



Personal Independence Payment (PIP) Assessment consultation

A response from

Spina bifida • Hydrocephalus • Information •
Networking • Equality - **Shine**

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Charity number: 249338

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Introduction

Established in 1966, Spina bifida • Hydrocephalus • Information • Networking • Equality - Shine, (formerly Association for Spina Bifida and Hydrocephalus) is an independent charity working across England, Wales and Northern Ireland to support individuals with spina bifida and/or hydrocephalus to overcome challenges and achieve the best for them and their families.

Shine is the largest organisation working in this field in Europe. We are a membership organisation of over 9,500 individuals living with spina bifida and/or hydrocephalus and a community of over 75,000 members, families, friends, and professionals, sharing achievements, challenges and information on living with hydrocephalus, or spina bifida, and related issues.

The views expressed in this response are as a direct result of consultation with:

- Shine Members
- Shine's Health team
- Shine's team of Support and Development Workers across England, Wales and Northern Ireland

All respondents reported a degree of scepticism about the introduction of a completely new system. Many believe the primary purpose of a new system is to make cuts to expenditure, not to improve and enhance quality of life for individuals and families living with disability. They also question the cost of the introduction of such a scheme in this time of austerity

Shine members report being 'filled with dread' about the introduction of PIP. Some find the consultations and information being issued about PIP to be confusing and complicated.

However, the main concerns are not so much about the descriptors themselves, but about:

- How the assessments will be carried out
- The potential for ambiguity or subjectivity of the assessment
- The reliance on doctors and other health care professionals, who will have little or no experience of spina bifida or hydrocephalus.

This consultation response reflects these concerns and presents constructive suggestions for improvement. Shine hopes that the information will be taken into consideration in any ensuing review or reform of PIP.

We would also welcome the opportunity to be directly involved in further work on this issue.

For further information in relation to any aspect of this response, please contact Kate Thomas, on 01656 864102 or email kate.thomas@shinecharity.org.uk

Q1 – What are your views on the latest draft Daily Living activities (Listed in Appendix 1)?

1. Shine members feel that the list of daily living activities do not reflect the real issues faced by severely disabled people on a daily basis.

The definitions of activities demonstrate a very narrow view of everyday life. We question whether the list really represents society's view of a full, active and equal life. The descriptors are too general and do not lend themselves to the needs and personal circumstances of individual people.

We suggest that the list should be reviewed.

For example:

- Why should '**bathe**' be taken to mean only the cleaning of 'one's torso, face, hands and underarms'? Do disabled people not wash all over? It implies that this descriptor has been drawn up to ensure reduced weighting for this activity, hence lowering the likelihood of someone qualifying for PIP.
- '**Groom**' includes washing hair, but makes no reference to drying hair. Some disabled people have restricted mobility in one or both arms. Whilst a hand-held shower can facilitate washing hair, drying hair is infinitely more difficult. We suggest the descriptor is changed to 'washing and drying hair'.
- '**Prepare food**' fails to take into account practical difficulties, such as shopping and putting away food supplies.
- A nutritional diet is essential to maintain health yet members feel there is an implication in this activity that disabled people should rely on simply heating and serving microwave food to nourish themselves!
- '**Dress**' and '**undress**' – includes putting on and taking off socks and slip-on shoes. This implies that everyone has the ability to wear slip on shoes, thus alleviating issues with putting on and taking off shoes. However, many people with spina bifida cannot wear slip-on shoes, and we therefore suggest that 'slip on' is an unnecessary distinction. Using the phrase 'suitable footwear' would be more appropriate.
- For visually impaired people, assistance with '**dress**' and '**undress**' would need to include colour co-ordinating, checking for cleanliness and possibly suitability of clothing.

2. Members are also concerned that '**fitness and exercise**' are omitted from the list of 'daily living' activities.

3. The descriptors and weightings do not take account of the additional costs of living with as disability. An individual may manage their toileting needs, and wash him/her self unaided, but what of the additional costs associated with double incontinence (extra washing and drying of clothes and bedding, continence products, protective clothing etc...), which many people with spina bifida experience.

4. The term '**unaided**' needs to be coupled with '**unsupervised**' as there are tasks a disabled person may be able to do unaided, yet which will require essential supervision and prompting to ensure they are completed in a safe and timely manner.

