Personal Independence Payment: second draft of assessment criteria

An explanatory note to support the second draft of the assessment regulations
Large print

November 2011

DWP Department for Work and Pensions

Contents

1. Executive summary

1.1 In December 2010, the Government published its proposals to introduce a new benefit, Personal Independence Payment, from 2013/14. This would replace Disability Living Allowance for eligible working age claimants (aged 16 to 64).

1.2 At the heart of these proposals was the development of an assessment for the new benefit which would enable an accurate, objective, consistent and transparent consideration of individuals. In May of this year, following a collaborative development process with an advisory group of relevant specialists, the Department published its initial proposals for the criteria to be used in this assessment. These proposals were in the form of draft regulations and a supporting technical note.

The informal consultation

1.3 During the summer, we consulted on the initial draft criteria, to hear from disabled people and their organisations how well the proposals would be likely to work and if they could be improved. We met with around 60 user-led and representative organisations and received over 170 written responses, from both organisations and individuals.

1.4 Respondents raised a number of key themes as well as detailed comments on the proposed activities and descriptors. Some of the comments which were made most frequently were:

- There were strong feelings that the initial proposals did not adequately assess disability-related costs, and that issues such as utility bills, access to transport and suitability of housing should be included.

- Suggestions were made that the criteria should include additional activities such as leisure or community activities, social relationships and housework.
- It was often felt that the criteria were too low level and did not fully assess ability to participate.
- Concern was expressed that the draft criteria did not consider supervision and that the assessment required too high a level of support from another person. It was also questioned why the criteria did not explicitly assess night time needs separately from day time needs.
- Respondents strongly welcomed the inclusion of an activity assessing communication ability. However, it was generally felt that the initial proposals assessed too basic a level of ability and did not capture social engagement and ability to access written information.
- A large number of responses questioned why ability to manage everyday finances was limited to planning and buying food and drink; it was suggested that this should be widened to general budgeting or financial management.

Refining the draft criteria to produce a second draft

1.5 Taking account of the feedback we received through the summer consultation, we have developed a second, revised draft of the assessment criteria. While it has not been possible to reflect all comments, these proposals build heavily on the views of disabled people and their organisations. As a result of the changes which have been made, we believe that the second draft of the criteria enable a fairer assessment of an individual's ability to participate than the initial draft.

1.6 Some of the key changes that have been made to the draft criteria are:

- To ensure that the assessment adequately takes account of where the presence of another person is needed, the criteria now refer to supervision from another person where this is required to enable an individual to carry out an activity safely. This is similar to the approach taken in Disability Living Allowance.
- Descriptors continue to be considered in light of whether they apply for the 'majority of the time', which has been defined as on the majority of days. However, to ensure that the impact of a fluctuating condition is accurately captured, where two or more descriptors in an activity apply on less than 50 per cent of days individually but reach this threshold when combined, the descriptor which applies for the greatest proportion of the time will apply.
- For clarity and to ensure a broader assessment of ability to make everyday decisions, the previous *Planning and buying food and drink* activity has been replaced with the new activity 9, *Making financial decisions.*
- The previous *Communicating with others* activity has been split into two new activities: *Communicating* and *Engaging socially*. The former focuses on expressive and receptive communication and accessing written information; while the latter assess ability to interact with others in a contextually and appropriate manner, understand body language and establish relationships. This change should enable a more accurate assessment of an individual's ability to communicate.
- A number of the definitions used within the criteria have been broadened. For example, a 'simple meal' is now one made only from fresh ingredients, not frozen (*Preparing food and drink*); medication and therapy may now be recommended as well as prescribed (*Managing*

therapy or monitoring a health condition); and communication support can be from a person experienced in communicating with the individual, as well as from someone who is trained to provide such support (*Communicating*).

- To ensure that the assessment does not unfairly penalise individuals who choose to use aids and appliances to improve their independence, the assessment now also considers cheap, widely available aids and appliances which can 'reasonably be expected' to be used, in a similar way to Disability Living Allowance. We also recognise that aids and appliances do not necessarily remove barriers and may attract costs; therefore descriptors which refer to these normally attract a scoring descriptor.

1.7 The second draft also includes our initial thoughts on possible weighting of descriptors. These have been developed following consideration of the comments received on the first draft, discussion with our advisory group and qualitative and quantitative analysis of some of the initial testing results. We know that it is crucial to get these weightings right and we are publishing our proposals now to enable a meaningful debate. We do yet have firm views on the entitlement thresholds for the rates and components for the benefit. This information will be published as soon as possible.

Testing our proposals

1.8 Alongside the informal consultation, we carried out a testing exercise during the summer, considering volunteers who currently receive or have previously claimed Disability Living Allowance against the draft criteria. Around 900 volunteers from Great Britain and 180 from Northern Ireland took part, which involved having a single face-to-face appointment with a health professional.

1.9 The detailed information gathered at these appointments enabled us to test whether the proposals were accurately and consistently identifying individuals' level of need. We found that the second draft of the assessment criteria identified individuals' levels of need more accurately and consistently than the initial proposals.

1.10 While the data gathered during the testing will enable us to better understand the likely impact of the proposals, we are not yet in a position to estimate this. In particular, firm views on the entitlement thresholds for the rates and components for the benefit are necessary to enable us to model the impact of the second draft. The findings of this part of the testing will therefore be published at a later date.

Developing the draft criteria further

1.11 We view the development of the assessment criteria for Personal Independence Payment as an iterative process and we recognise that these proposals may require some further refinement. We intend to discuss this draft with disabled people and their organisations and to consult formally once we have firmer views on the descriptor weightings and likely entitlement thresholds. In the meantime, we would welcome any comments people have on the changes we have made.

2. Introduction and context

2.1 Since late last year, the Department for Work and Pensions has been developing proposals for the assessment criteria for Personal Independence Payment – the benefit with which the Government intends to replace Disability Living Allowance, for individuals aged 16 to 64, from 2013/14. These criteria will assess an individual's ability to participate in society, as a proxy for the impact of disability and the extra costs disabled people can face.

2.2 We have approached this work with a number of key principles in mind. We want to develop criteria which are clear to understand and apply; consistent in their outcome; consider the impact of impairments rather than what the impairments are; fairly take account of all impairment types; and accurately assess variable and fluctuating ability. The development of the criteria is an iterative process and throughout we have been keen to learn from the experience and expertise of disabled people. We have therefore tried to have open discussions about our emerging proposals as early on as possible, to enable adequate time to address and reflect feedback both from disability organisations and from disabled people themselves.

2.3 The Department has been supported in developing the assessment criteria by an advisory group of relevant specialists in disability, social care and health. This Assessment Development Group was established to provide technical expertise and membership was chosen to reflect a broad understanding of the impact of disability and experience of working with disabled people. We believe that good consensus has been achieved both within the Group and between the Group and Departmental officials on the second draft of proposals for the assessment criteria.

However, ultimately these proposals should be viewed as the Department's and not the Group's.

2.4 As the primary legislation for this reform continues its passage through Parliament, this document aims to enable further discussion on our proposals and to provide context to the second draft of the assessment regulations, published concurrently. The final draft regulations for the assessment will not be laid until 2012, subject to Royal Assent of the Bill, and will be subject to Parliamentary scrutiny through the affirmative procedure.

The development process since May 2011

2.5 We published our initial proposals for the assessment criteria for Personal Independence Payment on 9 May 2011, to provide an early opportunity for disabled people and their organisations to comment and help to shape the development process. Between May and August, we met with around 60 disabled people and their organisations as well as receiving 173 written submissions from both organisations and individuals as part of an informal consultation.

2.6 We also wanted to know how the initial proposals would work in practice, how the descriptors would be applied to a range of individuals, whether this would adequately reflect their circumstances and whether there would be aspects of need missed. To enable this, we carried out a testing exercise across the UK between May and September using around 900 volunteers from Great Britain and 180 from Northern Ireland, who were considered against the first draft of the criteria without affecting their current or future benefit entitlement. Once we have firmer views on the descriptor weightings and, in particular, the possible entitlement thresholds for the benefit, the data we have gathered will also enable us to understand what the likely impact on numbers of people claiming the benefit would be.

2.7 Having considered both the initial testing findings and the feedback received through the summer informal consultation, we sought to improve upon our initial proposals to produce a second draft of the assessment criteria. We also tested whether this revised draft accurately and consistently identified individuals' levels of need.

The purpose of this document

2.8 This document explains where we revised the first draft assessment criteria and how this was influenced by feedback and testing, as well as accounting for where changes have not been made. We have included our initial thoughts on descriptor weightings.

2.9 To ensure that we get the criteria right, we want to build upon the views of stakeholders and in particular, the experience and knowledge of disabled people to refine our proposals further where necessary. For this reason, we will be seeking views from disabled people and their organisations on the changes we have made and intend to carry out a formal consultation once we have firmer views on descriptor weightings and entitlement thresholds.

What this document does not cover

2.10 As with the technical note we published in May, this document does not consider the delivery of Personal Independence Payment assessments as work on the claims and assessment processes of the new benefit is still ongoing. It considers only the work undertaken to develop the second draft of the assessment criteria. However, we are able to be clear on a few points:

- For all claims, decisions on entitlement will involve consideration of evidence from a range of sources – such as professionals involved in supporting the individual and of course from the individual themselves.

Individuals will be able to advise us on the best sources of supporting evidence.

- Individuals' claims for the benefit and supporting evidence will be considered by an independent assessor, probably a health professional, working on behalf of a third party supplier. The Department has recently begun a tendering exercise to identify the third party supplier.
- The assessor will provide advice to a Departmental decision maker who will make the final decision on entitlement to the new benefit, using all the available evidence.
- Both the assessor and the Departmental decision maker will have appropriate training, guidance and support to carry out their roles effectively. We will seek to work with disabled people and their representatives on the development of this.
- Most individuals will have a face-to-face consultation with the assessor as part of their claim. This will provide individuals with an opportunity to explain how their impairment affects their everyday lives.
- Decisions on where a face-to-face consultation would not be appropriate will be made on a case-by-case basis as impairments affect people in very different ways. For example, this is likely to apply to individuals with the most severe impairments, or where we already have enough evidence to determine entitlement.
- Individuals will be able to bring another person such as a family member, friend, carer or advocate with them to the face-to-face consultation, where they would find this helpful.

3. The informal consultation: what you told us

3.1 The first draft of the assessment criteria represented our initial views on how to ensure that priority in Personal Independence Payment goes to those most affected by their health condition or impairment. We know the importance of getting this right, which is why we sought views on how well the draft criteria might work and if they could be improved, through a 16-week informal consultation period.

3.2 Between 9 May and 31 August, we received 78 submissions from organisations and 95 written responses from individuals. We also met with around 60 user-led and representative disability organisations in order to hear their comments on the draft criteria first hand, both through group discussions with several organisations and one-to-one meetings. A list of the organisations with whom we met, or who submitted written responses, can be found at Annex D.

3.3 This informal consultation period was immensely helpful. Many responses, both written and verbal, provided similar general comments on our initial proposals and we have grouped these below into several overarching themes. We also received detailed comments on specific activities and the wording of some descriptors and we have covered this feedback in more detail on pages 20-27.

3.4 Many responses included feedback on the assessment process to be used for Personal Independence Payment. For example, comments were made regarding:

- The importance of ensuring high-quality training and guidance for both assessors and Departmental decision

- The need to use assessors with appropriate skill sets.
- Allowing an advocate, family member or carer to also attend the face-to-face consultation.
- The importance of taking account of additional evidence and where this would fit into the overall process.
- The need to reflect the recommendations from Professor Malcolm Harrington's independent review of the operation of the Work Capability Assessment, where these are relevant to Personal Independence Payment.

3.5 These issues are not discussed here as the informal consultation was focused on the detail of the assessment criteria. However, we recognise that they are nonetheless important issues and they are being actively considered as part of the development of the claim and assessment processes for the new benefit.

The activities to be assessed

The initial proposals

The first draft of the criteria proposed assessing the impact of impairments on an individual's ability to carry out everyday activities, acting as proxies for ability to participate. As it would not be possible to assess all activities, only those which we felt to be most important for enabling participation were included. These were:

Daily Living component

1 *Planning and buying food and drink*
2 *Preparing and cooking food*
3 *Taking nutrition*
4 *Managing medication and monitoring health conditions*
5 *Managing prescribed therapies other than medication*
6 *Washing, bathing and grooming*
7 *Managing toilet needs or incontinence*
8 *Dressing and undressing*
9 *Communicating with others*

Mobility Component

10 *Planning and following a journey*
11 *Moving around*

Your responses

3.6 Many respondents felt that the proposed activities were too low-level and the approach too medical, focusing on simply surviving rather than full ability to participate. A number of responses also expressed concern that the activities chosen lacked flexibility and therefore would not be able to capture accurately the impact of a health condition or impairment on an individual's ability to participate.

