



Personal Independence Payment: assessment thresholds and consultation: A response from Sense

About Sense

Sense is a national charity that supports and campaigns for children and adults who are deafblind. We provide tailored support, advice and information as well as specialist services to all deafblind people, their families, carers and the professionals who work with them. In addition, we support people who have a single sensory impairment with additional needs.

About deafblindness

Deafblindness is a combination of both sight and hearing difficulties. Most of what we learn about the world comes through our ears and eyes, so deafblind people can often face problems with communication, access to information and mobility. People can be born deafblind, or become deafblind through illness, accident or in older age.

Our 2011 research, *Belonging and Participating*, asked deafblind people, their families and support staff to identify the activities that are important to their participation in society and what barriers prevent them from fully participating. 128 different activities were identified as being important to participants' participation in society. The five most frequently cited activities were:

- Accessing shopping and being as independent as possible;
- Getting out and about in local communities to participate in society, for exercise and health, to meet other people and to see new places;
- Spending time with and visiting family;
- Accessing information and sharing information with others;
- Taking part in both mainstream clubs and societies and those specific to people with a sensory loss.¹

Unfortunately many people reported facing barriers in taking part in the activities that are important to them. The top five most frequently mentioned barriers were: lack of support from another person with the right skills, transport,

¹ Sense (2011) *Belonging and participating: a consultation report on citizenship and deafblind people*.

communication, attitudes or awareness and financial. It is therefore essential that the assessment criteria identify these key activities and barriers.

Introduction

We still remain concerned by the overall aim of reducing the future DLA spend by over £1 billion. We believe this will negatively impact on designing a benefit that can address the wide range of barriers faced by disabled people and additional costs. We recognise that some improvements have been made to the first draft of the criteria, including an improved understanding of communication support needs, however we still have significant concerns about the criteria, specifically whether they fully assess the needs of deafblind people and award an appropriate level of points. We have actively involved deafblind people, family members and practitioners in drafting this response. Proposed amendments to the current descriptors are in bold red text and starred for anyone who may be using assistive technology.

Summary of key recommendations

- ‘Activity 7 – Communicating’ should recognise the double disadvantage and additional costs faced by people who face difficulties accessing both written and verbal information;
- ‘Activity 8 – Social support’ should take account of the extra non-verbal information that deafblind people are unable to access, separate to their communication support needs;
- ‘Activity 10 - Planning and following a journey’ should recognise that individuals who require assistance or use orientation aids or taxis as facing significant barriers and additional costs, should focus on ‘routes’ rather than ‘destinations’ and recognise the additional costs for people who manage the risk of unexpected incidents;
- The definition of ‘assistance’ should be clarified to include instances where another person uses a bodily function such as vision and hearing to compensate for an individual’s impairment;
- Changes should be made to a number of other descriptors across the daily living and mobility activities to ensure that they do not disproportionately disadvantage deafblind people;
- There should be a new Daily Living activity on maintaining a safe and liveable home environment;
- Amendments should be made to the regulations regarding the deadline for providing written evidence, the notice period for a face to face consultation and the matters taken into account when considering good reason for failure to provide information or attend a consultation.

Q1 – What are your views on the latest draft Daily Living activities?

Q2 – What are your views on the weightings and entitlement thresholds for the Daily Living activities?

Activity 2 – Taking nutrition

Some deafblind people will require an aid or appliance to take nutrition, as well as assistance to cut up food. These are two distinct areas of need and additional cost. So an individual may need a combination of adapted utensils for preparing ingredients, a non-slip mat, pre-prepared food such as ready chopped and peeled ingredients or an adapted oven or stove and in addition to this require assistance from a sighted person to cut up food. However, this double disadvantage is not reflected under the current version of the criteria. We therefore propose this amendment under (d) to ensure this is recognised.

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| 2. Taking nutrition. | 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 |
| | d. *Either – i.* Needs prompting to take nutrition*; or ii. Needs <u>both</u> to use an aid or appliance to take nutrition <u>and</u> assistance to cut up food.* | 4 |
| | e. Needs assistance to manage a therapeutic source to take nutrition. | 6 |
| | f. Needs another person to convey food and drink to their mouth. | 10 |

In the first draft of the assessment this activity also covered individuals' ability to buy food; this is an important issue for deafblind people who often require assistance to pick up items and check use by dates. Since this has now been removed from this second draft, it is now very important to recognise these barriers shopping under 'Activity 9 – Making financial decisions' (see below).

Activity 3 – Managing therapy or monitoring a health condition

We are very surprised and concerned that no points are awarded to someone who requires an aid or appliance to complete this activity. This fails to meet the Government's commitment to recognising the barriers and additional costs faced by individuals who need to use aids and appliances. Given the vital importance of meeting health needs, it is essential to award at least one point to these people.

