

Personal Independence Payment: assessment thresholds and consultation

A response by the National Deaf Children's Society

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1. Introduction

- 1.1. The National Deaf Children's Society (NDCS) welcomes the opportunity to respond to the consultation on the Personal Independence Payment (PIP) assessment thresholds. We are concerned that many deaf young people will not qualify for PIP under the thresholds proposed. We believe this is unfair as the majority still face barriers to full participation in society and have to spend money on additional support to overcome them.
- 1.2. NDCS is the national charity dedicated to creating a world without barriers for deaf children and young people. We represent the interests and campaign for the rights of all deaf children and young people from birth until they reach independence. There are over 45,000 deaf children in the UK. Three are born every day.
- 1.3. NDCS believes that the family is the most important influence on a deaf child's development. NDCS supports the deaf child through the family as well as directly supporting deaf children and young people themselves and has a team of family officers and benefits appeals advisers working to support deaf children and young people and their families in their applications for DLA.
- 1.4. NDCS is a member of the Every Disabled Child Matters Campaign (EDCM) and intend our response to provide additional evidence in support of their submission.
- 1.5. By deaf, we mean anyone with a permanent or temporary hearing loss. This could be a mild, moderate, severe or profound hearing loss. The term deaf does not presuppose the use of any one communication method and could refer to children who communicate orally or through sign language. We also include children who have a hearing loss in one ear.

2. Answer to consultation questions

2.1 (Questions 1 and 2) What are your views on the latest draft Daily Living activities?

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

2.1.1 Activity 3 – Managing therapy or monitoring a health condition

Deaf young people may use certain therapies to help them improve their communication skills which NDCS recommend are considered a therapy under this activity and that this is made explicit in guidance to professionals, for example:

- Speech and language therapy – which may include some exercises to be carried out on a regular basis and may need supervision, prompting or assistance to manage

- Lip reading exercises - which again may include some exercises to be carried out on a regular basis and may need supervision, prompting or assistance to manage
- Arts therapy which is sometimes used for young people with mental health conditions.

However, we are concerned that no points are awarded to someone who requires an aid or appliance to complete the activity. This not only goes against the Government's commitment to recognising the barriers and extra costs faced by people who need to use aids and appliances, but also appears to be inconsistent with other activities in the assessment criteria which do take aids and appliances in to account.

2.1.2 Activity 7 – Communicating

General comments

We are concerned that the descriptors used and the weightings given to them under Activity 7 do not give enough weight to the importance of communication in daily living. What is being assessed here is an individual's ability to communicate face to face, one to one in a quiet environment with no background noise. This will not give an accurate picture of the barriers that deaf people face in communicating in everyday life where there are many other barriers which these assessment criteria do not take in to account such as:

- Background noise which is encountered in any busy environment from shops, to classrooms, university campuses, workplaces, doctor's waiting rooms and social occasions, as well as outside. Hearing aids amplify all sounds including background noise to the same level which can make it impossible to distinguish what actually needs to be heard in noisy places.
- The familiarity of the speaker/s and whether or not they have an unfamiliar accent. It is much easier for deaf people to lip-read people who are familiar to them, new people and people with accents they don't usually come across can be much more difficult to understand.
- How many people are involved in the conversation. When a deaf person who is lip reading is involved in a conversation with a number of people, in order to follow what is going on people must speak one at a time, and the deaf person needs time to work out who is speaking next and inevitably loses some of what is being said when turning their attention from one person to another.
- The acoustic environment where a conversation is taking place. In large rooms with high ceilings, and hard surfaces such as glass and concrete it is often difficult for deaf people using hearing aids or cochlear implants to pick out speech.

The need to address sign language in the regulations

NDCS welcomes the statement in the explanatory note (p.36) that “While we recognise that individuals’ native language 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”. However, this must be addressed in the regulations and should be on the face of the law. If not, the intention expressed above will not be achieved.

Definition of ‘communication support’

In the notes under Activity 7 in the explanatory note (p. 56) we welcome the updated definition of ‘communication support’ to include “support from someone directly experienced in communication with the individual, such as a friend, family member or carer” as recommended in the comments we submitted to the Department on the first draft. However, we would further recommend that this wording is included specifically in the descriptors, so that assessors are left in no doubt that communication support is not only provided by professionals.

We also recommend that the following sentence in the notes under Activity 7 include the addition of the word ‘spoken’, added in bold below:

*This activity considers the capability to convey information and understand other people in the person’s native **spoken** language*

This would clarify the aim of the assessment for those carrying it out.