3.7 It was suggested that the criteria did not include some additional activities which were felt to be equally key to enabling participation. For example:

- Including leisure or community activities and what an individual would like to do, but may need support to do. It was felt that this would provide a better assessment of an individual's ability to participate.
- Taking account of an individual's social context, such as ability to form social relationships, carry out parenting activities and access informal support networks.
- Considering ability to do housework, clean clothes and maintain a safe home environment. These issues were felt to be important both in terms of enabling social participation and safeguarding health.
- A broader approach to assessing ability to manage finances – for example, to include household bills, insurance and bank accounts.
- While the inclusion of a specific activity assessing communication ability was strongly welcomed, there was concern that the initial proposal assessed too basic a level of ability and did not capture social engagement and accessing written information.

3.8 Across responses there was a general concern that the proposed approach would result in individuals with lower level needs not being entitled to Personal Independence Payment. It was often suggested that without this support, these individuals would be unable to remain independent; and that this would undermine the role of the benefit in preventing circumstances worsening and therefore reducing individual reliance on state support.

Taking greater account of extra costs

The initial proposals

Like Disability Living Allowance, Personal Independence Payment will provide a contribution towards the extra disability-related costs an individual may incur. Rather than assess the actual extra costs incurred by an individual, which could be subjective, inconsistent and expensive to administer, we proposed assessing ability to carry out key everyday activities.

Your responses

3.9 Many respondents raised strong concerns that some key drivers of extra disability-related costs would not be adequately captured through an assessment of the above activities. It was felt that the criteria would therefore not enable support to be targeted at those individuals who incurred the greatest additional costs. The most common suggestions of environmental and social barriers which were not being adequately taken into account were utility bills; cost of aids, appliances and adaptations; access to transport; and suitability of housing.

3.10 To enable extra costs arising from these environmental and social barriers to be directly assessed, some respondents suggested that additional activities should be included. Others felt that these issues could be incorporated into the existing activities and descriptors.

Capturing fluctuations in ability

The initial proposals

The first draft suggested that an individual's ability to carry out the activities should be considered over a 12 month period, in order to enable a more coherent picture of the impact of impairments. The activity descriptor which applied for the 'majority of the time' – for six months when aggregated across a 12-month period – should be chosen. If several descriptors within an activity could apply, the appropriate choice would be the one which applied for the greatest proportion of the time.

In all cases, an individual would need to be able to complete an activity descriptor 'safely, reliably, repeatedly and in a timely manner' in order for that descriptor to apply. For example, if an individual could dress unaided but it would take them a very long time to do so and would lead to exhaustion, they would be considered unable to dress unaided and a higher scoring descriptor would instead apply.

Your responses

3.11 While there was general support for assessing ability over a 12 month period, a number of respondents remained unsure that the criteria would be able to accurately capture variations in ability. Particular examples given included progressive health conditions and those whose impact may differ according to the weather. Similarly, there were concerns that using a 'majority of the time' approach would not take account of short, acute episodes of severe impairment. To counter this, it was suggested that a measure of frequency, severity and duration might be more appropriate.

3.12 There was strong support for considering whether an individual could do an activity 'safely, reliably, repeatedly and in a timely manner'. To ensure that these factors are taken into account, many organisations felt that this wording should be included within the criteria and/or regulations, rather than only in guidance. This suggestion was supported by the fact that a large number of respondents questioned whether the proposals took adequate account of safety of self and others, in particular the issues of risk; recognising hazards; the impact of pain and fatigue; and where carrying out the activities may cause deterioration to an individual's health.

Reflecting support required from another person

The initial proposals

The initial draft criteria took account of where individuals would need the support of another person to carry out an activity. It was proposed that two types of support should be considered, each defined as follows:

- **Assistance**: Support requiring the physical presence and physical intervention of another person, i.e. actually doing the task in question
- **Prompting**: Support provided by reminding or encouraging an individual to undertake or complete a task but not physically helping them; also requiring the physical presence of an individual.

The amount of support required was defined either as ***continual***, where support was provided for the entire duration of the activity; or ***intermittent***, where the support was provided for over half the time taken to complete the activity.

Your responses

3.13 Many respondents felt that the definitions of‘continual’ and ‘intermittent’ were difficult to apply and that the thresholds were set too high – particularly for ‘intermittent’ support. It was also suggested that the differentiation between ‘intermittent’ and ‘continual’ support was ineffectual as, in practice, both may require similar support levels or incur similar cost.

3.14 A number of respondents felt that the focus on support was too physical. In particular, concerns were raised that ‘prompting’ did not feature often enough in the criteria; that it was not given enough weight when it did feature; and that the definition used did not adequately encompass the support which may be required. Examples given included the need for a greater consideration of motivational issues; discouraging an individual from harmful activity; warning an individual of danger; and reassuring an individual experiencing distress. Similarly, it was questioned why the use of assistive technology, including telecare and telephone prompting, was excluded from the definition of ‘prompting’.

3.15 Strong concerns were raised that the proposed approach to look at support required from another person did not capture the requirement for the continual presence of another person to ensure the individual’s or others’ safety, similar to the concept of ‘supervision’ within Disability Living Allowance. In particular, responses highlighted the need for supervision where an individual may be unable to recognise or react to danger; to safeguard vulnerability and protect against exploitation; and to prevent deliberate self-harm.

Accurately assessing all impairments

The initial proposals

We want the assessment criteria for Personal Independence Payment to take a comprehensive approach to disability, reflecting the needs arising from the full range of impairments. The initial proposals were therefore developed to consider a broad range of everyday activities and assess the impact of impairments on ability to carry these out, regardless of the nature of that impairment. We do not want to create criteria which prioritise support to individuals with a physical impairment over those with mental health conditions or cognitive or intellectual impairments where the overall impact on participation is the same – as can often happen with the Disability Living Allowance assessment.

Your responses

3.16 There was general support for the principle of creating criteria which accurately assess the impact of all impairments. However, many respondents did not feel that the initial proposals achieved this aim. While a small number believed that the criteria gave too much weight to mental health conditions, a more frequent response was that the draft criteria focused too heavily on physical impairments. The most common suggestions of impairments which were not adequately captured were sensory impairments, learning disabilities, mental health conditions and autistic spectrum disorders. More specifically, concerns were raised that the criteria did not take enough account of a lack of insight; motivational issues; memory problems; support for challenging behaviour; self-neglect; and self-harm.

3.17 A number of responses expressed concern that the proposed activities and component structure would prevent an accurate consideration of impairments which impact on

ability to move around or to communicate. It was felt that the two activities proposed for the Mobility component (*Planning and following a journey* and *Moving around*) presented too simplistic an approach and that more proxies were required; or that the threshold for entitlement to the component was likely to be too high. In a similar vein, it was suggested that communication ability should be assessed as a third component, rather than as part of daily living or mobility activities, to ensure that impairments impacting upon ability to communicate received due consideration.

3.18 There was also some concern that the criteria would not accurately reflect the support requirements for individuals with lower level needs across a number of the activities. Respondents felt that such individuals would not gain sufficient priority to be entitled to the new benefit, even though their overall need for support may be greater than another individual who scored highly in just one activity. Such responses suggested that weightings should be aggregated across all the activities, rather than relating to a particular component, to better reflect the cumulative impact of impairments. Similarly, a few respondents questioned whether the criteria were flexible enough to take adequate account of interaction effects, where barriers for one activity may impact on ability to carry out another.

How aids and appliances should be considered

The initial proposals

The first draft took account of aids and appliances that are normally used by an individual in their everyday lives:

- **Aids** were defined as devices which helped the performance of a function, for example walking sticks or spectacles.
- **Appliances** were defined as devices which provided or replaced a missing function, for example artificial limbs, collecting devices (stomas) and wheelchairs.

Recognising that some aids and appliances attract significant ongoing costs, the draft criteria attempted to reflect this where appropriate. For example, the descriptors for activity 11, *Moving around*, differentiated between the use of manual aids and wheelchairs or assisted aids, with the latter descriptors ('E' and 'F') being likely to be weighted more highly than the former ('A', 'B' and 'D'). Individuals who used aids or appliances would therefore generally receive more priority than those who could carry out the activity unaided.

Your responses

3.19 There were a considerable number of comments made on our approach to considering the use of aids and appliances in the assessment criteria. Organisations in particular questioned whether using aids and appliances would still enable an individual to receive the new benefit. Some respondents were concerned that taking them into account might penalise individuals who have higher levels of independence as a result of using aids. Only a few

organisations suggested removing all consideration of the use of aids and appliances from the criteria.

3.20 Many respondents argued that the use of an aid or appliance does not necessarily remove a barrier to participation. For example, it was particularly highlighted that using a wheelchair could be affected by obstacles and social and environmental barriers, such as accessible transport and shops. It was also felt that the criteria should recognise the upfront and ongoing costs associated with aids and appliances; that they may not be freely or cheaply available; or an individual may choose not to use them.

3.21 There was strong support for only taking account of aids and appliances which are being used, rather than all those which might theoretically help. However, a number of respondents were concerned that this might penalise individuals who try to overcome barriers. Similarly, it was questioned whether the approach would create incentives for individuals to not use aids or appliances, as doing so could potentially reduce their entitlement to Personal Independence Payment.

3.22 A few respondents felt that prostheses should not be considered appliances.

Weighting the activities and descriptors

The initial proposals

When the assessment criteria are finalised, each descriptor will have a weighting attached to it, reflecting both level of ability and the overall importance of that activity. Whether an individual is entitled to the rates and components of Personal Independence Payment will be determined by adding up the descriptor weightings which apply to that individual.

The cumulative weightings for all the daily living activities will determine entitlement for the Daily Living component, while the cumulative weighting for the mobility activities will determine entitlement for the Mobility component. Each component will be payable at either a standard or enhanced rate, determined by the level of cumulative weighting individuals receive.

The first draft of the assessment criteria did not include descriptor weightings or thresholds for entitlement to the rates and components of the new benefit, as we did not have firm views on these. Instead we provided an indicative weighting of low, medium or high scoring for the activities, to demonstrate the relative importance of each within the assessment, as follows:

1 *Planning and buying food and drink* – medium scoring
2 *Preparing and cooking food* – medium scoring
3 *Taking nutrition* – medium scoring
4 *Managing medication and monitoring health conditions* – low scoring
5 *Managing prescribed therapies other than medication* – low scoring
6 *Washing, bathing and grooming* – medium scoring
7 *Managing toilet needs or incontinence* – medium scoring
8 *Dressing and undressing* – medium scoring
9 *Communicating with others* – high scoring
10 *Planning and following a journey* – high scoring
11 *Moving around* – high scoring

Your responses

3.23 Many responses – those from organisations in particular – said that without the inclusion of descriptor weightings and entitlement thresholds for the rates and components of

Personal Independence Payment, it was difficult to understand the impact of the criteria and therefore to comment fully on the proposals.

3.24 Notwithstanding the above point, a large number of respondents suggested that activity 4 (*Managing medication and monitoring health conditions*) should be weighted as medium or high scoring, rather than low, in recognition of the potential for a severe adverse effect if vital medication is not taken. A smaller number suggested that activity 5 (*Managing prescribed therapies other than medication*) should be medium scoring, rather than low; and that activities 2 (*Preparing food and drink*), 3 (*Taking nutrition*), 7 (*Managing toilet needs and incontinence*) and 8 (*Dressing and undressing*) should be highly weighted, rather than medium.

Assessing ability across 24 hours

The initial proposals

The initial draft criteria for Personal Independence Payment did not differentiate between assessing an individual's ability to carry out the activities during the day and during the night. Instead, the assessment would consider the time of day when each activity usually takes place. For example, preparing food and drink would usually take place during the day; while management of toilet needs and incontinence may take place during the day or the night.

Your responses

3.25 Many responses expressed concern with this approach, particularly organisations, often referring to the Disability Living Allowance assessment which explicitly assesses an individual's support needs during the day and night. Such respondents felt that an individual may have greater support

needs during the night, or that support may be less available at this time. Specific examples of this which were given included disturbances in sleeping patterns; managing medication throughout the night; pain management; or support for toilet needs.

Assessing ability, not disability

The initial proposals

When developing the criteria, we wanted to create a more active and enabling benefit which considers an individual's ability rather than focusing on disability. To reflect this, the initial draft was written in positive language wherever possible. In particular, the bottom descriptors for each activity – which would apply if an individual could not do the activity at all – were written in this manner. For example, the last descriptor for activity 3, *Taking nutrition*, was worded as 'Can take nutrition only with continual assistance'.

Your responses

3.26 It was apparent from the comments received that the positive language used often made it unclear which descriptor would apply. There was concern that there were not appropriate descriptors for individuals who could not complete all, or parts of, an activity. For example:

- It was questioned why only activities 9 (*Communicating with others*) and 11(*Getting around*) seemed to have a descriptor which applied if an individual could not do the activity at all.
- It was queried why descriptor 'D' in activity 1 (*Planning and buying food and drink*) was not worded more simply as 'Cannot plan food and drink'.