The definition of therapies should explicitly include activities carried out outside the home in a non-medical setting. Deafblind people will often be told by medical professionals to take part in regular exercise regimes such as walks outside the home. Despite reassurance from officials that the intention is not to exclude such therapies, the definition in the draft regulations states that the therapy must be ‘undertaken at home’. We are therefore very concerned that this could exclude therapies conducted outside the home but not in a medical setting. We therefore propose that the definition is changed to ‘undertaken at home or in a non-medical setting outside the home’. Individuals’ ability to implement the current NHS guidelines on activity levels for adults should also be covered by to this activity, as these support basic wellbeing and also prevent longer term health problems.²

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| 3. Managing therapy or monitoring a health condition. | a. Either – (i) Does not receive medication, therapy or need to monitor a health condition; or (ii) can manage medication, therapy or monitor a health condition unaided. *[Delete: or with the use of an aid or appliance.]* | 0 |
| | *b. Can only manage or receive medication, therapy or monitor a health condition with the use of an aid or appliance.* | *1* |
| | *c.* Needs supervision, prompting or assistance to manage medication or monitor a health condition. | *2* |
| | *d.* Needs supervision, prompting or assistance to manage therapy that takes up to 3.5 hours a week. | 2 |
| | *e.* Needs supervision, prompting or assistance to manage therapy that takes between 3.5 and 7 hours a week. | 4 |
| | *f.* Needs supervision, prompting or assistance to manage therapy that takes between 7 and 14 hours a week. | 6 |
| | *h.* Needs supervision, prompting or assistance to manage therapy that takes at least 14 hours a week. | 8 |

Activity 4 – Bathing and grooming

The criteria still fail to address the challenge faced by deafblind people in relation to bathing and grooming. Indeed these criteria are imbalanced towards identifying personal care needs in relation to bathing and grooming, rather than

² NHS, Physical activity guidelines for adults, <http://www.nhs.uk/Livewell/fitness/Pages/physical-activity-guidelines-for-adults.aspx>

the fact that for people with sensory impairments the barriers are not about being physically able to perform a task but being able to check that they are doing it correctly. The criteria should therefore be amended to recognise this important factor.

The definition of 'grooming' should also be amended to include shaving, cutting one's nails and applying make-up. While these may be physically possible for visually-impaired people, use of vision to perform and check these tasks is necessary to complete the task reliably. This is extremely important for individuals' participation, whether socially or for employment and job interviews.

Deafblind people have also welcomed the inclusion of 'supervision to bathe' in this activity. While some deafblind people may be able to physically bathe themselves, they require another person to be nearby due to severe balance issues caused by either their hearing or dual impairment.

"There will be those that are able to bath themselves, but need someone they can call out to, if they have bad balance problems. I myself cannot have a bath, unless someone is in the house. This is because I have very bad balance."
(Deafblind man)

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| 4. Bathing and grooming. | a. Can bathe and groom unaided. | 0 |
| | b. Needs to use an aid or appliance to groom. | 1 |
| | c. Needs prompting to groom. | 1 |
| | d. Needs assistance to groom *or to check grooming.* | 2 |
| | e. Needs supervision or prompting to bathe. | 2 |
| | f. Needs to use an aid or appliance to bathe. | 2 |
| | g. Needs assistance to bathe. | 4 |
| | h. Cannot bathe and groom at all. | 8 |

Activity 5 – Managing toilet needs or incontinence

We believe that this activity should identify where visually-impaired people experience difficulties locating toilets outside of the home. Visually-impaired people frequently rely on support either from someone assisting them or strangers to locate toilets. This has a very significant impact on individuals' independence and deafblind people may often take this factor into account when deciding to participate in an activity in their community or not.

"When I'm out of my flat and that is about 55% of my life, I need my guide to help me get to the toilet as I'm deafblind and a wheelchair user." (Deafblind person)

"We need help when out and about. How do we find the toilet when in town?"
(Deafblind man)

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| 5. Managing toilet needs or incontinence. | a. Can manage toilet needs or incontinence unaided. | 0 |
| | b. Needs to use an aid or appliance to manage toilet needs or incontinence. | 2 |
| | c. Needs prompting to manage toilet needs. | 2 |
| | d. *Needs either - i.* Assistance to manage toilet needs*;or ii. Assistance to locate a toilet in an unfamiliar location.* | 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 7 – Communicating

Identifying the double disadvantage faced by deafblind people in accessing both written and verbal information

The current descriptors fail to take account of the combined impact for someone who uses both assistance or aids to access written information and communication support to access verbal information, such as people with a dual sensory impairment or some people living with autism, learning disabilities or multiple impairments. As only one of the descriptors can be selected, under the current version of the criteria such a person would opt for (f) as this awards 8 points, but this fails to account for the additional barriers they face to accessing written information; they do not receive the 2 points under (b) in recognition of this double-disadvantage. Therefore, people who use both assistance or aids to access written information and communication support to access verbal information should be awarded at least 10 points under the current points allocation. However we believe that individuals who face multiple and severe barriers to accessing both written and verbal information should be eligible for the enhanced rate of the daily living component based on this fact alone.