5. The descriptors appear to focus on physical disability. Clarity needs to be given on how the effects of hydrocephalus (the hidden disability) and mental health issues will be taken into consideration.

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

6. Members feel strongly that the weighting has the potential to penalise people with ‘**can do**’ attitudes, or who develop greater confidence and skill to undertake tasks.

Despite their ‘**can do**’ attitudes and/or independence, people with disabilities still need the additional support that DLA has provided to enable them to lead full, active and independent lives. We fear that the lack of clarity for assessment criteria, and consequently the potential for subjective assessments, will take away potential for vital financial support.

For example:

- Eating a nutritional diet is essential to maintain health. The point system takes account of aids or equipment but assumes these are always available. This may not be the case if staying with friends or family or being away on holiday.
- ‘**Cook**’ is assumed to be at waist height. The new criteria do not specify what score would apply if an individual is not working at waist height. Many people with spina bifida are below average height and may need a kitchen step to facilitate their ability to cook. Would a kitchen step qualify as an appliance, in which case the individual will score 2, but take the kitchen step away (i.e. take the ability to cook and lead an independent life away, and the individual scores 8)?
- Most people with spina bifida are doubly incontinent. Many manage their continence, yet incur considerable costs for new clothes, washing clothes and bedding etc... From the proposed weighting, it is unclear whether people with spina bifida who manage their continence will qualify for PIP, despite the obvious additional costs to their daily living.

7. Pain does not seem to be taken into consideration. A person may be able to do some of the above daily living activities, but experience pain and may cause further problems by trying to dress bath or manage incontinence.

For example:

- Some people with paralysis can dress their lower body by sitting on the bed or in a wheelchair and lifting one leg up over the opposite knee to dress each leg in turn and then rocking from side to side in order to pull on lower clothing. If someone is expected to do this day after day and sometimes many times a day, if incontinence is hard to manage, with no assistance over a period of time the body begins to wear and then pain becomes a problem factor. Often shoulders, hands, elbows (joints in general) wear out.

8. We would suggest that more consideration is given to the weighting for assistance with activities such as bathing, dressing and managing incontinence.

9. As mentioned in Q1, the descriptors and weighting do not take account of both physical and mental capability. Clarity needs to be given on how the effects of hydrocephalus (the hidden disability) and mental health issues will be taken into consideration. Will there be sufficient support

and information, and qualified staff at the assessment to ensure that someone with hydrocephalus has a fair and just assessment?

10. We also suggest the inclusion of degrees of difficulty and frequency for assessment (e.g. with ease, some difficulty, mildly difficult, very difficult, extremely difficult, never, occasionally, sometimes etc...)

Q3 – What are your views on the latest draft Mobility activities (Listed in Appendix 1)?

11. The mobility activities are too narrow. We question whether the focus on just two activities ('planning and following a journey' and 'moving around') will enable a thorough and fair assessment of all the range of disabilities and the degree to which disability affects an individual's ability to carry out mobility activities.

12. Given the proposed criteria, members are concerned at whether they will qualify for mobility support, despite currently receiving higher rate mobility under DLA. Making the criteria too difficult to enable those in need to qualify will limit daily living activities and independence. One member has told us that her life would be 'curtailed'.

13. Mobility activities seem to be weighted in favour of individuals in wheelchairs. Many people with spina bifida and/or hydrocephalus do not use wheelchairs full-time, yet experience difficulty with getting around and require assistance. Individual circumstances need to be taken into consideration.

14. On its own, "move" does not indicate that any other factors are to be taken into account (e.g. pain; breathlessness, heart condition, balance, back problems etc...). We also question why 'walk' has been replaced with the word 'move'?

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

15. As mentioned above, mobility activities seem to be weighted in favour of individuals in wheelchairs. Many people with spina bifida and/or hydrocephalus do not use wheelchairs full-time, yet experience difficulty with getting around and require assistance.

For example:

- Anyone who has significant difficulty in moving up to 50 metres should meet the conditions for enhanced rates, regardless of the aids they use to do so, as they too will incur additional costs of transport etc...

16. We also suggest the inclusion of degrees of difficulty and frequency for assessment (e.g. with ease, some difficulty, mildly difficult, very difficult, extremely difficult, never, occasionally, sometimes etc...)