- It was noted that activity 10, *Planning and following a journey*, had only two descriptors ('B' and 'D') which focused on what an individual cannot do.

In general, many respondents – particularly individuals – said it was important for the criteria to consider what an individual cannot do, not only what they can do.

Comments on specific activities and descriptors

Activity 1: Planning and buying food and drink

The initial proposals

This considered the mental, intellectual and cognitive ability of individuals to plan and buy food and drink for themselves, including therapeutic diets. It assessed ability to determine what food and drink was reasonably required for sustenance; to choose appropriately; to budget and prioritise the money required; and to purchase food and drink. Physical ability to shop was not considered directly as the component parts were assessed as elements of other activities.

Your responses

- Many responses were concerned that budgeting for food was not a broad enough measure of an individual's ability to manage day-to-day finances.
- Some respondents felt that this activity should consider ability to carry out other essential shopping, such as for clothing.
- It was questioned why this activity did not assess physical ability to buy food and drink, including the impact of sensory impairment. Such responses often

highlighted issues such as identifying food and drink, recognising money, getting to a shop and unpacking shopping.

- In a similar vein, several responses highlighted the extra costs associated with buying food online and having to get it delivered.
- A number of organisations felt that special dietary requirements and the ability to understand what constitutes appropriate food and a healthy, balanced diet should be captured, as well as the extra costs this may cause.
- Some organisations felt that motivational issues and obsessive behaviour should be captured.

Activity 2: Preparing and cooking food

The initial proposals

This considered an individual's ability to prepare either a simple meal or an uncooked snack, due to the impact of impairments on the tasks required. A 'simple meal' was a one-course meal for one prepared from either fresh or frozen ingredients. The activity assessed ability to open packaging; serve food; pour a drink; peel and chop food; and use a microwave oven or cooker hob to cook or heat food. It assumed that all actions were carried out at waist level.

Your responses

- It was suggested that the descriptors did not reflect the impact of visual impairment. In particular, the ability to read sell-by dates or cooking instructions, to check that food is fresh and/or cooked, and to avoid burns.
- Some responses raised concerns that this activity did not take adequate account of the impact of mental

health conditions, such as motivational issues, a lack of appetite, concentration and eating disorders.

- It was questioned why the descriptors did not reflect a need for intermittent assistance and/or prompting.
- Several respondents – organisations in particular – expressed concern that use of a microwave was included and that a 'simple meal' could be prepared from frozen ingredients. It was questioned whether this implied that the Government thinks disabled people should not have a healthy diet. It was also noted that using a microwave could be more expensive.
- A number of respondents felt the assumption that this activity was carried out at waist height did not fully consider environmental barriers or safety issues, or take account of accessing food stored in cupboards, a refrigerator or a freezer.

Activity 3: Taking nutrition

The initial proposals

This assessed an individual's ability to be nourished, either by cutting food into pieces, conveying to the mouth, chewing and swallowing; or through the use of therapeutic sources (enteral or parenteral feeding).

Your responses

- Several respondents felt that this activity did not take adequate account of the impact of mental function impairments, such as motivational issues; a lack of appetite; eating disorders; and whether an individual was able to eat appropriate portion sizes at appropriate times.
- It was suggested that help with identifying and cutting up food should be included.

- A few respondents raised concerns that this activity would not recognise the additional help needed by an individual who requires small but frequent meals.

Activity 4: Managing medication and monitoring health conditions

The initial proposals

This considered an individual's ability to take prescribed medication at the right time and to monitor and detect changes in a health condition, without which their health was likely to deteriorate significantly. The descriptors assessed the frequency of support required. The ability to convey items to the mouth was not considered, as the same ability was assessed in activity 3 as part of ability to convey food to the mouth – i.e. the actions required in putting tablets in ones mouth and drinking water are the same as required during eating and drinking. Individuals at risk of accidental or deliberate overdose or deliberate self harm were captured, as support would be required from another person in order to safeguard against this.

Your responses

- The potential cost of prescriptions in England was highlighted by a number of organisations, who felt that this additional cost should be explicitly included within the criteria.
- A number of respondents felt that the impact of side effects from medication should be reflected.
- It was questioned whether this activity would take account of necessary emergency medication.
- Several respondents felt that the impact of visual impairment was not fully captured. For example, prompting required to ensure the right medication is taken at the right time; self-managing a health condition;

and help required to label and collect prescriptions.

- There was concern from some respondents that the focus on frequency of support may mean that individuals with moderate but more frequent needs may receive higher priority than those with less frequent but severe needs.
- A number of responses suggested that medication should not be limited to that prescribed. It was suggested that this would better reflect individuals' choices about what works best for them, as well as reflecting that the existence of prescribed medication does not necessarily reflect the severity of impairments.
- Some respondents felt that this activity should explicitly cover deliberate self-harm and overdose.

Activity 5: Managing prescribed therapies other than medication

The initial proposals

This sought to identify an individual's ability to manage long-term, prescribed, non-pharmaceutical home therapeutic activities, without which their health is likely to deteriorate significantly. The descriptors assessed the duration of support required, according to the type of procedure undertaken.

Your responses

- A number of organisations felt that 'prescribed therapies' was too narrow in focus. Respondents suggested widening the definition to include 'recommended' therapies, to reflect choice and control and that individuals may also benefit from non-prescribed therapies.
- A few responses questioned why the therapies had to

take place at home.

- Several responses suggested that this activity should take account of condition management more widely, including a healthy lifestyle and ability to adhere to a fitness programme.
- A number of respondents felt that the activity appeared to be focused heavily on therapies relevant to physical function impairments.
- It was questioned why there was no descriptor for managing prescribed therapies only with continual assistance.

Activity 6: Washing, bathing and grooming

The initial proposals

This assessed an individual's ability to wash (clean face, hands and underarms), to bathe (clean face, hands, underarms and torso) and to groom (to brush teeth and brush and wash hair), to a level above 'self-neglect' (socially unacceptable). Shaving was not explicitly considered as the same broad ability was assessed as part of brushing teeth and brushing and washing hair. Ability to clean the perineum was excluded as this was included in activity 7.

Your responses

- Strong concerns were raised in many responses about the phrase 'to a level above self-neglect'. Some suggested that this should be replaced with a broader definition which better reflected a socially appropriate level of cleanliness.
- A number of respondents, particularly organisations, suggested that this activity should include the ability to shave, to apply make-up and to cut fingernails and/or toenails.

- Many responses questioned why the ability to wash lower limbs and/or feet was not included.
- It was felt that the impact of a mental health condition was not adequately captured, for example where motivational issues may mean that prompting is needed to carry out the activity.
- Several respondents felt that the ability to wash the perineum should be included in this activity, rather than as part of activity 7.

Activity 7: Managing toilet needs or incontinence

The initial proposals

This considered an individual's ability to get on and off the toilet; to clean afterwards; and to manage evacuation of the bladder and/or bowel, including the use of collective devices. It did not include washing self and changing clothes. For the purposes of this activity, individuals with catheters and collecting devices were considered incontinent. Ability to manage menstruation was not explicitly assessed as the necessary activities were considered to be similar to those required to manage toilet needs.

Your responses

- Several respondents felt ability to manage menstruation differed to ability to manage toilet needs and should therefore be assessed separately.
- A number of responses suggested that support required to manage toilet needs might be greater at night and that this should be taken into account.
- Some respondents suggested that ability to get to the toilet should also be considered within this activity.
- It was felt that barriers which impact on ability to manage toilet needs when outside the home should be

considered. For example, the ability to find public toilets; the availability of handrails; and anxiety about managing toilet needs or incontinence when out.

- A few respondents felt that that the descriptors should include the ability of an individual to wash themselves, change their clothes and carry out any extra toilet cleaning required.
- It was questioned why there was no descriptor to capture when prompting is required for an individual to go to the toilet.

Activity 8: Dressing and undressing

The initial proposals

This assessed an individual's ability to appropriately select, put on and take off culturally appropriate and un-adapted clothing, including the need for fastenings such as zips or buttons. It did not include putting on a tie or tying shoe laces.

Your responses

- A number of respondents believed that the ability to select and shop for co-ordinated and appropriate clothing should be incorporated.
- It was felt that this activity should include the ability to know whether clothing is clean or dirty.
- A number of respondents felt that this activity should include consideration of ability to wash, dry and iron clothes.
- A few respondents felt that this activity did not adequately reflect prompting which may be needed by individuals with mental health conditions, to encourage them to get dressed and undressed.
- It was suggested that ability to put on socks and shoes

and to tie ties and shoelaces should be included.

Activity 9: Communicating with others

The initial proposals

This sought to identify an individual's ability to engage socially (interact with others in a contextually and socially appropriate manner, understand body language and establish relationships), convey information to and understand other people. The need for communication support was included – defined as either support from a person trained to communicate; or appropriate aids or appliances. The descriptors took account of overwhelming psychological distress and uncontrollable behaviour and distinguished between ability to convey a choice and a basic need. The activity did not include ability to access written information as this was assessed elsewhere, for example in activities 2 and 10.

Your responses

- There were strong concerns that this activity did not take account of ability to process and understand written information.
- It was suggested that the descriptors should reflect the impact of a memory deficit.
- A few respondents felt that if an individual relies on another person for communication support, the individual should be assessed as having a continual need for support.
- It was strongly felt that restricting 'communication support' to support from trained individuals was too narrow and did not reflect the fact that support may be given by a friend, family member or carer.
- A number of respondents felt that this activity confused

capacity and decision making with communication, and that it did not capture the support needed by individuals who may be vulnerable due to acquiescence.

- The recognition of the impact of psychological distress was welcomed but there was strong concern about the proposed threshold of 'overwhelming' for such distress to be taken into account.
- A few responses argued that the immediate environment could have a substantial impact on an individual's ability to communicate. For example, whether there is a lot of background noise; if communication is one-to-one or in a group; or the familiarity of the situation.

Activity 10: Planning and following a journey

The initial proposals

This assessed an individual's mental, intellectual and cognitive ability to work out and safely follow a route for a journey. The descriptors took account of the impact of overwhelming psychological distress and whether the journey was simple (to a familiar destination and/or using a single mode of transport) or complex (to an unfamiliar destination and/or using several modes of transport). Guide dogs were not considered aids or appliances.

Your responses

- A number of respondents questioned why this activity did not apply to individuals with physical function impairments, other than those with sensory impairment. It was felt that such individuals may need support with extensive planning and/or physical access barriers.
- The definitions used for 'simple' and 'complex' were generally believed to be unhelpful and it was recommended that only 'familiar' and 'unfamiliar'

journeys should be considered.

- A few responses suggested that all journeys requiring more than one mode of transport should be considered ‘unfamiliar’.
- Many responses expressed concern that the descriptors did not take account of the impact of an unexpected disruption to a journey.
- A number of respondents felt that this activity did not capture the support needed by individuals who may be particularly vulnerable around strangers.
- There was strong concern about the proposed threshold of ‘overwhelming’ for psychological distress to be taken into account.
- It was suggested that spatial awareness, the ability to orientate independently and the impact of sensory overload should be included within this activity.
- A number of respondents felt that ability to understand transport information and to communicate when travelling were significant omissions.
- Concerns were raised that descriptor ‘B’ did not reflect the proposed approach on fluctuation of impairments, as it required an individual to never be able to leave the home without another person.

Activity 11: Moving around

The initial proposals

This assessed physical ability to move around outdoors – to transfer unaided between two seated positions; to move up to 50 metres; up to 200 metres; and over 200 metres. A normal outdoor surface, including kerbs, was to be considered, as were pain, breathlessness, fatigue and abnormalities of gait. The descriptors differentiated between the use of manual aids, such as sticks or prostheses; self-propelled wheelchairs; and assisted aids propelled by another person or a motor, such as electric wheelchairs.

Your responses

- It was welcomed that this activity considered ability to move around outdoors and incorporated kerbs and a normal outdoor surface.
- A large number of respondents questioned why the ability to move around indoors and/or navigate stairs or steps was not included.
- It was questioned why this activity did not include getting in and out of bed.
- A few respondents felt that this activity should take account of the impact of unexpected obstacles when moving around.
- There was some concern that the descriptors differentiated between the use of manual wheelchairs and ‘assisted aids’. It was suggested that this was a tenuous distinction as it could reflect a subjective choice rather than an objective level of need.
- It was questioned whether this activity would take account of environmental and terrain specific factors, such as the weather and the gradient and texture of the ground.

- Many respondents felt it was important that the criteria recognised that even with the use of aids and appliances, barriers still exist. For example, using a wheelchair in an inaccessible shop.
- It was recommended that the descriptors should take account of the speed and comfort of movement, including issues such as stiffness and pain.
- Many responses questioned why the descriptors did not reflect the need for physical support from another person when walking or the likelihood of falling, stumbling and/or poor balance.