Specific comments on the descriptors under Activity 7

D – We recommend that this descriptor is given a higher rating as not being able to access written information is a significant barrier to full participation in society. We also recommend the addition of needing help to write down information is added to the descriptor e.g. when filling in a form, which is the case for some deaf young people who may have delayed language as a result of their deafness, or may use British Sign Language as their first language.

E- We strongly recommend that this descriptor carries a higher weighting of 8 and scoring here should be the threshold for the standard rate of the benefit. In order to fully participate in society an individual must be given the opportunity to understand and respond to the complicated things that people are saying to them, as well as the basic, which is why we believe that the threshold for the standard rate of PIP should be scoring on this descriptor. Young deaf people have told us that they feel that the Government does not recognise them as having a right to fully participate in society if the support they need to understand complex information is not recognised as a threshold for support for Personal Independence Payment.

F- NDCS recommends that the weighting for this descriptor is increased to 12 and that scoring on this descriptor be the threshold for the enhanced rate of PIP. Being able to express or understand basic verbal information is fundamental to full participation in society and, requiring support to do this is very costly to the individual indeed and not being able to do this is a very substantial barrier.

2.1.3 Activity 8 – Engaging socially

We are concerned that the criteria under this activity are designed only to assess the needs of people with mental and cognitive impairments. We believe this is unfair as deaf young people often find there are many barriers to taking part in social activities which they need support to overcome. Social occasions with more than one person speaking at a time, in a noisy atmosphere and dim light where it is difficult to lip read are often impossible for deaf people to join in with, without support. This can mean that deaf young people will choose not to engage in social activities as they feel these barriers are too much to overcome without embarrassment. This is not a 'preference by the individual' as laid out in the notes under the activity and we would seek assurance that those individuals who limit their social activity due to the difficulties they face are not understood to have done this through 'preference'. Engaging socially is an activity that it is particularly important for the 16 -25 age group who will often need additional support to develop these skills for later life. We would welcome consideration by the Department of how to meet the needs of this age group which are distinct from those of older claimants as they require additional support in order to establish independence.

In the notes on this descriptor in the explanatory note (p.58) we recommend that 'Social support...from a person trained or experienced in assisting people to engage in social situations" explicitly includes a friend, family member or carer, as with Activity 7.

Specific comments on the descriptors

C – We recommend that this descriptor carries a higher weighting and is the threshold for the standard rate of PIP, as being able to engage socially is essential to full participation in society.

D (i) – The notes for this descriptor state "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." We are concerned by this wording as some deaf young people may experience this level of mental distress, and therefore the barriers caused by this, without ever having had a medical diagnosis or the opportunity to gather evidence from professionals. If PIP is to be based on the social rather than the medical model of disability as stated by the Government, NDCS recommends that evidence of distress from whatever

source, without the need for a medical diagnosis, should be enough to score here. We also recommend that this descriptor carries a higher weighting and is the threshold for the enhanced rate of PIP.

2.1.4 Activity 9 – Making financial decisions

Many of the deaf young people and their parents we have discussed the assessment criteria with feel that they need assistance or support to make complex financial decisions. The current descriptors refer only to 'prompting'. Therefore we would recommend an additional descriptor, 'Needs support to make complex financial decisions', be added at 4 points. This again is particularly important for the 16 to 25 age group who will require extra support in making financial decisions in order to enable them to establish independence.

2.2 (Questions 3 and 4) What are your views on the latest draft Mobility activities? What are your views on the weightings and entitlement thresholds for the Mobility activities?

2.2.1 Activity 10 – Planning and following a journey

We welcome the inclusion of travel by public transport as well as walking in the mobility activities in the draft PIP criteria.

Definition of 'supervision'

NDCS is concerned that the definition of supervision as 'continuous' will be problematic. Some deaf young people will need supervision on unfamiliar journeys, either because they cannot hear approaching traffic, or judge distance and speed of vehicles so need to be prevented from stepping out in to the road when it is unsafe, or they may need support to communicate with staff members on public transport. They will only need this 'supervision' at various points along the way, but they will need it for the whole duration of the journey. We would welcome clarity on the definition of supervision so that young people who need the presence of another person at various points along a journey, and for the entire duration of the journey, although not continuously, are not excluded. We recommend that this wording is changed from 'continuous' to 'most of the time' as it is currently under DLA.

Taking account of the support an individual may need if their journey is disrupted or they become lost

We are concerned that the descriptors under this activity do not cover the situation where a journey is interrupted, due to a breakdown, accident or road works which may pose problems for a deaf young person who may become lost as a result and unable to plan a new route without support due to communication barriers.