“The communication activity needs to take into account the different ways we communicate and the very high costs.” (Deafblind man)

Barriers to accessing verbal information

We do not think it is necessary to distinguish between ‘complex’ and ‘basic’ information, especially given the very restricted definition given to ‘basic’ verbal information. Given that the criteria will only award points to people who face barriers for the majority of the time, we feel that requiring communication support for any kind of verbal information for the majority of the time should be

considered an appropriate tipping point. We therefore recommend that the criteria are simplified to allow for this and that people who require communication support to access verbal information should be awarded at least 8 points.

A realistic approach to assessing barriers to verbal information

The external environment and situations can impact massively on individuals' ability to communicate independently. It seems that assessors will consider people's communication ability as if they were in 'a quiet environment'. If the criteria are to fairly assess individuals' ability to communicate, they must consider how everyday environmental factors such as lighting and noise levels impact on individuals' ability to access verbal information.

Definition of 'communicate'

Communication can only be considered successful if it encompasses both receptive and expressive communication, even 'basic' communication as covered by this activity. For example it is essential to know whether a safety instruction has been successfully conveyed to an individual; this individual would need to be able to communicate back that they have received and understood this. Therefore the definition of communication should be amended to include explicit reference to the ability to both receive and express communication:

"Communicate" means ***convey, understand and communicate understanding of*** information in the claimant's native language."

Taking account of the wide range of aids used to access written information

There's a very significant difference between someone who needs, for example, a specialist magnifier to access written information and someone who needs a scanner, computer and braille display and can still then only access scannable information. The criteria do not recognize this important difference. While those in the first group should have a level of points awarded, the criteria fail to account for the greater barriers faced by individuals in the second group. Therefore, the criteria should be amended to make a distinction between different kinds of aids used when accessing written information and offer a higher level of points to those who rely on complex aids and the additional costs they face.

"The machine with which I write is an old Mpower Brailnote which is getting closer and closer to its last legs. They now only do fairly basic repairs to patch things up with the Mpower as they now only sell the smaller and compact Apex but it costs £4395 plus VAT and in the 5 years I've had the machine, £2300 of repairs have been done on it." (Deafblind man)

Barriers to accessing written information

It is essential that guidance for assessors states clearly that ‘written information’ should be interpreted widely to ensure that the assessment covers the range of everyday barriers faced by deafblind people. Written information such as household bills, correspondence and information on food and drink packaging are important, but so are other items such as an information poster in a train station or a warning sign. Given the cross-cutting barrier caused by difficulties accessing written information, we propose that this descriptor should be increased to at least 8 points.

Recognising the persistent barriers faced by people, despite their successful use of aids and appliances

Although the case study 11 from the explanatory notes that accompany the second draft of the criteria proposes the enhanced rate for those who have recently lost their sight, case study 10 shows that a blind person who has successfully adapted (in this case by reading braille) will no longer receive the enhanced rate. Yet this individual would face additional barriers to accessing information in the right format, for example being at a bus stop and being unable to identify which bus is approaching or read information on service changes. The assessment should also be realistic in terms of the barriers that people face to be sent information in an accessible format such as braille or accessible electronic versions, examples that we know of include the DWP itself, hospitals, utility companies, banks and other service providers.

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| <p>“A Braille display can cost up to £5000 and then there is training costs, and ongoing repairs.” (Deafblind person)</p> |
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This appears to be contrary to ministerial commitments that people will not be penalised for using aids and appliances. Therefore, the criteria must not penalise those who successfully use aids by assuming that successful use of aids means that individuals do not face ongoing disadvantages.

Use of specialist spectacles

Additionally, no distinction is made in the current descriptors between spectacles that may be required to correct short-sightedness and specialist spectacles that may be required to correct more serious eye conditions. This means that a partially sighted person who wears specialist spectacles may be penalised. Therefore, the descriptors should draw a clear distinction between using spectacles to correct minor sight problems and using specialist spectacles to help mitigate more serious eye conditions.

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| 7. Communicating. | a. Can communicate unaided and access written information unaided, or using *non-specialist* spectacles or contact lenses. | 0 |
| | b. Needs to use a *basic* aid or appliance ³ other than *non-specialist* spectacles or contact lenses to access written information. 2 | 2 |
| | c. Needs to use an aid or appliance to express or understand verbal communication. | 2 |
| | d. *Needs either – i.* Assistance to access written information*; or ii. A complex aid or appliance⁴ to access written information.* | 8 |
| | *[Delete: e. Needs communication support to express or understand complex verbal information. | 4]* |
| | *e.* Needs communication support to express or understand *[Delete: basic]* verbal information. | 8 |
| | *f. Needs communication support to express or understand verbal information <u>and</u> needs to use a basic aid or appliance to access written information.* | *10* |
| | *g. Either - i. Needs communication support to express or understand verbal information <u>and</u> needs assistance or a complex aid or appliance to access written information; or ii.* Cannot communicate at all. | 12 |

Activity 8 – Social engagement

We are very disappointed that we have been told that people with sensory impairments will be excluded from this activity, despite deafblind people requiring ‘social support’ to access non-verbal information. This fails to recognise the additional barriers faced by deafblind people including body language, understanding the layout of the room, the environment and how groups of people are behaving together. Therefore individuals find it very difficult to be proactive in social situations and are often partially or totally excluded. Individuals often

³ For example a simple manual aid such as a magnifier

⁴ For example a complex electronic aid such as computer braille display or CCTV device

decide to limit their own social activities due to these difficulties.