4. Refining the criteria: developing a second draft

4.1 We have revised our initial proposals for the draft criteria in light of feedback received through the informal consultation, the findings from the testing and further internal development work. We believe that the second draft offers an improved assessment of an individual's ability to participate than the first draft and that it delivers fairer outcomes for disabled people.

4.2 This chapter explains where we have made changes to the activities in the assessment; the key elements of how the assessment will work; and the detailed wording of the descriptors. It also covers where the criteria remain unchanged from the first draft. Throughout the chapter, specific activities and descriptors are referred to using the wording of the second draft of the criteria (where 'previous' is used, this highlights an activity found only in the first draft).

4.3 The changes we have made are intended both to ensure that the Personal Independence Payment assessment delivers effective, fair results and to make the overall approach simpler and clearer to understand. We have tried to reflect comments received on the initial draft wherever possible, learning from the knowledge and experience of disabled people and their organisations. Our testing work, detailed later, was also vital in helping us to understand how the criteria would work and how they would affect people, helping us to challenge some areas of our initial proposals and validate others. The criteria will be refined further before final draft regulations for the assessment are laid and debated in Parliament, probably in 2012.

4.4 The detailed second draft of the assessment criteria with supporting guidance can be found at Annex A. As discussed previously, unlike the first draft, we have now proposed draft weightings for the descriptors.

The activities to be assessed

4.5 We are proposing that the assessment considers ability to carry out daily living and mobility activities as a proxy for an individual's ability to participate in society and their potential extra disability-related costs. Many responses submitted to the informal consultation suggested that the number of activities should be increased, including areas such as housework and social activities. We also received feedback that the criteria should include a direct assessment of an individual's extra costs.

4.6 One of our key principles has been to develop criteria which are clear to understand and apply and which enable consistent outcomes. In order to achieve this, it is not possible to assess every activity where individuals may face barriers to participation or where extra costs may be incurred. We have instead chosen a series of key activities which cumulatively act as a proxy for them. We continue to believe that the activities we have chosen enable the assessment to act as a good proxy.

4.7 However, we have made significant changes to four of the initial activities following feedback we received:

- ***Planning and buying food and drink***: This has been redrafted to enable a broader assessment on an individual's ability to make everyday financial decisions;
- ***Managing medication and monitoring health conditions*** **and** ***Managing prescribed therapies other than medication***: These two activities have been merged into one new combined activity; and

- ***Communicating with others***: This has been split into two activities to enable a more accurate assessment of an individual's ability to communicate and socially engage.

More detail on each of these changes is provided later in this chapter.

4.8 We do not propose to broaden the scope of the criteria to include a more direct assessment of extra costs, as we remain of the belief that criteria act as a good proxy for the impact of impairments and disability-related costs. In addition, many of the costs that have been flagged are already taken into account within this proxy. For example, individuals who have difficulties getting out are likely to have higher utility bills, while those who need support planning a journey and moving about are likely to have higher transport costs.

4.9 Furthermore, we remain concerned that taking greater account of issues such as housing, access to transport, informal support and utilities would make the assessment more subjective and lead to inconsistent outcomes for individuals. Many of these issues will be dependent on local circumstances and availability of services, meaning that results might differ depending on location across the country. We do not want to introduce an indirect form of means or needs-testing in Personal Independence Payment by taking account of other support which is available. Such an approach would also need us to gather much more information from individuals, which would require claim forms and face-to-face consultations to be longer and more complicated for claimants. These are all issues which we are very keen to avoid in the new benefit and for this reason the broad principles of the criteria remain unchanged.

Key elements of the assessment approach

Assessing fluctuations and variations in ability

4.10 The assessment considers a 12 month period and, in order to accurately capture fluctuations in ability within this timeframe, we proposed that an activity descriptor should apply where it reflected an individual's ability for the 'majority of the time'. This will ensure that the assessment accurately identifies individuals who are consistently least able to carry out the activities. In order to provide greater clarity on this approach, the assessment now considers the impact experienced on the 'majority of days' (more than 50 per cent) rather than the 'majority of the time'. This has been included in the second draft regulations.

4.11 The accompanying notes highlight that if a descriptor applies during a 24-hour period, it should be considered as applying on that day. That day would then count towards meeting the threshold of more than 50 per cent of days for the relevant activity descriptor. However, we recognise that this approach might disadvantage individuals whose level of ability fluctuates over the period.

4.12 Therefore, when choosing descriptors, the following rules now apply:

- If one descriptor in an activity applies on more than 50 per cent of the days in the period then that descriptor should be chosen.
- As before, if more than one descriptor in an activity applies on more than 50 per cent of the days in the period, then the descriptor chosen should be the one which applies for the greatest proportion of the time.
- Where one single descriptor in an activity is not satisfied on more than 50 per cent of days but a number of different descriptors in that activity, when added

together, are satisfied on more than 50 per cent of days, the descriptor satisfied for the highest proportion of the time should be selected. For example, if descriptor ‘B’ is satisfied on 40 per cent of days and descriptor ‘C’ on an additional 30 per cent of days, the correct descriptor would be ‘B’.

4.13 This approach ensures that individuals who meet scoring descriptors on at least 50 per cent of days should also score in the assessment.

4.14 There was some concern expressed through the informal consultation that the impact of severe, acute effects of impairments was not being taken into account. While we can appreciate this concern, we have not altered the general principle of considering the impact of impairments – including those that fluctuate – which are long-term. This is because Personal Independence Payment is intended to provide financial support for those individuals who face the greatest barriers to participating in everyday life. The Government therefore does not believe that support needs arising from short, acute periods of impairment should be met by this benefit.

Safely, reliably, repeatedly and in a timely manner

4.15 We received strong positive feedback on the proposal that we assess ability to carry out the activities in light of whether they can be done ‘safely, reliably, repeatedly and in a timely manner’. However, it was suggested that in order to ensure these issues are always taken into account, these concepts should be incorporated within the descriptors or assessment regulations.

4.16 While we recognise the desire to define these terms in the regulations, we believe it is important to retain appropriate flexibility of interpretation and clear, easily understood descriptors. ‘Safely’, ‘reliably’, ‘repeatedly’ and ‘in a timely manner’ are therefore currently defined within the notes

accompanying the second draft criteria. We intend to seek views on the proposed definitions and to consult on whether these terms should be defined within the regulations when we formally consult on the revised draft criteria later this year.

4.17 A large number of comments on the initial draft were concerned that the impact of pain and fatigue were not being taken into account. For clarity, we would like to provide reassurance that it was always the intention that these issues would be included when considering an individual's ability to carry out the activities 'safely, reliably, repeatedly and in a timely manner'. To emphasise this, 'pain' and 'fatigue' are now both referred to in the notes accompanying the second draft.

Support needed from another person

4.18 We received strong feedback that the proposed approach to considering where support from another person is required could result in individuals with significant barriers being inaccurately assessed. In particular, respondents were concerned about the omission of the concept of 'supervision'; the high thresholds applied to 'intermittent' and 'continuous' support; and that 'prompting' required the physical presence of another individual.

4.19 In light of these concerns we have substantially revised the approach in the second draft of the criteria. The terms 'intermittent' and 'continuous' have been removed and the descriptors now refer only to 'assistance' and 'prompting'. Furthermore, such support now only needs to be required for part of the activity to apply. This is a significant difference from the thresholds for 'intermittent' (over half of the time taken to complete the activity) and 'continual' (the entire duration of the activity) used in the first draft.

4.20 We recognise that there are numerous different ways in which an individual could require prompting to ensure that

they carry out the prescribed activities. In light of this, the definition of 'prompting' used in the second draft criteria does not explicitly require the presence of another individual. However, such prompting must be essential for the activity to be carried out.

4.21 A lot of the feedback we received questioned why the initial proposals did not reflect the need for supervision to ensure an individual's safety while carrying out activities. We have recognised and addressed this in the second draft of the criteria. The descriptors now take account of whether an individual requires 'supervision' from another person – defined as their continuous presence throughout the task to prevent a potentially dangerous incident occurring. This approach is very similar to that currently taken in Disability Living Allowance.

4.22 The broader definitions used in the second draft enable the assessment to reflect support required from another person more accurately. Requiring support for only part of the activity and taking account of the need for supervision should ensure that the assessment better captures the impact of impairments.

Accurately assessing all impairments

4.23 There was some confusion from respondents to the informal consultation regarding whether certain activities could apply to individuals with particular impairments. We are clear that the impact of all impairment types can be taken into account across the activities, where they affect an individual's ability to carry out the activity and achieve the stated outcome.

4.24 However, some activities are focused such that certain impairment types may not affect ability to carry out the relevant tasks. For example, the *Moving around* activity relates to physical ability to move around, while *Engaging socially* relates mainly to mental, cognitive or intellectual

ability to engage with others. This approach ensures that the right balance is achieved in the criteria between the various activities and barriers individuals face.

The approach to aids and appliances

4.25 Some respondents felt that we should not take the use of aids and appliances into account in the assessment. We do not feel that this approach is appropriate as we want entitlement to Personal Independence Payment to be based on an individual's level of participation in society. As such, if individuals are participating well with the help of aids or appliances, we believe that this should be reflected.

4.26 However, we recognise that barriers and costs may not be removed by the use of support aids and so descriptors describing the use of an aid or appliance to carry out activities will usually attract a score in the assessment. The use of some aids, such as wheelchairs, will attract higher priority, reflecting the greater barriers and costs where these aids are used. Individuals who use aids or appliances may well be entitled to the benefit, depending on their circumstances.

4.27 Feedback we received on the first draft suggested that taking account of only aids and appliances which are actually used by individuals could unintentionally encourage people to not take steps to reduce their barriers to participation. Reflecting on this, we are now proposing that the assessment considers both aids and appliances which are normally used and those which can 'reasonably be expected' to be worn or used, in the same way as Disability Living Allowance.

4.28 Whether use of an aid or appliance could 'reasonably be expected' will reflect issues of availability, cost and cultural considerations. For example, it might be reasonable to expect someone to use adapted cutlery or a walking stick,

but it would not be reasonable to expect them to use a therapeutic source for feeding or a wheelchair. This approach will ensure that individuals who choose to use aids and appliances to improve their independence will not be unfairly penalised compared to others.

Day and night support needs

4.29 Neither the first nor second draft of the assessment criteria explicitly assesses whether an individual's need for support may differ between day and night. Instead we have taken the approach that the assessment should consider the time of day when each activity usually takes place and an individual's ability should be assessed with regard to this. For example, preparing food and drink would usually take place during the day; while management of toilet needs and incontinence may take place during the day or the night.

The use of positive language

4.30 We had a strong desire to draft the criteria in positive language where possible, to focus on an individual's ability and the extent to which they are able to complete an activity, not the barriers that might prevent them from doing so. However, comments received made it clear that this approach did not always work. Therefore in the second draft some descriptors have been reworded where the meaning was previously unclear. In particular, the bottom descriptor for most activities is now worded to give greater clarity that it would apply if an individual could not do the activity at all.

Detailed changes to the descriptors

4.31 We have redrafted specific wording throughout the criteria, to broaden the scope or to remove words or phrases which feedback suggested were either too vague or too subjective. There were also a number of areas where it was not possible to reflect comments regarding the wording of descriptors or the proposed definitions.

Activity 1: Preparing food and drink

- The differentiation between cooking a ‘simple meal’ and a ‘snack’ has been removed and the activity now only refers to a ‘simple meal’.
- A ‘simple meal’ is now defined as one made only from fresh, rather than fresh or frozen, ingredients.
- The majority of the descriptors no longer distinguish between ability to prepare or cook a meal. This means that if an individual can do only one of the two, a descriptor can still apply.
- Whether ‘supervision’ is necessary to enable an individual to prepare or cook food is now included.
- The descriptors continue to take account of ‘assistance’ and ‘prompting’.
- Ability to prepare and cook food continues to be assessed at waist height or above.
- The distinction between ability to use a cooker hob and a microwave to cook a meal has remained. This recognises that the use of a microwave requires may provide a safer alternative for preparing food, depending on the impact of an individual’s impairment.

Activity 2: Taking nutrition

- Physical support required to cut up food is now specifically incorporated within the descriptors.
- The descriptors continue to take account of both ‘prompting’ and ‘assistance’ required to carry out the activity.

Activity 3: Managing therapy or monitoring a health condition

- Two previous activities (*Managing medication and monitoring health conditions* and *Managing prescribed therapies other than medication*) have now been

merged, following feedback that they covered similar activities. The new activity considers ability to take medication, to manage long-term home therapeutic activities and to monitor health conditions.

- We have broadened the scope of the medication and therapy which would be considered, from ‘prescribed’ to ‘prescribed or recommended’ by a health professional. There must, however, be an evidence base to support their use.
- To be taken into account, an inability to take medication, monitor a health condition or manage therapy now needs to be likely – rather than ‘significantly’ likely – to cause an individual’s health to deteriorate.
- We have now included both ‘supervision’ required to enable an individual to take medication, monitor a health condition or manage therapy; and ‘prompting’ necessary to enable an individual to manage therapy.
- The descriptors also continue to take account of any ‘assistance’ needed.
- Ability to convey tablets to the mouth remains excluded as the same broad ability is assessed in activity 2, as part of ability to convey food to the mouth.

