

## **Personal Independence Payment: Assessment thresholds and consultation**



### **Children in Wales Plant yng Nghymru**

Children in Wales is the national umbrella organisation in Wales, bringing organisations and individuals from all disciplines and sectors together. Its aim is to make the United Nations Convention on the Rights of the Child a reality in Wales. Children in Wales fights for sustainable quality services for all children and young people, special attention for children in need, and ensuring children and young people have a voice in issues that affect them.

Children in Wales has over 200 organisations in membership, including the major voluntary children's agencies, professional associations, local authorities and health bodies, as well as many smaller community groups. Children in Wales facilitates a variety of forums including a disability forum for professionals and a network for young disabled people, a parenting forum, a poverty network and practice exchange groups in North and South Wales. Children in Wales works in partnership with the National Children's Bureau in England, Children in Scotland, and internationally with Eurochild and the International Forum for Child welfare.

This response has been completed in conjunction with the members of Children in Wales from social services, education, health and the voluntary sector who work with disabled children and young people and their families.

#### **Q1 What are your views on the latest draft Disability Living Allowance activities?**

Children in Wales welcomes the addition of three new activities; communicating, engaging socially and making financial decisions as an improvement on the earlier draft. We still have some concerns on the weighting and entitlement thresholds assigned to these and the other activities and these are outlined below.

#### **Q2 What are your views on the weightings and entitlement thresholds for the Daily Living Activities?**

##### **Activity 1: Preparing food and drink**

We note that with the sole exception of descriptor G, which makes a passing reference to drink, the other descriptors refer to preparing food only. We therefore recommend that the scope of this activity is expanded to include "preparing a simple cooked meal and making a hot drink" and that both of these activities are required to be completed to meet the descriptor. Additionally the descriptors do not take into account the difficulty people with visual impairments face when they are unable to see labels or weigh and measure food themselves or the assistance that some people need with shopping and the purchasing of food.

### **Activity 2 : Taking nutrition**

Children in Wales is concerned that the descriptors fail to take into account the need that some people have for support or supervision when they are taking nutrition.

### **Activity 3: Managing therapy or monitoring a health condition.**

We believe that the impact of managing medication has not been given sufficient weighting and that the points score should allow for the potential severity of consequences which arise because of possible mistake with medication. The descriptors should also allow for the additional costs that some people incur in using specialist aids to manage conditions independently.

### **Activity 4 : Bathing and grooming**

The scoring here gives insufficient weighting to the importance of bathing and grooming in maintaining self-confidence and esteem and social relationships. The descriptors should therefore be expanded to include nail cutting, shaving and applying makeup and also allow for some people's need for assistance with regards to safety issues when grooming. The additional costs involved in grooming should also be recognised.

### **Activity 5: Managing toilet needs or incontinence.**

The descriptors should take account of the fact that many disabled find difficulty finding and using toilets when away from home. They should also allow for the frequency and severity of incontinence and the higher cost that can be incurred through this. Clarification should be provided on whether incontinence pads count as an aid.

### **Activity 6: Dressing and undressing.**

The descriptors should be broadened to include assistance with selecting appropriate clothing and checking whether the clothes are clean and in a decent state of repair. The additional cost of buying special equipment such a colour identifier is not recognised.

### **Activity 7: Communicating.**

We believe that the score for needing assistance to access written information is too low, especially when given the frequency and level of assistance that individuals may require and the impact that this may have on ability to live independently.

The descriptors should also be broadened to include the accessing of information in preferred formats and the scoring should take account of the additional issues and costs arising from this. We also recommend that points should be awarded for difficulties that many disabled people face with writing.

### **Activity 8: Engaging socially.**

The stress and embarrassment caused by having conditions which are socially embarrassing should be recognised in the descriptors as should anxiety and panic attacks, and all scored appropriately.

The descriptors should be broadened to avoid people with sensory impairment receiving no points – as per case studies 10 and 11.

