility, Sense and Visionary) |
| The Wessex Autistic Society | Wales Council for Deaf People |
| Torbay Mencap Society | Wales Mobility and Driving Assessment Service |
| Torfaen County Borough Council | Waltham Forest Low Vision Forum |
| Tower Hamlets Local Authority Mobility Support Services | Waltham Forest People First |
| Trafford Council | Wansbeck Disability Forum |
| Transgender Wales | Watford Mencap |
| TreeHouse – the national charity for autism education | Wavertree Citizens Advice Bureau |
| Tunbridge Wells & District Citizens Advice Bureau | Welsh Assembly Government: Deputy Minister for Social Services |
| Turning Point | Welsh Local Government Association |
| Turning Point Scotland | West Lothian Council, Disability West Lothian and the West Lothian Disability Equality Community Forum (joint response) |
| UNISON | West Midlands Regional Network of Parent Carer Forums |
| UNISON Northern Ireland | WheelchairDriver.com Forum |
| UNISON South-West Region Disabled Members' SOG | Wiltshire and Swindon Users' Network (WSUN) |
| Unite – the Union | Wiltshire People First |
| Unite National Disabled Members Committee | Wirral Autistic Society |
| United Kingdom Disabled People's Council (UKDPC) | Wirral SILC (Supported Independent Living in the Community) |
| United Response | Wokingham Borough Council Service Users |
| University and College Union (UCU) | Working Families |
| Visual Impairment Sector (joint response with Action for Blind People, Deafblind UK, The Guide Dogs for the Blind Association, The Macular Disease Society, The National Blind Children's Society, The National Federation of the Blind of the United Kingdom | York Carers Centre and Candi (joint response) |
| | Your Life Your Choices Transition Project |
| | 25% ME Group |



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