Activity 4: Bathing and grooming

- The definitions have been simplified by removing the distinction between ‘bathing’ and ‘washing’.
- ‘Level of self-neglect’ has been removed.
- ‘Prompting’ necessary to groom and ‘supervision’ required for bathing are now both included.
- ‘Assistance’ required for both grooming and bathing, and ‘prompting’ for bathing, both remain.
- Ability to wash the perineum after going to the toilet is still assessed within a different activity (*Managing toilet needs or incontinence*). It is no longer excluded from

this activity, as we recognise that it is part of normal bathing; however, the same ability should not be assessed twice.

Activity 5: Managing toilet needs or incontinence

- The definition of 'managing incontinence' no longer excludes the ability to clean oneself after evacuation of the bladder and/or bowels.
- 'Prompting' to manage toilet needs has now been included.
- The descriptors continue to take account of 'assistance' required to manage toilet needs and/or incontinence.

Activity 6: Dressing and undressing

- The definition of 'dress and undress' now includes the ability to put on socks and slip-on shoes.
- The need for 'prompting' to dress or undress has now been included, as has 'assistance' required to select appropriate clothing.
- The descriptors continue to take account of 'assistance' and 'prompting' required for other parts of the task.

Activity 7: Communicating

- The initial proposals included an explicit assessment of communication ability, a significant departure from the current Disability Living Allowance assessment. While this approach received strong positive feedback, concerns were voiced that the proposed activity did not reflect the many different facets of communication and assessed too basic a level of ability. In recognition of these concerns, the previous activity has now been split into two new activities: *Communicating* and *Engaging socially.*
- The first of these new activities focuses on expressive and receptive communication – the ability to convey information, make oneself understood, receive and

understand information conveyed and access written information.

- The definition of ‘communication support’ has now been broadened to refer either to support from a trained person; or from someone directly experienced in communicating with the individual, such as a friend, family member or carer.
- The descriptors now reflect the impact of impairments on an individual’s ability to access written information – whether using an aid or appliance or requiring ‘assistance’.
- Definitions of ‘basic’ and ‘complex’ communication have now been included. The definition of ‘complex’ is broad, simply incorporating all communication which is not ‘basic’.
- ‘Communicate’ continues to be defined as conveying and understanding information in the individual’s native language. While we recognise that individuals’ native languages may include sign language, the assessment criteria are designed to ensure that people using sign language are not disadvantaged, as we recognise the barriers they face due to the need to have someone who understands or can interpret sign language to communicate.

Activity 8: Engaging socially

- This new activity focuses on interacting with others in a contextually and appropriate manner, understanding body language and establishing relationships. This change should ensure a more accurate assessment of the impact of impairments in this area.
- The activity takes account of non-physical support required to enable an individual to engage socially.
- To reflect support required by an individual to understand aspects of social engagement, such as body

language and social cues, the need for ‘social support’ is included. This has a broad definition – support from a trained or experienced person – similar to ‘communication support’ used within activity 7.

- ‘Prompting’ to enable an individual to engage socially has been included.
- Inability to socially engage must be due to the impact of impairments, rather than a matter of preference or normal levels of shyness.
- The descriptors still refer to ‘overwhelming psychological distress’, which has been defined as distress caused by an enduring mental health condition or an intellectual or cognitive impairment. However, the accompanying notes no longer require such distress needing to have an effect for several hours after the activity in order to be taken into account.

Activity 9: Making financial decisions

- The purpose of the previous *Planning and buying food and drink* activity was not well understood. Although it was intended to assess general mental, intellectual and cognitive ability to plan and manage day-to-day finances, by using ability to purchase food as a proxy, respondents often questioned why only buying food and drink was considered. To rectify this, in the second draft this activity has been replaced with a new activity: *Making financial decisions*.
- While looking at similar skills, the new activity looks beyond purchasing food to budgeting and financial decisions more widely. It considers ability to make both ‘complex’, abstract decisions and ‘simple’, more concrete decisions. This change in focus should enable a more accurate assessment of ability to manage their own everyday finances.
- The descriptors differentiate between ability to make ‘complex’ financial decisions, defined as calculating

- The descriptors reflect the need for ‘prompting’ to carry out the activity.

Activity 10: Planning and following a journey

- The definitions of ‘simple’ and ‘complex’ journeys have been removed.
- It has been clarified in the notes that an individual should only be considered able to journey to an unfamiliar destination if they are able to use public transport such as a bus or a train.
- References to ‘assistance’ required to follow a journey have been replaced with ‘supervision’.
- Two of the descriptors now explicitly refer to needing a ‘support dog’ to follow a journey, to ensure clarity on how this support should be taken into account. ‘Support dogs’ have been defined as those which are trained to guide or assist individuals with sensory impairment.
- The descriptors continue to take account of ‘prompting’ required.
- The descriptors still refer to ‘overwhelming psychological distress’, which has been defined as distress caused by an enduring mental health condition or an intellectual or cognitive impairment. This is to ensure that the descriptor does not apply for normal levels of ‘shyness’. However, the accompanying notes no longer require such distress needing to have an effect for several hours after the activity in order to be taken into account.

Activity 11: Moving around

- For simplification, the terms ‘manual aid’ and ‘assisted aid’ have been removed from this activity.
- The accompanying notes clarify that an individual’s ability to move around generally is considered, not just ability to move around outdoors.
- The descriptors continue to differentiate between the use of aids such as walking sticks and crutches; self-propelled manual wheelchairs; and wheelchairs propelled by others or a motorised device. This ensures that the extra costs associated with some mobility aids are reflected.

Proposed draft descriptor weightings

4.32 When the assessment criteria are finalised, each descriptor will have a weighting which reflects both the level of ability it represents and the relative importance of that activity within the criteria. An individual’s entitlement to the rates and components of Personal Independence Payment will be determined by the cumulative weightings which apply to that individual. For both the Daily Living and Mobility components, it will be possible for an individual to be entitled to the standard rate; the enhanced rate; or neither.

4.33 The second draft of the criteria includes our initial thoughts on possible weightings for each of the descriptors. These were developed following the findings from testing the criteria, through both qualitative and quantitative analysis of the results. We examined a wide range of reports from the face-to-face appointments, considering individuals’ circumstances, how they would fare under the assessment and whether the level overall weighting they received were reasonable and compared fairly with other individuals. This enabled us to understand better where particular descriptors or activities were over- or under-accounting for

the impact of impairments, as well as the impact of the criteria as a whole on particular impairment groups.

4.34 Discussions with the Assessment Development Group about the relative weightings of the 11 activities, and comments received through the summer informal consultation, have also been taken into account. For example, a particular concern raised through the informal consultation was that individuals who use aids and appliances would not be entitled to the new benefit, effectively penalising them for greater independence. It was also questioned whether the costs of aids and appliances – and wheelchairs in particular – would be recognised; and a number of activities were felt to be weighted too low relative to others.

4.35 For the Daily Living component, scoring descriptors will apply if an individual requires aids, appliances or prompting to carry out a number of the daily living activities. Individuals who need aids and appliances are likely to require these in a number of areas and the cumulative weightings will reflect their overall level of need. For the Mobility component, the descriptor weightings for activity 11 (*Moving around*) reflect the extra costs associated with mobility aids, ensuring that individuals who require aids and appliances to move very short distances receive some priority in the weightings, while individuals who use a wheelchair would receive greater priority. The approach taken with the mobility activities ensures that an individual who is unable to get around as a result of either a physical or non-physical impairment should receive the same weighting.

4.36 The weightings proposed in the second draft criteria are our initial proposals only, to enable us to start a meaningful debate. We know that it is crucial to get this right and we want to hear the views of disabled people and disability organisations. We will also be formally consulting on the criteria – including the proposed descriptor weightings –

once we have reached firmer views on the weightings and, in particular, entitlement thresholds. While we recognise that there is strong interest in what the thresholds will be, it is important that we get this right and do not publish anything that might be misleading. We will publish this information as soon as possible.

5. Testing our proposals

Our approach

5.1 To help development of the assessment criteria we need a good understanding of how the proposals are likely to affect disabled people. We have therefore tested our initial proposals early on to learn how the draft criteria are likely to affect current Disability Living Allowance claimants. The testing we have carried out will also enable us to analyse the likely impact of the proposals, once we have firmer views on entitlement thresholds.

5.2 The testing was based on sample assessments of volunteers who currently receive or had previously claimed Disability Living Allowance. These assessments were carried out by trained health professionals and involved a face-to-face appointment with each volunteer. During these appointments information on the individual's circumstances was gathered and considered against the initial draft of the criteria.

5.3 The appointments were carried out by health professionals from either Atos Healthcare or G4S Medical Services, who produced a written report following each appointment. All of the health professionals involved in the testing were experienced practitioners with a broad range of training and experience, who had a strong knowledge of a wide range of health conditions and impairments. Each health professional also underwent a tailored training package.

5.4 The analytical testing we have carried out so far has focused on the reliability and validity of the draft criteria, considering whether they were accurately and consistently identifying individuals' level of need. We also looked closely at a wide range of reports from the face-to-face

appointments to help inform the detail of our development work when refining the initial proposals.

5.5 The testing focused solely on the draft assessment criteria and was not concerned with the assessment process or its delivery. The Department is carrying out a separate tendering exercise to identify a third party supplier for the eventual delivery of Personal Independence Payment assessments.

Identifying volunteers

5.6 Volunteers for the testing were identified from across Great Britain and reflected the range of different Disability Living Allowance rates, allowing us to work with people who had a wide range of health conditions and impairments.

5.7 In order to ensure a statistically robust sample, the majority of volunteers were randomly identified using Departmental administrative data. These individuals were first contacted by Departmental officials by telephone to ask if they would be willing to take part. If they consented, they were sent a letter from the Department reiterating the purpose of the exercise and giving details of how to withdraw if they changed their mind. In addition, we also identified several small samples of volunteers with specific conditions through a number of disability organisations in order to allow us to look at specific issues that had been raised during development, such as the impact on fluctuating conditions. Please see paragraph 9.3 in Annex C for more details.

5.8 In total, around 1600 volunteers were identified in Great Britain with the intention of achieving a final sample of around 1000 (taking into account volunteer availability and their right to withdraw at any point in the testing process). Around 900 of the original 1600 individuals identified actually took part.

5.9 It was made clear to all individuals contacted that involvement in the testing was completely voluntary; that it would not affect any benefits they were claiming or may claim in the future; and that they could change their mind about participating at any time, for any reason. Individuals were also assured that the information collected would be treated in the strictest confidence and that all records would be anonymous and would be destroyed after the results were analysed.

5.10 Only the contact details of those who consented to take part were shared with the relevant company. All volunteer data relating to the exercise held by the Department was anonymised and the information sent back by the companies could only be linked to the original data by random unique identification numbers.

5.11 Not all those who initially agreed to take part were contacted by either Atos Healthcare or G4S Medical Services, either due to time limitations or an inability to make further contact following the initial telephone call by the Department.

Northern Ireland

5.12 At the request of the Northern Ireland Department for Social Development, 180 people in Northern Ireland also took part in face-to-face appointments carried out by G4S Medical Services (from 390 potential volunteers). The composition of the Disability Living Allowance caseload in Northern Ireland differs to that of Great Britain; for example, claimants are generally younger and a higher proportion have mental health conditions. These cases were considered when determining how the first draft of the criteria should be revised (see paragraph 5.17 below), thus ensuring that the development of the second draft criteria involved consideration of cases from across the United Kingdom.

The face-to-face appointments

5.13 All individuals who agreed to take part had a face-to-face appointment with a trained health professional from either Atos Healthcare or G4S Medical Services. Individuals were able to choose whether they wished to have the appointment at their home or at accommodation arranged by the provider, with the majority taking place in the individual's home. A family member or friend was encouraged to be present if the volunteer wished this.

5.14 During the appointment, the health professional gathered a range of information about the impact of the individual's impairment on their lives, including:

- The history of their health condition or impairment.
- Any medications or treatment they were receiving.
- Any aids or appliances they were using.
- Their social and occupational history, including any parental responsibilities.
- How they spent a typical day.
- How their impairment might fluctuate.
- In some cases, where helpful, the health professional also carried out a relevant brief clinical examination.

5.15 Using the information gathered during the appointment, the health professional completed a written report, designed specifically for the testing, which included consideration of the draft criteria and determination of appropriate descriptor choices. This report was anonymous, with the volunteer identified only by a random unique identification number. The report was then passed back to the Department for analysis. Following their appointment, volunteers were able to request a copy of their report from the relevant company if they wished.

5.16 All individuals who took part were sent a high street voucher following their appointment, as a token of appreciation for taking part.