“For all the good of today's digital hearing aids, it's still possible to get mixed up when two different people have similar sounding voices. Fully sighted people who are deaf can rely on the visuals to recognise people, but as someone who is partially sighted and also hearing impaired like me, I can't always do that. I have to rely on hearing aids to help me differentiate between people, if two voices are similar enough then this becomes very difficult and confusing. I sometimes need another person to tell me who I am talking to.” (Dual sensory impaired person)

“We need one to one support to help us get to know other people and take part leisure activities.” (Deafblind man)

These are separate issues to the barriers related to accessing written and verbal information covered by activity 7. So deafblind people who face these barriers and need ‘social support’ should be able to fall under (c) of this activity. Additionally to this, the external environment and situations can impact massively on individuals’ ability to social engage. It seems the assessors will consider people’s ability to do this as if they were in ‘a quiet environment’. If the criteria are to fairly assess individuals’ ability to engage socially, they must consider how normal environmental factors such as lighting, noise level and the behaviour of others impact on this. These factors must be covered in guidance to assessors.

Activity 9 – Making financial decisions

We are very concerned that the intention is to exclude people with sensory impairments from this activity. This fails to recognise the barriers faced by sensory-impaired people on a daily basis to complete vital transactions. For example, there is no universal model for chip and PIN devices; this poses genuine difficulties for deafblind people who are therefore unable to learn a regular pattern of where to insert the card and buttons to press, especially as the buttons to approve, amend or clear are in different places. This creates real risks in terms of individuals’ financial security and it is for this reason why individuals are likely to need prompting or assistance in these situations. The criteria should therefore be amended. It’s also important to consider young disabled people who are starting to become independent. Over a number of years they will develop their financial independence and make judgements about spending choices. Therefore the definition of both complex and simple financial decisions should include this suggested subsection: ‘() making these decisions by comparing costs’.

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| 9. Making financial decisions | a. Can manage complex financial decisions unaided. | 0 |
| | b. *Either – i.* Needs prompting to make complex financial decisions *; or | 2 |

| | | |
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| | ii. Needs assistance to make complex financial decisions.* | |
| | c. *Either – i.* Needs prompting to make simple financial decisions*; or ii. Needs assistance to make simple financial decisions.* | 4 |
| | d. Cannot make any financial decisions at all. | 6 |

New Daily Living activity ‘Maintaining a safe and liveable home environment’

The purpose of this additional activity is to recognise additional barriers for those living independently at home; specifically to recognise the challenges faced by blind, partially sighted and deafblind people with cleaning, gardening and laundry.

“I have had to get a cleaner because of my visual impairments due to Usher syndrome preventing me from keeping my home hygienic. I have to pay the cleaner about £5 every week.” (Deafblind woman living alone)
 “Without my cleaner my flat would never be clean or safe: I’m always dropping tons of crumbs and breaking glass and I can’t get down to clean it up!” (Deafblind man)

| | | |
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| Maintaining a safe and liveable home environment. | (a) Can ensure their home and garden are hygienic and safe unaided. | 0 |
| | (b) Needs assistance to keep garden maintained safely. | 2 |
| | (c) Needs assistance to carry out essential household maintenance. ⁵ | 4 |
| | (d) Needs assistance to keep low risk rooms hygienic. ⁶ | 4 |
| | (e) Needs assistance to wash and dry clothes. | 4 |
| | (f) Needs assistance to keep kitchen, bathroom and main bedroom hygienic. | 6 |

⁵ For example changing a light bulb and bleeding radiators

⁶ ‘Low risk rooms’ are rooms other than the kitchen, bathroom and main bedroom

Q3 – What are your views on the latest draft Mobility activities?

Q4 – What are your views on the weightings and entitlement thresholds for the Mobility activities?

Activity 10 – Planning and following a journey

We welcomed the Work and Pensions Select Committee's recommendation that the assessment criteria should look at a wide range of factors that impact on individuals' ability to get around, not simply look at individuals' ability to travel a certain distance.⁷ For deafblind people environmental factors and unexpected incidents can have a massive impact on individuals' ability to carry out even familiar journeys; the current draft of the assessment criteria do not appear to take this into account. This is a particular issue for young deafblind people and people who have recently acquired sensory impairments; it takes people a number of years to develop good mobility skills and ways of managing unforeseen incidents. But we must be clear that additional costs are still faced by those who have developed skills – for example guiding support and taxis are an ongoing significant cost.

Assistance

We are very concerned that the need for assistance is not currently included in these descriptors. By including only prompting and supervision (as they are currently defined), we think this will exclude deafblind people who require guiding support from another person. To ensure the criteria focus on the ability to complete the task in a non-impairment specific way, we believe that all three forms of support from another person should be included.