Taking account of young people developing independent travel skills

Unlike older deaf people, deaf young people aged 16-25 may require additional support and incur additional costs as they learn independent travel skills and we would recommend that the assessment criteria and thresholds take account of this.

Specific comments on the descriptors under Activity 10

D – NDCS would welcome clarity on the definition of ‘overwhelming psychological distress’ as stated above in comments on Activity 8 D (i). We recommend that this does not mean only for diagnosed psychological conditions, as some deaf young people may experience this level of mental distress, and therefore the barriers cause by this, without ever having had a medical diagnosis or the opportunity to gather evidence from professionals.

E - NDCS agrees that scoring on this descriptor should be the threshold for the enhanced rate of PIP.

2.3 (Question 5) What are your views on how the regulations work regarding benefit entitlement?

With regard to Part 2 (5) (2) of the draft regulations, we believe these should be amended so that people are given six weeks at the very minimum to complete the PIP application form and written evidence document. This will allow time for those who need to, to arrange suitable support in filling out the form and for all to gather the evidence.

We also recommend that Part 2 (7) (3) of the regulations should be amended so that individuals are given at least 14 days written notice before an appointment for a face to face assessment. 7 days as is currently proposed, does not allow individuals enough time to arrange time off work and for someone to accompany them to the assessment if they require it.

Under Part 2 (7) (1) we recommend adding ‘by webcam with a signer, or by minicom’ to (b), so that the consultation is accessible to individuals who do not use the telephone.

We believe Part 2 (7) (4), should be amended to explicitly state that this written notice must have been sent in the claimant’s preferred format which should include British Sign Language for those who require it and have stated so in their application for PIP.

Under Part 2 (8) a claimant’s ability to use the phone, and the availability of appropriate communication support at the consultation, should also be taken in to account as good reason for not attending a consultation.

2.4 (Question 7) What are your views on the definitions of ‘safely’, ‘timely’, ‘repeatedly’ and ‘in a timely’ manner?

We would like to draw attention to the fact that ‘reliably’ has been omitted from question 7 as printed in the consultation document. We hope and assume this is an error.

We share the concern of other disability organisations that the definition of ‘reliably’ is unclear as a ‘reasonable standard’ is not defined. We recommend that this be defined as the same standard to which a non-disabled individual would expect to complete the activity.

We are also concerned that the definition of ‘In a timely fashion’ is not suitable for Activity 7 – Communicating as ‘in less than twice the time it would take for an individual without any impairment’ does not seem a suitable measure for a conversation. We recommend that a sentence is added to the notes under Activity 7 which makes it clear that for this activity ‘In a timely fashion’ means ‘in enough time to ensure that communication flows between individuals’.

We recommend these definitions are on the face of the regulations clearly stated at the beginning. In addition, it should also be clearly stated in the regulations that an individual should score on any descriptor that they cannot complete safely, reliably, repeatedly and in a timely manner.

2.5 (Question 8) What are your views on the definitions in the regulations?

We welcome the inclusion of ‘(b) support from someone experienced in communicating with the claimant’ under the definition of ‘communication support’.

We also welcome the statement in the explanatory note (p.36) that “While we recognise that individuals’ native language 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”. However, this must be addressed in the regulations and should be on the face of the law. If not, the intention expressed above will not be achieved.

2.6 (Question 9) Do you have any other comments on the draft regulations?

We would like to highlight that face to face assessment for benefits can be a very stressful experience for deaf young people and can harm their self esteem. Many will not present accurate information on the impact of their disability to an unfamiliar professional. Research shows that deaf young people are often likely to simply

answer 'yes' or 'no' to a question they haven't understood than to seek clarification of the question¹ giving assessors an inaccurate picture of their abilities. Young people who are still coming to terms with being deaf and developing a deaf identity, may also play down the impact that being deaf has on their lives. We therefore, recommend that assessment questions are tailored for deaf young people in order to be able to obtain accurate answers. Assessors will also need training in deaf awareness and how to communicate effectively with deaf young people.

In the assessment deaf young people are likely to be accompanied by another individual or family member for support who may provide informal communication support. This may include using signs or repeating questions, as an unfamiliar professional may be harder to lip-read. This gives the professional carrying out the assessment an unrealistic view of the child or young person's ability to communicate in unfamiliar situations with strangers. Assessors will also need to be able to pick this up during the assessment.