Analysing the information gathered

Using the data to refine the criteria

5.17 We examined a wide range of reports from the face-to-face appointments to help us in developing the second draft of the assessment criteria. This qualitative analysis significantly contributed to the changes made, described in chapter 4. In doing so we considered:

- Individuals' circumstances.
- Which descriptors were selected and individuals' cumulative weighting.
- Whether these descriptors and cumulative weighting were appropriate, and/or whether elements of need were being missed.
- How different individuals with varying circumstances fared compared with each other and whether this was fair.

Validity and reliability of the draft criteria

5.18 To test the reliability and validity of the proposals, we compared multiple assessments of the same 99 volunteers. For both drafts, this assessment was carried out on a paper basis, considering the detailed written reports produced by the health professionals following the face-to-face appointments. Qualitative and quantitative analyses were carried out on both the first and second drafts of the criteria.

5.19 For the first draft, we brought together small expert panels to consider the written reports against the criteria. Qualitative analysis showed that the experts experienced particular difficulties correctly interpreting or applying a

number of the descriptors; and that there were several general issues which impacted on their ability to apply the assessment consistently. The quantitative results largely backed up these findings, indicating that were problems both with the validity and reliability of the initial proposals. The findings of this analysis were combined with the feedback from the summer informal consultation to produce the second draft of the criteria, discussed in chapter 4.

5.20 We then tested the second draft, using trained health professionals to re-assess the original written reports against the revised criteria. Qualitative analysis suggested that the descriptors were clearer and easier to understand and to apply. This was supported by the quantitative analysis which showed that there were no reliability issues with the revised proposals. Although individuals with learning disabilities appeared to be over-scored, overall the second draft was found to be more valid than the first.

5.21 More detail on the sample used to test validity and reliability, the methodology of the analysis and the findings can be found in Annex B.

Impact of the draft criteria

5.22 The data gathered during the testing will also enable us to understand the likely impact of the proposals on numbers of people claiming the benefit. However, we are not currently able to fully model this, as we do not yet have firm views on the entitlement thresholds for the rates and components for the benefit. This information will be published at a later date. Annex C provides further information on the volunteer sample which will be used for this part of the analysis.

6. Next steps

6.1 We view the development of the assessment criteria for Personal Independence Payment as an iterative process and we recognise that this second draft may require some further refinement. We intend to discuss this draft with disabled people and their organisations and to consult formally once we are in a position to publish initial proposals for the entitlement thresholds. In the meantime, we would welcome any comments people have on the changes we have made.

6.2 Any comments can be sent to either of the following addresses:

pip.assessment@dwp.gsi.gov.uk

PIP Assessment Development Team
Department for Work and Pensions
2nd floor, area B
Caxton House
Tothill Street
London SW1H 9NA

6.3 Copies of this document and the revised draft regulations will be made available in alternative formats. Please contact us at the above addresses if you require an alternative format.

6.4 The final draft regulations for the assessment are not likely to be laid until 2012, subject to Royal Assent of the Welfare Reform Bill. These regulations will be subject to Parliamentary scrutiny through the affirmative procedure.

Annex A: Second draft of assessment criteria

General notes explaining the criteria

7.1 The assessment will consider an individual's ability to undertake the activities detailed below. Inability to undertake activities must be due to impairment with disabling effects, and not simply a matter of preference by the individual.

7.2 Impairment may be physical, sensory, mental, intellectual, or cognitive; or any combination of these. The impact of all impairment types can be taken into account across the activities, where they affect an individual's ability to complete the activity and achieve the stated outcome. However, some activities focus on specific tasks. For example, *Moving around* relates to the physical aspects of walking, whilst *Engaging socially* relates mainly to mental, cognitive or intellectual aspects of communication.

Descriptor choice

7.3 When assessing an individual, the descriptor most appropriate to the individual for each activity will be chosen. An activity descriptor is generally deemed to apply if the disabling effect applies, at some stage of the day, on more than 50 per cent of days. Where more than one descriptor specified in an activity applies to the individual, the one applying for the greatest proportion of the time should be chosen.

7.4 An individual must be able to complete an activity descriptor reliably, in a timely fashion, repeatedly and safely; and where indicated, using aids and appliances or with support from another person (or, for activity 10, a support dog).

Otherwise they should be considered unable to complete the activity described at that level.

- **Reliably** means to a reasonable standard.
- **In a timely fashion** means in less than twice the time it would take for an individual without any impairment.
- **Repeatedly** means completed as often during the day as the individual activity requires. Consideration needs to be given to the cumulative effects of symptoms such as pain and fatigue – i.e. whether completing the activity adversely affects the individual's ability to subsequently complete other activities.
- **Safely** means in a fashion that is unlikely to cause harm to the individual, either directly or through vulnerability to the actions of others; or to another person.

Risk and Safety

7.5 When considering whether an activity can be undertaken safely it is important to consider the risk of a serious adverse event occurring. However, the risk that a serious adverse event *may* occur due to impairments is insufficient – there has to be evidence that if the activity was undertaken, the adverse event is likely to occur.

Aids and appliances

7.6 The assessment will take some account of aids and appliances which are used in everyday life. In this context:

- **Aids** are devices that help a performance of a function, for example, walking sticks or spectacles.

- **Appliances** are devices that provide or replace a missing function, for example artificial limbs, collecting devices (stomas) and wheelchairs.

7.7 The assessment will take into account aids and appliances that individuals normally use and low cost, commonly available ones which someone with their impairment might reasonably be expected to use, even if they are not normally used.

7.8 Individuals who use or could reasonably be expected to use aids to carry out an activity will generally receive a higher scoring descriptor than those who can carry out the activity unaided.

7.9 We recognise that some aids or appliances can help an individual but also attract significant ongoing costs. We have attempted to reflect this in the detail of the descriptors and in the weightings associated with these. For example, descriptor ‘F’ in activity 11 identifies individuals who are reliant on motorised devices separately from those who are reliant on manual aids, recognising the difficulties and cost of using motorised devices.

Support dogs

7.10 We recognise that guide, hearing and dual sensory dogs are not ‘aids’ but have attempted to ensure that the descriptors capture the additional barriers and costs of needing such a dog where they are required to enable individuals to follow a journey safely. Descriptors ‘C’ and ‘E’ in activity 10 therefore explicitly refer to the use of a ‘support dog’.

Support from other people

7.11 The assessment will take into account where individuals need the support of another person or persons to carry out an activity – including where that person has to carry out the activity for them in its entirety. The criteria refer to three types of support:

- **Assistance** is support that requires the presence and

physical intervention of another person i.e. actually doing some or all of the task in question. This specifically excludes non-physical intervention such as prompting or supervision which are defined below. To apply, this only needs to be required for part of the activity.

- **Prompting** is support provided by reminding or encouraging an individual to undertake or complete a task but not physically helping them. To apply, this only needs to be required for part of the activity.

- **Supervision** is a need for the continuous presence of another person to avoid a serious adverse event from occurring to the individual. There must be evidence that any risk would be likely to occur in the absence of such supervision. To apply, this must be required for the full duration of the activity.

'Unaided'

7.12 Within the assessment criteria, the ability to perform an activity 'unaided' means without either the use of aids or appliances or assistance/prompting/supervision from another person.

Variable and fluctuating conditions

7.13 Taking a view of ability over a longer period of time helps to iron out fluctuations and presents a more coherent picture of disabling effects. Therefore the descriptor choice should be based on consideration of a 12 month period.

7.14 Scoring descriptors will apply to individuals where their impairment(s) affects their ability to complete an activity on more than 50 per cent of days in the 12 month period. The following rules apply:

- If one descriptor in an activity applies on more than 50

per cent of the days in the period – i.e. the activity cannot be completed in the way described on more than 50 per cent of days – then that descriptor should be chosen.

- If more than one descriptor in an activity applies on more than 50 per cent of the days in the period, then the descriptor chosen should be the one which applies for the greatest proportion of the time.
- Where one single descriptor in an activity is not satisfied on more than 50 per cent of days, but a number of different descriptors in that activity together are satisfied on more than 50 per cent of days – for example, descriptor ‘B’ is satisfied on 40 per cent of days and descriptor ‘C’ on 30 per cent of days – the descriptor satisfied for the highest proportion of the time should be selected.

7.15 If someone is awaiting treatment or further intervention it can be difficult to accurately predict its level of success or whether it will even occur. Descriptor choices should therefore be based on the likely continuing impact of the health condition or impairment as if any treatment or further intervention has not occurred.

Epilepsy

7.16 Epilepsy is a marked example of a fluctuating condition where an individual can have no functional limitation one minute and considerable limitation the next. Assessment should be based on the impact this causes.

7.17 Key to assessing individuals with epilepsy is the consideration of risk. Within each activity, the relevant descriptor should apply to a person with epilepsy if there is evidence that a serious adverse event is likely to occur if the person carried out the activity in that descriptor. It is essential to consider the likely effects of any seizure – type and frequency of fit, associated behaviour, the post-ictal

phase and whether there is likely to be sufficient warning to mitigate any risk of danger.

Draft assessment criteria

Part 1 – Daily living activities

Activity 1 – Preparing food and drink		
This activity considers an individual's ability to prepare a simple meal. This is not a reflection of an individual's cooking skills but instead a consideration of the impact of impairment on ability to perform the tasks required. It assesses ability to open packaging, serve food, pour a drink, peel and chop food and use a microwave oven or cooker hob to cook or heat food. *Notes:* *Preparing food means the activities required to make food ready for cooking and eating, such as peeling and chopping.* *Cooking food means cooking or heating at above waist height – for example, using a microwave oven or on a cooker hob. It does not consider the ability to bend down – for example, to access an oven.* *A simple meal is a cooked one-course meal for one from fresh ingredients.* *Packaging includes tins, which may require the use of a tin opener.* *In this activity aids and appliances could include, for example, prostheses, perching stool, lightweight pots and pans, easy grip handles on utensils and single lever arm taps.*		
A	Can prepare and cook a simple meal unaided.	0

B	Needs to use an aid or appliance to either prepare or cook a simple meal.	2
C	Cannot cook a simple meal using a conventional cooker but can do so using a microwave.	2
	For example: may apply to individuals who cannot safely use a cooker hob and hot pans.	
D	Needs prompting to either prepare or cook a simple meal	2
	For example: may apply to individuals who lack motivation, who need to be reminded how to prepare and cook food or who are unable to ascertain if food is within date.	
E	Needs supervision to either prepare or cook a simple meal.	4
	For example: may apply to individuals who need supervision to prepare and cannot safely use a microwave oven.	
F	Needs assistance to either prepare or cook a simple meal.	4
	For example: may apply to individuals who cannot prepare food because of reduced manual dexterity; or who cannot safely heat food	
G	Cannot prepare and cook food and drink at all	8

Activity 2 – Taking nutrition		
This activity considers an individual's ability to be nourished, either by cutting food into pieces, conveying to the mouth, chewing and swallowing; or through the use of therapeutic sources. *Notes:* *A therapeutic source means parenteral or enteral tube feeding using a rate limiting device such as a delivery system or feed pump.*		
A	Can take nutrition unaided.	0
B	Needs either – i. to use an aid or appliance to take nutrition; **or** ii. assistance to cut up food.	2
C	Needs a therapeutic source to take nutrition	2
	For example: may apply to individuals who require enteral or parenteral feeding but can do so unaided.	
D	Needs prompting to take nutrition.	4
	For example: may apply to individuals who need to be reminded to eat.	

E	Needs assistance to manage a therapeutic source to take nutrition.	6
	For example: may apply to individuals who require enteral or parenteral feeding and require support to manage the equipment.	
F	Needs another person to convey food and drink to their mouth.	10

Activity 3 – Managing therapy or monitoring a health condition

This activity considers an individual's ability to;

(i) appropriately take medications that are prescribed or recommended by a registered doctor, nurse or pharmacist;
(ii) monitor and detect changes in a health condition; and
(iii) manage long-term home therapeutic activities that are prescribed or recommended by a registered doctor, nurse, pharmacist or healthcare professional regulated by the Health Professions Council;

and without any of which their health is likely to deteriorate.

Examples of prescribed or recommended medication include tablets, inhalers and creams and therapies could include home oxygen, domiciliary dialysis, nebulisers and exercise regimes to prevent complications such as contractures. Whilst medications and therapies do not necessarily have to be prescribed, there must be an evidence base that supports their use in treatment of the condition.

Notes:

Managing medication means the ability to take prescribed medication in the correct way and at the right time.

Monitoring a health condition or recognise significant changes means the ability to detect changes in the condition and take corrective action as advised by a healthcare professional.

This activity does not take into account medication and monitoring requiring administration by a healthcare professional.