Aids and appliances for mobility

The criteria do not fairly and rationally consider the full range of aids people use to support their mobility. The 'moving around' descriptors focus on some mobility aids such as wheelchairs or walking frames. It is unclear if use of orientation aids, other than support dogs, that support mobility for people with sensory impairments, such as long canes, hearing aids and GPS locators, will be considered under this descriptor. People with sensory impairments who rely on orientation aids or taxis to get around should be considered to be in the same position as those who use support dogs.

Definition of an unfamiliar destination

We are very cautious of the definition that someone should 'be considered able to journey to an unfamiliar destination if they are capable of using public transport (bus or train)'. We are concerned that assessors will not fully understand the

⁷ Work and Pensions Select Committee (February 2010) Government support towards the additional living costs of working-age disabled people, 57

need for individuals to not only be able to physically access public transport and be able to be met at either end of the journey, but also know the route well enough to be able to get off at the correct stop. For example for deafblind people, this will often involve knowing the number of stops on a train journey and counting each stop. Obviously if a train makes an unexpected stop, this can disorientate a deafblind person who may not be able to locate or ask a fellow passenger for help. This is why we suggest that the criteria be amended to refer to a route rather than a destination as this should ensure a fairer assessment of this activity.

"I have problems seeing the stations' name signs in the dark and missed my destination and had to get help to get back on track. I usually spend money on taxis to get around in unfamiliar routes in daylight and especially night, and use guides as well if they are available. My mobility cane is really useful and vital. Travelling is very hard work where destinations and unfamiliar places are concerned, especially if I am to commute to work every day from home in terms of health and safety." (Deafblind woman)

"I'm deafblind and a wheelchair user and I'm asked about familiar journeys: I can't go anywhere outside my flat without someone pushing my wheelchair and only get out when family or people from public transport help and even public transport helpers (taxis) bump into the back of others' cars giving me the fright of my life in London! My neck and back are vulnerable to any accident!" (Deafblind man)

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| 1. Planning and following a journey. | a. Can plan and follow a journey unaided. | 0 |
| | b. Needs prompting for all journeys to avoid overwhelming psychological distress to the claimant. | 4 |
| | c. Needs either – i. *Assistance,* supervision, prompting, a support dog *, orientation aid⁸ or taxi* to follow a journey *along an unfamiliar route* ; or ii. A journey *along an unfamiliar route* to have been entirely planned by another person. | 8 |
| | d. Cannot follow any journey because it would cause overwhelming psychological distress to the claimant. | 10 |
| | e. Needs either – i. *Assistance,* supervision, prompting, a support dog *, orientation aid or taxi* to | 15 |

⁸ An orientation aid is a specialist aid or appliance used by a blind, partially sighted or deafblind person to assist with safe travel.

| | | |
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| | follow a journey *along an familiar route* ; or ii. A journey *along a familiar route* to have been planned entirely by another person. | |
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Q5 – What are your views on how the regulations work regarding benefit entitlement?

This is an appropriate point to underline again the experiences of deafblind people and families involved in the testing of the first draft of the assessment criteria in summer 2011 which were brought together in a report published by Sense.⁹ Individuals' experiences were extremely varied, with some positive examples of good practice, but also some examples of inaccessible and on occasion unacceptable practice. Bad practice included individuals receiving information in inaccessible formats (where their communication preferences were already known to the Department), allowing very little time to read documents and extremely short notice before appointments. We welcome that this report has been taken seriously by the Department, but the draft Regulations fail to reflect the reality for individuals with sensory impairments.

This learning informs our comments in relation to Part 2 (7) of the draft regulations. While we accept the testing was just that, it demonstrated how short notice of appointments and delays in providing information in accessible formats and allowing reading time significantly increased stress and anxiety amongst claimants. In at least one case a test did not go ahead as G4S stated they could not find an interpreter in time.

We believe that people should be given at least 6 weeks to submit the PIP application form and written evidence and the regulations should be amended accordingly under Part 2 (5) (2). We also disagree that under Part 2 (7) (3) individuals should only be given 7 days written warning of an appointment for a face to face consultation. We believe this should be at least 14 days.

Part 2 (7) (4) should also be amended to explicitly state that this written warning must have been sent in the claimant's preferred written format (where this information has been conveyed on the application form for PIP). So we propose this wording:

'(4) In paragraph (3), ***where preferences have been previously indicated written notice should be sent in a claimant's preferred written format and*** reference to written notice includes notice sent electronically, where the claimant has agreed to accept correspondence in that way.'

⁹ Sense, November 2011, Personal Independence Payment and Deafblind People: Learning the lessons from the testing of the first draft assessment criteria in Summer 2011

Part 2 (8) should also be amended to cover provision of written notice in an individual's preferred written format (where this has already been indicated), the claimant's ability to answer the phone and provision of communication support at the consultation when determining whether the claimant has good reason for not attending a consultation. These subsections should be added:

- '(c) the claimant's limited ability to answer the telephone due to their disability;
- (d) the accessibility of written information sent to the claimant;
- (e) provision of appropriate communication support at a consultation.'