Q5 – What are your views on how we are dealing with fluctuating conditions? (as described towards the end of the section on The Activities Tests on Page 3)

17. Shine welcomes recognition of the fact that people are individuals, with individual conditions whose support needs vary daily, weekly or yearly. We hope that assessments will also relate to the individual and the fluctuation in their condition.

18. We question how the assessment of someone with hydrocephalus (the hidden disability) will be undertaken. The ability or inability of an individual with hydrocephalus to undertake daily tasks cannot necessarily be seen and may lead to the under-award of points. The assessment will be subjective, depending on the assessor's knowledge and understanding of the condition. Failure to correctly assess, and support, individuals with hydrocephalus will result in increased anxiety, stress and ill-health. We therefore strongly recommend the need for expert assessors to ensure a fair and thorough assessment.

Q6 – What are your views on the definitions of ‘safely’, ‘timely’, ‘repeatedly’ and ‘in a timely manner’? (as described in Appendix 1). In the assessment an individual must be able to complete an activity descriptor reliably, repeatedly, safely and in a timely manner. Otherwise they should be considered unable to complete the activity described at that level.

19. The words (safely, timely) are not present in the descriptors and need to be included.

20. The definitions should also include **‘and that does not cause further damage or risk to their condition and is in line with current health advice regarding managing the condition’**.

What an individual can do and what they have to do out of necessity/lack of facilities and what he/she ought to do are entirely different things.

For example:

- Someone with spina bifida may be able to walk but the cumulative effect will cause long-term damage. However, he/she may have to walk as his/her house may not be adapted for wheelchair use.

21. The assessment will be open to subjectivity by the individual assessors.

For example:

- How will an assessor proceed when faced with someone with a severe walking impairment who does not currently use a wheelchair, and clearly cannot complete 50 metres in less than twice the time it would take a non-disabled person? Does he assess as though the claimant uses a wheelchair and award the points necessary for an enhanced rate award? If not, then the claimant does not get the enhanced award even though he clearly cannot complete the activity. Will the assessor opt for the safer standard rate award, which will inevitably lead to more appeals?

22. We suggest that more clarity is required in the scoring of assessments.

Q7 - Is there anything else you would like to tell us?

23. Shine members wish it to be noted that they feel a review of Disability Living Allowance (DLA) should have been undertaken and that a completely new programme (Personal Independence Payments – PIP) is unnecessary. These views were expressed in our consultation response on DLA reform in March 2012. We are disappointed that they have not been taken into consideration.

24. The majority of Shine members remain sceptical about the Government's decision to introduce a completely new system. Many believe the primary purpose is to make cuts to expenditure, not to improve and enhance quality of life for individuals and families living with disability.

25. Shine members report being 'filled with dread' about the introduction of PIP and the new assessment process. Some find the consultations and information being issued about PIP to be confusing and complicated. We would suggest that it is extremely important to ensure the application and assessment process for PIP to be clear, easy to understand and led by experts who understand the issues that people living with spina bifida and/or hydrocephalus face.
26. Concerns are not so much about the descriptors themselves, but to how they will be assessed, and in particular the reliance on doctors and other health care professionals. In general, Shine knows that GPs and consultants have very little direct knowledge and experience of the impact of spina bifida and hydrocephalus on an individual's everyday life. We have grave concerns that our members will be incorrectly assessed.
27. Many of adult members tell us that they are not in regular contact with health care professionals (physiotherapists, occupational therapists etc...), mainly because the system does not provide on-going support once they reach adulthood. Therefore may have difficulty in providing supporting evidence about their conditions, particularly if there is a charge to obtain the supporting evidence.
28. It is Shine's understanding that everyone will undergo a new assessment when DLA is discontinued and that individuals will be re-assessed? However, who will assess the people with lifelong conditions? And who will be awarded the lifetime awards? Will there be any PIPs awarded indefinitely?
29. Shine also recommends that clear guidance for timescales for the assessment process are set. (E.g. how long will Lay Decision Makers take to interpret medical assessments)? Members have experienced lengthy delays in the current migration from incapacity benefit to employment support allowance, causing undue stress, anxiety and financial hardship whilst decisions are being made.