Supervision due to the risk of accidental or deliberate overdose or deliberate self harm is captured in these descriptors as the person would require support from another person in order to prevent this.		
A	Either – i. Does not receive medication, therapy or need to monitor a health condition; **or** ii. Can manage medication, therapy and monitor a health condition unaided, or with the use of an aid or appliance.	0
B	Needs supervision, prompting or assistance to manage medication or monitor a health condition.	1
C	Needs supervision, prompting or assistance to manage therapy that takes up to 3.5 hours a week.	2
D	Needs supervision, prompting or assistance to manage therapy that takes between 3.5 and 7 hours a week.	4
E	Needs supervision, prompting or assistance to manage therapy that takes between 7 and 14 hours a week.	6
F	Needs supervision, prompting or assistance to manage therapy that takes at least 14 hours a week.	8

Activity 4 – Bathing and grooming		
This activity considers an individual's ability to clean their face, hands, underarms and torso, to clean their teeth and to comb/brush and wash their hair. *Notes:* *Bathing is the ability to clean one's torso, face, hands and underarms.* *Grooming means the ability to clean teeth, comb/brush and wash hair.*		
A	Can bathe and groom unaided.	0
B	Needs to use an aid or appliance to groom.	1
	For example: suitable aids could include modified hair brushes, combs and mirrors.	
C	Needs prompting to groom.	1
	For example: may apply to individuals who lack motivation or need to be reminded to groom.	
D	Needs assistance to groom.	2
	For example: may apply to individuals who are unable to make use of aids.	
E	Needs supervision or prompting to bathe.	2
	For example: may apply to individuals who need to be reminded to bathe or require supervision for safety.	

F	Needs to use an aid or appliance to bathe.	2
	For example: may apply to individuals who cannot either get into the bath or shower or remain standing without suitable aids or appliances, such as a walk in shower or bath/shower seat.	
G	Needs assistance to bathe.	4
H	Cannot bathe and groom at all.	8

Activity 5 – Managing toilet needs or incontinence		
This activity considers an individual's ability to get on and off the toilet, to clean afterwards and to manage evacuation of the bladder and/or bowel, including the use of collecting devices. *Notes:* *Toilet needs means the ability to get on and off the toilet and clean oneself afterwards.* *Managing incontinence means the ability to manage evacuation of the bladder and/or bowel including using collecting devices but does not include changing clothes.* *Individuals with catheters and collecting devices are considered incontinent for the purposes of this activity.*		
A	Can manage toilet needs or incontinence unaided.	0
B	Needs to use an aid or appliance to manage toilet needs or incontinence.	2
	For example: suitable aids could include commodes, raised toilet seats, bottom wipers or bidets.	
C	Needs prompting to manage toilet needs.	2
	For example: may apply to individuals who need to be reminded to go to the toilet.	
D	Needs assistance to manage toilet needs.	4

E	Needs assistance to manage incontinence of either bladder or bowel.	6
F	Needs assistance to manage incontinence of both bladder and bowel.	8
G	Cannot manage incontinence at all.	8

Activity 6 – Dressing and undressing		
This activity assesses an individual's ability to appropriately select, put on and take off culturally appropriate and un-adapted clothing, which may include the need for fastening such as zips or buttons. This includes the ability to put on/take off socks and slip on shoes.		
A	Can dress and undress unaided.	0
B	Needs to use an aid or appliance to dress or undress.	2
	For example: suitable aids could include modified buttons, zips, front fastening bras, trouser, velcro fastenings and shoe aids.	
C	Needs either – i. prompting to dress, undress or determine appropriate circumstances for remaining clothed; **or** ii. assistance or prompting to select appropriate clothing.	2
	For example: may apply to individuals who need to be encouraged to dress. Includes a consideration of whether the individual can determine what is appropriate for the environment, such as time of day and the weather.	
D	Needs assistance to dress or undress lower body.	3
E	Needs assistance to dress or undress upper body.	4

F	Cannot dress or undress at all.	8

Activity 7 – Communicating

This activity considers an individual's ability with regard to expressive (conveying) communication, receptive (understanding) communication and accessing written information.

Notes:

This activity considers the capability to convey information and understand other people in the person's native language.

Communication support means support from another person trained to communicate with people with specific communication needs (for example, a sign language interpreter) or someone directly experienced in communicating with the individual themselves (for example, a family member).

Basic communication is conveying or understanding basic information, for example a basic need such as asking for help with an activity of daily living or understanding a simple safety instruction.

Complex communication is conveying or understanding complex information which is any communication that is more complicated than conveying a basic need.

A	Can communicate unaided and access written information unaided, or using spectacles or contact lenses.	0

B	Needs to use an aid or appliance other than spectacles or contact lenses to access written information.	2
	For example: may apply to individuals who require low vision aids.	
C	Needs to use an aid or appliance to express or understand verbal communication.	2
	For example: may apply to individuals who require voice aids such as a voice synthesiser	
D	Needs assistance to access written information.	4
	For example: may apply to individuals who require another person to read the information to them.	
E	Needs communication support to express or understand complex verbal information.	4
	For example: may apply to individuals who require a sign language interpreter.	
F	Needs communication support to express or understand basic verbal information.	8
	For example: may apply to individuals require a sign language interpreter.	
G	Cannot communicate at all.	12

Activity 8 – Engaging socially

This activity considers an individual's ability to engage socially, which means to interact with others in a contextually and socially appropriate manner, understand body language and establish relationships.

Notes:

An inability to engage socially must be due to the impact of impairment and not simply a matter of preference by the individual.

Social support means support from a person trained or experienced in assisting people to engage in social situations, who can compensate for limited ability to understand and respond to body language, other social cues and assist social integration.

For descriptor (d) (i), there must be evidence of an enduring mental health condition, intellectual impairment or cognitive impairment. There must be evidence that overwhelming distress has/would occur, not just that it might.

A	Can engage socially unaided.	0
B	Needs prompting to engage socially.	2
	For example: may apply to people who need encouragement to interact with others by the presence of a third party.	

C	Needs social support to engage socially.	4
	For example: may apply to people who are only able to interact with others by the presence of a third party.	
D	Cannot engage socially due to such engagement causing either – i. overwhelming psychological distress to the individual; **or** ii. the individual to exhibit uncontrollable episodes of behaviour which would result in a substantial risk of harm to the individual or another person.	8

Activity 9 – Making financial decisions

This activity considers the ability of an individual to make financial decisions.

Notes:

Complex financial decisions are those that are involved in calculating household and personal budgets, managing and paying bills and planning future purchases.

Simple financial decisions are those that are involved in activities such as calculating the cost of goods and change required following purchases.

A	Can manage complex financial decisions unaided.	0
B	Needs prompting to make complex financial decisions.	2
	For example: may apply to individuals who need to be encouraged or reminded to make complex financial decisions.	
C	Needs prompting to make simple financial decisions.	4
	For example: may apply to individuals who need to be encouraged or reminded to make simple financial decisions.	
D	Cannot make any financial decisions at all.	6

Part 2 – Mobility activities

Activity 10 – Planning and following a journey		
This activity considers an individual's ability to work out and follow a route. *Notes:* *A person should only be considered able to journey to an unfamiliar destination if they are capable of using public transport (bus or train).* *For those descriptors which refer to overwhelming psychological distress, there must be evidence of an enduring mental health condition, intellectual impairment or cognitive impairment. There must be evidence that overwhelming distress has/would occur, not just that it might.* *Safety and reliability are particularly important considerations here if there would be a substantial risk to the individual or others if they went out alone.*		
A	Can plan and follow a journey unaided.	0
B	Needs prompting for all journeys to avoid overwhelming psychological distress to the individual.	4
	For example: may apply to individuals who are only able to leave the home when accompanied by another person.	

C	Needs either – i. supervision, prompting or a support dog to follow a journey to an unfamiliar destination; **or** ii. a journey to an unfamiliar destination to have been entirely planned by another person.	8
D	Cannot follow any journey because it would cause overwhelming psychological distress to the individual.	10
	For example: may apply to individuals who are unable to leave the home at all.	
E	Needs either – i. supervision, prompting or a support dog to follow a journey to a familiar destination; **or** ii. a journey to a familiar destination to have been planned entirely by another person.	15

Activity 11 – Moving around

This activity considers an individual's physical ability to move around. This includes ability to transfer unaided between two seated positions, to move up to 50 metres, up to 200 metres and over 200 metres.

Notes:

This activity should be judged in relation to a type of surface normally expected out of doors such as pavements and roads on the flat and includes the consideration of kerbs.

50 metres is considered to be the distance that an individual is required to be able to walk in order to achieve a basic level of independence such as the ability to get from a car park to the supermarket.

50 to 200 metres is considered to be the distance that an individual is required to be able to walk in order to achieve a higher level of independence such as the ability to get around a small supermarket.

Aids or appliances that a person uses to support their physical mobility may include walking sticks, crutches and prostheses but do not include manual wheelchairs or any motorised device.

As with all activities, the person must be able to perform the activity safely and in a timely fashion - however, for this activity this only refers to the actual act of moving. For example, danger awareness (such as traffic) is considered as part of activity 10.

A	Can move at least 200 metres either – i. unaided; **or** ii. using an aid or appliance, other than a wheelchair or a motorised device.	0
B	Can move at least 50 metres but not more than 200 metres either – i. unaided; **or** ii. using an aid or appliance, other than a wheelchair or a motorised device.	4
C	Can move up to 50 metres unaided but no further.	8
	For example: identifies individuals who can move up to 50 metres unaided but then require a wheelchair for anything further.	
D	Cannot move up to 50 metres without using an aid or appliance, other than a wheelchair or a motorised device.	10
	For example: identifies individuals who can use an aid or appliance to move up to 50 metres but then require a wheelchair for anything further.	
E	Cannot move up to 50 metres without using a wheelchair propelled by the individual.	12
F	Cannot move up to 50 metres without using a wheelchair propelled by another person or a motorised device.	15

G	Cannot either – i. move around at all; **or** ii. transfer unaided from one seated position to another adjacent seated position.	15

Annex B: Reliability and validity analysis

The sample

8.1 The objectives of this exercise were to examine whether the draft criteria were:

- **Valid**: accurately identifying individuals for appropriate levels of Personal Independence Payment awards.
- **Reliable**: delivering consistent results across multiple assessors and producing the same result for multiple claimants with the same characteristics.

8.2 99 individuals from the total volunteer sample were considered for this part of the testing. Participants were identified from a wide range of impairment types using Departmental administrative data, as described in paragraph 5.7 in chapter 5. We could not use a larger sample at this stage because we would not have had time to complete the appointments and analysis before beginning work to analyse the second draft criteria.

8.3 This sample was not chosen to be representative of the current Disability Living Allowance caseload. However, identifying individuals across seven broad impairment groups enabled us to explore whether the test was equally valid and reliable regardless of impairment type.

Validity and reliability of the first draft

Methodology

8.4 As mentioned in paragraph 5.19 in chapter 5, testing the reliability and validity of the initial proposals consisted of

gathering independent expert feedback on the 99 cases and collecting and comparing multiple assessments of the same case. To do this, we brought together small expert panels to assess volunteers against the draft criteria. This assessment was done on a paper basis, using the detailed written reports produced by the health professionals following the face-to-face appointments.

8.5 To provide breadth of knowledge and experience, the panels consisted of either a doctor or a psychiatrist, an occupational therapist and, in around half of the cases, a lay disabled person. To identify these panel members, we approached the Royal College of Psychiatrists, the Royal College of Physicians, the College of Occupational Therapists and a number of user-led disabled people's organisations. Each volunteer was therefore assessed by three or four assessors – the original health professional and either two or three independent panel members. Panel members were not paid for their role in the testing.

8.6 Panel members received a half-day training session on the principles of disability analysis, Personal Independence Payment and the initial draft criteria. Each was provided with the guidance given to the health professionals carrying out the face-to-face appointments, which included specific information on applying each descriptor. When assessing individuals, panels were only given the parts of the written report which provided the information gathered during the face-to-face appointment – they were not given the health professional's descriptor choices. This was to ensure that they reached unbiased conclusions on which descriptors would be the most appropriate choice.

8.7 After reading each report, panel members firstly gave their subjective opinion on the individual's overall level of need, graded as either 'nil', 'low', 'medium' or 'high'. Each member also applied the draft criteria to each volunteer independently, using their expert knowledge to extract and

critically evaluate relevant information from the written report; noted whether any evidence was not accounted for in the descriptors; and gave feedback on how easy or difficult the cases were to assess.

8.8 Following this, the case was considered by the panel as a group to discuss and compare their assessment of the volunteer. The group were asked to provide their rationale for descriptor choices and overall level of need. They also gave details of any difficulties they had in interpreting the criteria, key areas they felt should be captured but were currently missing, or particular areas for assessor guidance.

8.9 The qualitative feedback from the expert panels was explored in detail, in conjunction with the original report, to reveal trends and themes. The focus was to reveal any underlying issues identified by the panels to contribute to refining the draft criteria. Quantitative analysis was also carried out on the data, comparing the experts' descriptor choices and opinion on level of need in order to determine the validity and reliability of the draft criteria.