Q6 – What are your views on how we are dealing with fluctuating conditions?

We welcome the definition of 'repeatedly' as meaning that a task should be completed as often as required during the day. We believe this is an improvement on DLA where an individual must be unable to complete an activity for the majority of the time. However it remains difficult for individuals to calculate whether they have been able to complete an activity on 50% of days.

Additionally, for many deafblind people seasonal changes have a huge impact on their ability to get around and communicate. For example low sun and glare in winter-time can make a journey very difficult when it would be much more easily completed in summer. Many people with Usher syndrome have night-blindness; due to the type of their visual impairment they are unable to move around at night, this is particularly limiting in winter-time when it is either dark or getting dark before or as the working day is ending.

"Variable conditions make a huge difference to a deafblind person's ability to do a journey – e.g. low sun and glare in winter can make a journey very difficult although it can be done easily in summer, the light on a cloudy November afternoon may prevent a journey that is do-able on a brighter day." (Parent of two people with Usher syndrome)

We therefore propose that individuals should be considered unable to perform an activity where seasonal changes, low levels of light or darkness mean they are unable to complete an activity.

Q7 – What are your views on the definitions of 'safely', 'timely', 'repeatedly' and 'in a timely' manner?

In order to ensure a fair assessment, these words and definitions should be placed on the face of the regulations.

Reliably

It is currently unclear how the 'reasonable standard' will be defined. We believe this should be defined as the same standard that a non-disabled individual would expect according to the activity, for example a social activity, training activity or job interview.

Q8 – What are your views on the definitions in the regulations?

Deafblind people have told us about the difficulties they sometimes face in explaining their needs for assistance or prompting under DLA. We therefore urge the Government to take this opportunity to provide clear guidance on the use of these terms.

"I have had problems explaining my need for assistance on my second DLA application for an upgrade to middle rate. I believe that they definitely need to be clear in terms of prompting and assistance for people with Usher syndrome."
(Deafblind person)

Prompting

The definition must be clear that this applies for 'some of the time' rather than the majority of the time.

Assistance

We are very concerned that some of the kinds of support that deafblind people need seem to not currently fit tidily within the defined categories of assistance, prompting or supervision. This is particularly concerning in relation to support people might need that may not be seen as assistance as it may not be seen as 'physical intervention'. For example a deafblind person who needs a situation described to them or a message relayed to them, such as if there is an unexpected situation at a train station a deafblind person might need someone to repeat announcements or explain the situation. As we understand it this would not be prompting or supervision, but we are concerned that as this will not involve a physical intervention in the literal sense, this kind of need will not be accepted by assessors.

Under DLA it has been long established that support with seeing and hearing is seen as 'attention' for the purposes of DLA and so on a par with 'physical' care needs. The House of Lords judgment in *Mallinson* (1994) provided in relation to an appellant who was blind that –

- The fact that a disability is so severe that a function cannot be exercised does not prevent attention being received in connection with that function,

- if it provides a substitute method of providing that function. So help with reading and writing -which do not of themselves count as bodily functions - do count as help with the function of seeing; and
- The need for attention to involve contact need not be physical contact, it can be established by the spoken word - e.g. encouraging someone to get up, telling them their clothing doesn't match or suit the weather conditions.

The House of Lords judgment in Halliday/Fairey (1997) which involved an appellant who was deaf provided that -

- Attention which enables someone to engage in a reasonable level of social activity (and that could include many daytime activities) can count; and
- Bodily functions did not just include help that was essential to living as opposed to merely desirable so that attention can include "any help that enables a person to as far as possible lead a normal life".

Therefore to continue this fair system under PIP, assistance should be defined in this way:

‘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. ***But this does include instances where another person uses a bodily function to compensate for an individual's impairment, for example using their vision or hearing.*** To apply, this only needs to be required for part of the activity.’

Q9 – Do you have any other comments on the draft regulations?

Disproportionately disadvantaging people with sensory impairments across the descriptors

We are extremely concerned that the draft criteria still fail to fairly assess the barriers faced by people with sensory impairments despite ministerial commitments that PIP will better meet the needs of people with sensory impairments. While ‘Activity 7 – communicating’ is a welcome addition, only a tiny group of people will receive enough points on this descriptor alone to receive the enhanced rate of the daily living component. People with sensory impairments are then excluded from both the social engagement and financial decisions activity, despite facing specific barriers to these activities which are additional to their communication needs. The current criteria therefore would fail to meet the Government’s aim to fairly identify those with the ‘greatest need’ irrespective of their impairment. We therefore urge the DWP to carry out and publish an analysis, such as RASCH analysis, to check that the criteria are not

disadvantaging people with sensory impairments against people with different types of impairments but who face similar levels of barriers and additional costs.