NDCS is a member of the Every Disabled Child Matters Campaigns and were involved with the development of their response to this consultation. We have not repeated all the points they make but we support their submission and recommendation that the Government look again at how assessment for PIP can be adapted to reflect the additional support and costs disabled 16-25 year olds need in the transition years to independent living.

3. Summary of recommendations

NDCS recommends that:

3.1 speech and language therapy, lip-reading courses and other therapies used by deaf young people are considered a therapy under Activity 3 of the PIP assessment criteria.

3.2 the use of an aid or appliance to complete descriptors under Activity 3 should score points in the assessment for PIP.

3.3 situational and environmental factors that affect deaf young people's ability to communicate such as, background noise, number of people involved in a conversation, acoustic environment and lighting are taken in to account when assessing individuals under Activity 7.

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http://content.ebscohost.com/pdf25_26/pdf/2011/C4F/01Oct11/65476009.pdf?T=P&P=AN&K=2011275638&S=R&D=c8h&EbscoContent=dGJyMNL80Sep7M4wtvhOLCmr0meprNSr6m4Sa%2BWxWXS&ContentCustomer=dGJyMPGnrIC3qLdRuePfgvex44Dt6fIA

3.4 the intention that “assessment criteria are designed to ensure that people using sign language are not disadvantaged” is stated on the face of the regulations, so that people using sign language are not disadvantaged.

3.5 that the definition of ‘communication support’ to include “support from someone directly experienced in communication with the individual, such as a friend, family member or carer” is included specifically in the descriptors, so that assessors are left in no doubt that communication support is not only provided by professionals.

3.6 that the following sentence in the notes under Activity 7 include the addition of the word ‘spoken’, added in bold below:

*This activity considers the capability to convey information and understand other people in the person’s native **spoken** language*

3.7 that descriptor D in Activity 7 is given a higher rating and the addition of needing help to write down information is added to the descriptor e.g. when filling in a form.

3.8 that descriptor E in activity 7 carries a higher weighting of 8 and scoring here should be the threshold for the standard rate of the benefit. Young deaf people have told us that they feel that the Government does not recognise them as having a right to fully participate in society if the support they need to understand complex information is not recognised as a threshold for support for Personal Independence Payment.

3.9 that the weighting for descriptor F in Activity 7 is increased to 12 and that scoring on this descriptor be the threshold for the enhanced rate of PIP. Being able to express or understand basic verbal information is fundamental to full participation in society.

3.10 that Activity 8 – *Engaging socially* applies to deaf young people and includes social support from a friend, family member or carer.

3.11 that descriptor C under Activity 8 carries a higher weighting and is the threshold for the standard rate of PIP, as being able to engage socially is essential to full participation society.

3.12 that proof of “overwhelming psychological distress under descriptor D in Activity does not need to be from a medical diagnosis of a mental health condition.

3.13 that an additional descriptor be added to Activity 9 ‘Needs support to make complex financial decisions’, for 4 points. This is particularly important for the 16 to 25 age group who will require extra support in making financial decisions in order to enable them to establish independence.

3.14 a clearer definition of supervision so that under Activity 10 young people who need the presence of another person at various points along a journey, and for the entire duration of the journey, although not continuously, are not excluded. We recommend that the definition of supervision is changed from 'continuous' to 'most of the time' as it is currently under DLA.

3.15 that an additional descriptor is added under Activity 10 to take account of an individual's ability to cope when a journey is interrupted, due to a breakdown, accident or road works

3.16 that the regulation are amended so that individuals are given six weeks at the very minimum to complete the PIP application form and written evidence document and at least 14 days written notice before an appointment for a face to face assessment.

3.17 that 'by webcam with a signer, or by minicom' is added to the regulations so that the consultation is accessible to individuals who do not use the telephone.

3.18 that the regulations should be amended to explicitly state that this written notice must have been sent in the claimant's preferred format which should include British Sign Language.

3.19 that a claimant's ability to use the phone, and the availability of appropriate communication support at the consultation, should also be taken in to account as good reason for not attending a consultation in the regulations.

3.20 that the term 'reliably' is defined as the same standard to which a non-disabled individual would expect to complete the activity.

3.21 that under Activity 7 'In a timely fashion' should mean 'in enough time to ensure that communication flows between individuals'.

3.22 that assessment questions are tailored for deaf young people in order to be able to obtain accurate answers and that assessors are given training in deaf awareness and how to communicate effectively with deaf young people.

3.23 that the Government look again at how assessment for PIP can be adapted to reflect the additional support and costs disabled 16-25 year olds need in the transition years to independent living.