Qualitative findings

General observations and areas for improvement

8.10 The expert panels gave feedback on several general issues which impacted on their ability to apply the assessment consistently:

- **Overarching principles**: Information provided in the notes accompanying the criteria was not regarded in the same way as the wording of the descriptors themselves. For example, the panels often felt that issues of safety, reliability and repeatability were not addressed by the descriptors, although guidance was provided on how these should be taken into account throughout the criteria;

- **Language**: There were some difficulties correctly interpreting the wording of the descriptors. While the experts were confident when an individual was able to do an activity independently, it was less clear which descriptor should be chosen when the individual was unable to do all or part of the activity.
- **Visual impairment**: There was difficulty understanding how to reflect the impact of visual impairment when choosing appropriate descriptors.

Correctly applying and interpreting the draft criteria

8.11 The experts experienced particular difficulties correctly interpreting or applying a number of the descriptors. Their comments focused on the precision of the wording which was used or uncertainties about the interpretation of evidence:

- ***Planning and buying food and drink* and *Planning and following a journey***: These activities assessed the impact of cognitive, intellectual or mental function impairment, but the descriptors were not understood as such and were often misapplied. For example, physical ability to buy food was frequently assessed.
- ***Preparing food and drink***: Several experts found this activity particularly difficult to assess, mainly due to difficulties understanding the wording of the descriptors and relating this to an individual's level of ability.
- ***Managing toilet needs and incontinence***: It was unclear how to account for intermittent incontinence and when to consider an individual incontinent with the use of particular aids and appliances.
- ***Moving around***: The experts had difficulty judging how far an individual could mobilise in an electric wheelchair and there was some confusion about which descriptor to

use if an individual used both manual and assisted wheelchairs.

Reflecting these findings

8.12 Qualitative analysis of the data provided us with important feedback on the clarity of the criteria and how to ensure that the descriptors could be interpreted and applied consistently across assessors. The exercise also highlighted the importance of training and guidance. It was evident that expert panel members often had difficulty evaluating the available evidence and choosing the descriptor which they felt described the level of ability most accurately. In contrast, the health professionals who carried out the face-to-face appointments benefited from this, finding it easier to choose descriptors as a result.

8.13 These findings were used to modify the health professionals' guidance and training before carrying out further face-to-face appointments. It was clarified how the impact of visual, mental, intellectual and cognitive impairments and variability within ability should be assessed; as well as which descriptor would apply if an individual was unable either to carry out parts of an activity, or the activity in its entirety, without support.

Quantitative findings

8.14 As stated in paragraph 8.1 above, the objective of this exercise was to investigate the validity and reliability of the initial draft criteria. In the case of validity, we wanted to know how closely the criteria approximated the true ability of the volunteer to participate. For reliability, we wanted to know whether different assessors would produce the same results for multiple volunteers with the same characteristics, having been given the same training and guidance.

Methodology

8.15 As mentioned previously, the experts on the panels provided their own opinion of an individual's level of need – 'nil', 'low', 'medium' or 'high' – before they went through the activity descriptors. The experts were asked to provide this so that we would have a gold standard estimate of ability to participate.

8.16 One limitation of this approach was that for each volunteer there was only one face-to-face appointment, meaning that each expert had only the second hand opinion of the health professional on which to base their judgement. It would have been better to have had multiple health professionals assess each volunteer in a face-to-face appointment. However, the experts' opinions were still valid as long as the different health professionals did not write their reports in ways which affected the experts' opinions. Only in a small proportion of cases did this happen, which means the judgement of the experts about level of need was swayed to a small extent by which health professional had written the report. However, the effect was not large enough to make further analysis invalid.

8.17 Given that we had the experts' view of level of need, the objective of the quantitative analysis was then to test whether the 11 activity scores could accurately predict the

level of need, or whether other information improved the predictions – i.e. could the gap between predicted level of need and actual level of need be explained by observed factors such as age or condition, or was there unexplained variation stemming from information in the report which was not captured in the scores, or personal variables (age, sex, condition).

8.18 In other words, we aimed to find that no information except the test scores significantly improved our understanding of level of need (i.e. ability to participate). If we found that the identity of the person doing the assessment mattered, for example, then the test would not be reliable.

8.19 We decided to investigate this using multivariate statistical regression as this would make maximum use of the data available and also allow objective tests for the significance of other information.

8.20 At this stage it is necessary to make two caveats:

- Even if there were no effect from the report writers, the assumption that the views of the experts are definitive is very strong. The fact that the experts themselves did not always agree on level of need is indicative of the fact that even if their estimates of level of need are unbiased, their judgements are ‘distributed’ around the true ability.
- Since this sample of 99 is not representative of all Disability Living Allowance claimants, any findings cannot be extrapolated beyond the sample.

Results

8.21 The key findings from analysing the first draft were:

- The identity of the member of the expert panel doing the assessment had a statistically significant effect.

- There were characteristics of the individuals which significantly affected level of need but were not captured in the scores (or gender, age or condition).
- The criteria and scores over-predicted the level of need for people with musculoskeletal disorders (i.e. the level of need as determined by the experts was lower than that implied by the draft weightings).
- The criteria under-predicted level of need for older people.

8.22 It is possible that the musculoskeletal impairments result may have been the result of biases stemming from the fact that there were only a small number of people in each impairment group (no more than 14). However, even if there was not specifically any problem with the criteria relating to musculoskeletal impairments, the result certainly indicated that there may have been some issues relating to different conditions.

Conclusions

8.23 The results largely backed up the findings from the qualitative work. The fact that the identity of both the assessor and the individual had statistically significant effects clearly reflected the difficulties the experts had in applying the criteria – without criteria that the assessor could apply confidently, their own personal judgement was more likely to affect which descriptor they selected. Similarly, if the criteria were not clear, then characteristics of the individual shaped the descriptor choice of whichever assessor was looking at their case.

8.24 Overall, the findings indicated that were problems both with the validity and reliability of the first draft criteria.[1]

[1] This quantitative analysis is interim and has not been reviewed by analysts outside of DWP. We plan to get this

Validity and reliability of the second draft

Methodology

8.25 As mentioned in paragraph 5.18 in chapter 5, the second draft of the criteria was tested on a paper basis using the written reports produced as part of the face-to-face appointments. To test the validity and reliability of the second draft, three separate health professionals reconsidered each of the original 99 cases.

8.26 These health professionals carried out a similar function to the expert panels used to test the initial draft criteria. Each health professional:

- Gave their subjective opinion on the individual's overall level of need.
- Chose appropriate descriptors.
- Commented on any evidence of which the criteria did not take account.
- Rated the ease of assessing the case.

Qualitative findings

8.27 Although analysis of the second draft focused on quantitative information, the health professionals also provided some qualitative feedback. Consensus amongst the three health professionals was that the second draft of the criteria were clearer, easier to understand due to changes in language and therefore easier to apply.

Quantitative findings

8.28 The methodology for quantitatively testing the validity and reliability of the second draft was the same as for the first

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validity and reliability work reviewed academically and will publish an update and a technical explanation at a later date.

draft – i.e. multivariate regression to assess the extent to which the level of need predicted by the assessors using the second draft criteria fit with the actual level of need given by the members of the independent expert panels.

8.29 The results from this analysis were as follows:

- The effect of the identity of the assessors was not significant.
- The criteria appeared to have over-scored people with sensory impairments, mental health conditions and people with musculoskeletal impairments (or alternatively, the criteria under-scored everyone else). This was consistent across assessors.
- No other individual characteristics were significant.

8.30 There are no reliability issues with the second draft of the criteria. However, the improvement in reliability appears to have resulted in some further validity issues becoming apparent, as detailed in the preceding paragraph. Given that this test was still done using the original sample of 99 volunteers, it is possible that any abnormalities relating to the activity descriptors or the impairment groups could have been the result of the small sample of people.

8.31 A further check of these effects was therefore carried out by testing this model on the full volunteer sample of around 900 people. A limitation of this approach was that it had to be done using the judgement of level of need provided by the health professionals who carried out the face-to-face appointments, rather than that provided by the expert panels. This was necessary because the expert panels saw only 99 cases from the total sample. The results of this test were that there were no reliability issues and the only validity issue was that people with learning disabilities appeared to be over-scored by the criteria compared to the level of need identified by the health professional.

Annex C: Impact analysis sample

9.1 The purpose of this exercise was to gather information to enable us to evaluate the impact of the proposals on the Disability Living Allowance caseload, using a larger sample than that used to test the validity and reliability of the criteria. Once we have firm views on entitlement thresholds, data from around 900 volunteers (including the 99 cases in Annex B) will be analysed in this manner.

9.2 The additional volunteers were identified using the processes described in paragraph 5.7 in chapter 5. The majority were selected from the Department's administrative data to be representative of the rate combinations in the current Disability Living Allowance caseload and included roughly equal number of individuals with physical and mental disabling conditions, defined as follows (brackets refer to the final number of volunteers who took part):

- **Physical function**: individuals with cardiovascular, respiratory, sensory, neurological and musculoskeletal impairments recorded as their primary impairment (306 volunteers).
- **Mental function**: individuals with cognitive, intellectual and behavioural impairments and mental health conditions recorded as their primary impairment (269 volunteers).

9.3 There were also a number of key impairment types where we selected specific samples, so we could ensure they were appropriately reflected in our overall sample and that we could examine the impact on individual cases. For these, we worked with disability organisations to identify

participants as well as using Departmental data. As above, the numbers given refer to those volunteers who took part. The groups were:

- Autistic spectrum disorders (40 volunteers)
- Learning disabilities (33 volunteers)
- Sensory impairments (41 volunteers)
- Chronic fatigue syndrome (52 volunteers)
- Epilepsy (47 volunteers)

All of these individuals were currently claiming Disability Living Allowance but the samples were not selected to be representative.

9.4 In addition, a small number of volunteers (50) who had recently claimed Disability Living Allowance but had been found not to be entitled also took part. This sample enabled us to look at the potential for these individuals to be entitled to Personal Independence Payment.

Annex D: Organisations which commented on the first draft

A2B

Access in Dudley

Action for Blind People

Action for ME

Action on Hearing Loss

Adapt

Advanced Personnel Management

Advice NI

Advice Services Coventry

Alzheimer's Society

Aspire

Awetu & Cardiff and Vale Coalition of Disabled People

Blackwood

Brigstowe Project

Bristol LINk Self Directed Support

British Polio Fellowship

The Broken of Britain

CALL Scotland

Capability Scotland

Centre for Mental Health

Child Poverty Action Group in Scotland

The Children's Society

Crohn's and Colitis UK

Citizen's Advice Bureau

Colchester Prosthetic User Group

Coleraine Disability Forum

Deafblind UK

Derby Mental Health Action Group

DIAL Peterborough

Disability Action In Islington

Disability Alliance

Disability Benefits Consortium

Disability Lambeth

Down's Syndrome Association

Dystonia Society

Ecas

ENABLE Scotland

Encephalitis Society

Enfield Disability Association

Essex Coalition of Disabled People

Family Action

Glasgow Centre for Inclusive Living

Great Yarmouth Visually Impaired User Group

The Guide Dogs for the Blind Association

Hackney Carers

Haemophilia Society

Hafal

Hanover

Hayfield Support Services with Deaf People

Headway

Headway Glasgow

Hertfordshire County Council

Ideal for All

Inclusion London

Inclusion Scotland

Independent Living in Scotland Project

Learning Disability Alliance Scotland

Leeds Skyline

Leonard Cheshire Disability

Limbless Association

Liverpool Mental Health Consortium Service User Group

London Borough of Lambeth

Lothian Centre for Inclusive Living

Macmillan Cancer Support

Mencap

Mental Health Action Group

Mental Health Foundation

Middlesbrough Council

Middlesbrough Welfare Rights Unit

Milton Keynes Physically Disabled and Sensory Impaired Consultative Group

Mind

Momentum Scotland

Motor Neurone Disease Association

MS Society

National AIDS Trust

National Autistic Society

National Blind Children's Society

National Deaf Children’s Society

National Federation of the Blind of the United Kingdom

National Rheumatoid Arthritis Society

Norfolk Coalition of Disabled People

Norfolk Disabled Parents Association

Northants Support with Eating Disorders

Northumberland County Council

Northumberland Disability and Deaf Network

Northumberland LINk

Papworth Trust

Parkinson’s UK

People First

Poverty Alliance

Quarriers

Rethink Mental Illness

Richmond AID

Royal College of Psychiatrists

Royal National Institute of Blind People

SeeAbility

Scope

Scottish Association for Mental Health

Scottish Campaign on Welfare Reform

Scottish Council For Single Homeless

Scottish Council on Deafness

Scottish Disability Equality Forum

Scottish Independent Advocacy Alliance

Scottish Personal Assistant Employers Network

Sense

Sense Scotland

South Gloucestershire LINk

Spinal Injuries Association

Spinal Injuries Scotland

TCell

Terence Higgins Trust

Tourettes Action

Turning Point Scotland

Visionary

Update, Disability Information Scotland