Aids and appliances

Aids and appliances play a crucial role in supporting the independence and wellbeing of disabled people and people with long-term conditions. The Government has the stated aim that Personal Independence Payment should better reflect the needs of disabled people in the 21st century. Technological advances mean that disabled people use a whole range of aids and appliances, which while assisting them in their everyday lives, bring both additional costs and do not by any means totally eliminate the barriers they face. We are concerned that the PIP assessment in its current form does not give due weight to individuals' use of aids and appliances leaving them ineligible for what we would consider the appropriate PIP award.

While some basic aids may be provided by local authorities or health services, many individuals purchase their own. This may be because they are deemed ineligible or because what is provided may not fully meet their needs or meet only a very basic level of need. Disability Living Allowance currently plays a crucial role in providing funding for individuals to make personalised choices to buy the aids and appliances that will make the most difference to them.

The criteria for the PIP assessment are designed to act as a proxy for identifying disabled people who face the greatest barriers. It is right that for some individuals the level of human support they require is a proxy of this. However for some individuals it is their level of use of aids that is the better proxy for identifying them as facing significant barriers. This is especially pertinent for people who live alone. Under the current system of weighting we believe that this group will be severely disadvantaged. Included below are particular instances when aids and appliances should be taken into account to better identify the barriers faced by deafblind people.

Level of adaptation

We are very concerned about apparent assumptions about how individuals' level of 'adaptation' could affect the level of barriers that they face. Training, aids, appliances and support from others do not totally eliminate barriers and additional costs. For example, a scanner and braille display enables someone to access only some print documents and being able to use a specialist communication method cannot be reasonably be equated to being able to communicate.

Indeed some people 'adapt' in a negative way, for example by limiting the destinations they would go to independently. Assessors should not assume that this means an individual is able to go independently to 'familiar destinations' as

these individuals have purposefully restricted themselves and often may not have the insight to recognise the extent to which they have done this.

Also, in many cases 'adapting' may actually increase additional costs faced by individuals. For example a deafblind person could ask someone to go shopping for them and if this is a family member or friend, the cost may be very low. However if an individual wishes to maintain their independence in this activity, they would require human support or aids to do this. These both cause ongoing additional costs.

In relation to adaptation, it is vital that assessors have an understanding of how many people with sensory impairments have fluctuating conditions. This can be caused in some cases by the variability of their impairments, for example tinnitus can vary from day to day, but also by external factors such as light and noise levels.

In relation to this it is vital to recognise that irrespective of the nature of individuals' impairments, the world is not static, with environments changing and in some cases becoming more complex to deal with. Therefore guidance that accompanies these Regulations must clearly set out how to fairly assess level of adaptation, taking into these points.

The needs of young people developing independence or living alone for the first time

We are very concerned that PIP currently fails to identify the specific needs of disabled young people. Transition is already a very complex and stressful process for deafblind young people and their families; DLA currently plays an important role in supporting growing independence and independent mobility. Therefore PIP should act as a facilitator to this process rather than an additional hurdle for young people and their families.

We support the work of Every Disabled Child Matters in exploring an additional activity covering 'Preparing for adulthood'. This activity would identify the specific needs of disabled young people during the transition period (16-25) as they develop the skills needed for independent living and the additional costs and barriers they face over this period. Given the number of years covered by the transition process, we believe this sits within the scope of PIP as a contribution towards longer terms needs faced by disabled people.

For deafblind young people, it is especially important that the criteria are able to pick up on their particular barriers to independent living. These include limited communication, mobility and orientation skills, for example it will take deafblind young people years to develop the confidence to make journeys independently.

It will also be vital that guidance for Decision-Makers and assessors includes recognition of the particular challenges in assessing disabled young people. For example disabled young people, especially those under 18 are unlikely to have the insight to fully judge whether they can carry out all activities 'safely'. Therefore a wide range of written evidence should be sought during the application process to allow individuals, families and the professionals who work with them to build a picture of their barriers and additional costs.

The stress caused by a face to face assessment for money young people should not be underestimated and this was reported by young people and their parents during the testing of the first draft of the assessment criteria in summer 2011. Making sure the assessment criteria specifically identify the needs of young disabled people will assist with keeping such stress and anxiety to a minimum.

Conclusion

We believe our proposals are backed up by a fair and evidenced analysis of the impact that the current draft criteria will have on deafblind people, a group of people who face significant barriers and additional costs that PIP should identify. We would of course welcome further opportunities to engage with officials as the third draft of the criteria is prepared.

27th April 2012

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Appendix 1: Full set of proposed amendments to the criteria

| | | |
|--|--|----------|
| 2. Taking nutrition. | 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 |
| | d. *Either – i.* Needs prompting to take nutrition*; or ii. Needs <u>both</u> to use an aid or appliance to take nutrition <u>and</u> assistance to cut up food.* | 4 |
| | e. Needs assistance to manage a therapeutic source to take nutrition. | 6 |
| | f. Needs another person to convey food and drink to their mouth. | 10 |
| 3. Managing therapy or monitoring a health condition. | a. Either – (i) Does not receive medication, therapy or need to monitor a health condition; or (ii) can manage medication, therapy or monitor a health condition unaided. *[Delete: “or with the use of an aid or appliance.”]* | 0 |
| | *b. Can only manage or receive medication, therapy or monitor a health condition with the use of an aid or appliance.* | 1 |
| | *c.* Needs supervision, prompting or assistance to manage medication or monitor a health condition. | 2 |
| | *d.* Needs supervision, prompting or assistance to manage therapy that takes up to 3.5 hours a week. | 2 |
| | *e.* Needs supervision, prompting or assistance to manage therapy that takes between 3.5 and 7 hours a week. | 4 |
| | *f.* Needs supervision, prompting or assistance to manage therapy that takes between 7 and 14 hours a week. | 6 |
| | *h.* Needs supervision, prompting or assistance to manage therapy that takes at least 14 hours a week. | 8 |

| | | |
|---------------------------------|---|---|
| 4. Bathing and grooming. | a. Can bathe and groom unaided. | 0 |
| | b. Needs to use an aid or appliance to groom. | 1 |
| | c. Needs prompting to groom. | 1 |
| | d. Needs assistance to groom *or to check grooming.* | 2 |
| | e. Needs supervision or prompting to bathe. | 2 |
| | f. Needs to use an aid or appliance to bathe. | 2 |
| | g. Needs assistance to bathe. | 4 |
| | h. Cannot bathe and groom at all. | 8 |

| | | |
|--|---|---|
| 5. Managing toilet needs or incontinence. | a. Can manage toilet needs or incontinence unaided. | 0 |
| | b. Needs to use an aid or appliance to manage toilet needs or incontinence. | 2 |
| | c. Needs prompting to manage toilet needs. | 2 |
| | d. *Needs either - i.* Assistance to manage toilet needs*;or ii. Assistance to locate a toilet in an unfamiliar location.* | 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 |

| | | |
|--------------------------|---|----------|
| 7. Communicating. | a. Can communicate unaided and access written information unaided, or using *non-specialist* spectacles or contact lenses. | 0 |
| | b. Needs to use a *basic* aid or appliance ¹⁰ other than *non-specialist* spectacles or contact lenses to access written information. | 2 |
| | c. Needs to use an aid or appliance to express or understand verbal communication. | 2 |
| | d. *Needs either – i.* Assistance to access written information*; or ii. A complex aid or appliance¹¹ to access written information.* | 8 |

¹⁰ For example a simple manual aid such as a magnifier

¹¹ For example a complex electronic aid such as computer braille display or CCTV device

| | | |
|--|--|-------------|
| | *[Delete: e. Needs communication support to express or understand complex verbal information. | 4]* |
| | *e.* Needs communication support to express or understand *[Delete: basic]* verbal information. | 8 |
| | *f. Needs communication support to express or understand verbal information <u>and</u> needs to use a basic aid or appliance to access written information.* | *10* |
| | *g. Either - i. Needs communication support to express or understand verbal information <u>and</u> needs assistance or a complex aid or appliance to access written information; or ii.* Cannot communicate at all. | 12 |

| | | |
|---------------------------------------|---|---|
| 9. Making financial decisions. | a. Can manage complex financial decisions unaided. | 0 |
| | b. *Either – i.* Needs prompting to make complex financial decisions *; or ii. Needs assistance to make complex financial decisions.* | 2 |
| | c. *Either – i.* Needs prompting to make simple financial decisions *; or ii. Needs assistance to make simple financial decisions.* | 4 |
| | d. Cannot make any financial decisions at all. | 6 |

New daily living activity:

| | | |
|--|--|---|
| Maintaining a safe and liveable home environment. | (a) Can ensure their home and garden are hygienic and safe unaided. | 0 |
| | (b) Needs assistance to keep garden maintained safely. | 2 |
| | (c) Needs assistance to carry out essential household maintenance. ¹² | 4 |
| | (d) Needs assistance to keep low risk rooms hygienic. ¹³ | 4 |
| | (e) Needs assistance to wash and dry clothes. | 4 |
| | (f) Needs assistance to keep kitchen, bathroom and main bedroom hygienic. | 6 |

| | | |
|---|---|----|
| 1. Planning and following a journey. | a. Can plan and follow a journey unaided. | 0 |
| | b. Needs prompting for all journeys to avoid overwhelming psychological distress to the claimant. | 4 |
| | c. Needs either – i. *Assistance,* supervision, prompting, a support dog *, orientation aid¹⁴ or taxi* to follow a journey *along an unfamiliar route* ; or ii. A journey *along an unfamiliar route* to have been entirely planned by another person. | 8 |
| | d. Cannot follow any journey because it would cause overwhelming psychological distress to the claimant. | 10 |
| | e. Needs either – i. *Assistance,* supervision, prompting, a support dog *, orientation aid or taxi* to follow a journey *along a familiar route* ; or ii. A journey *along a familiar route* to have been planned entirely by another person. | 15 |

¹² E.g. changing a light bulb, bleeding radiators

¹³ 'Low risk rooms' are rooms other than the kitchen, bathroom and main bedroom

¹⁴ An orientation aid is a specialist aid or appliance used by a blind, partially sighted or deafblind person to assist with safe travel.