**Activity 9: Making financial decisions.**

If someone is unable to make simple financial decisions without assistance they should be scored as being unable to make any financial decisions. We believe that considering the level of impact that difficulties in making financial decisions can have, the scorings should be higher.

**Q3 What are your views on the latest draft mobility activities?****Activity 10: Planning and following a journey**

We believe that the focus of this activity should be on routes to a destination and not just the destination itself. We also question the distinction made between familiar and unfamiliar journeys especially with the unpredictability of unforeseen hazards such as cars parked on the pavement, pot holes in the road etc. Additional points should also be awarded to people who find it difficult to cope with unexpected changes. We also recommend that the descriptors are reworded and rescored to address risk and safety issues e.g. for some people the fear of falling will be a main concern while for others it may be the risk of anxiety or panic attacks.

**Activity 11: Moving around**

Children in Wales believes that this activity should be reworded so that it explicitly addressed the ability to walk and not just move around, which could be subject to misinterpretation. The descriptors should also address the ability to walk on steps, uneven surfaces and include the impact of discomfort pain and fatigue on walking.

**Q4 What are your views on the weightings and entitlements thresholds for the mobility activities?**

We recommend that Descriptor E should be amended to state: "Cannot move repeatedly, reliably or safely up to 50 metres without encountering severe discomfort, pain and fatigue," scoring 12 points and therefore higher rate mobility. All mobilising activities should also list what average times taken should be over the distances given so people can assess whether they can do so in a "timely fashion".

**Q5 What are your views on how the regulations work regarding benefit entitlement?**

Children in Wales recognises the potential advantages of a points based assessment system, but we remain concerned that a computerised system will fail to take account of all an individual's circumstances. Much will depend upon the level of "empathy" employed by assessors, to use the terminology used in the Work & Pensions Select Committee report on Government support towards the additional living costs of working-age disabled people. The report states: "The assessment for PIP needs to be empathetic and avoid the mechanistic, box-ticking approach initially used in the WCA".

The report also states: "We recommend that, as part of the consultation with disability representative organisations on the second draft of the criteria now under way, the Government considers how activity descriptors could take account of the impact of such factors as housing, access to public transport and hilly locations."

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

A shorter time frame (e.g. one month) should be used for assessing the impact of fluctuating conditions, as this is more likely to provide an accurate assessment. Thought should also be given to how applicants can be reminded that points are scored on their ability to perform an activity “at some stage of the day”, to ensure that they do not under-assess their own abilities. We are concerned that the “points based” system may fail to reveal the bigger picture about an individual’s level of need. As it currently stands we cannot agree that the regulations, as worded, will reveal that the claimant’s ability is either “limited” or “severely limited” by their condition. Further thought should also be given as to how assessors can consider the overall circumstances of those who narrowly fail to meet the 50% of the day criteria.

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

Children in Wales feel that these definitions are generally helpful, but they need to be made more explicit. Reliably is said to mean “to a reasonable standard”. There is no definition of what this means leaving it open for individuals and decision makers to interpret matters very differently. Similarly “in a timely manner” is described as more than twice the time it would take a non-disabled person. It is therefore vital the government places figures on all activities so people know what estimated time.

We also feel that there is a risk that assessors will revert to evaluating individuals’ abilities on the day of the interview unless prominence is given to the words ‘safely’, ‘timely’, ‘repeatedly’ and ‘in a timely’ manner. Children in Wales therefore recommends that it is vital that “reliably, repeatedly, safely and in a timely manner” should be repeated throughout the regulations and a prompt should be provided on the face of each activity, otherwise there is a danger this will be overlooked.

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

Children in Wales believes that further clarification is needed on the following definitions and recommends that:-“Groom” should include shaving and drying oneself, as well as foot care, such as the ability to cut one’s toenails.

“Managing incontinence” it must be explicit that incontinence pads and wear are collecting devices.

“Overwhelming psychological distress” is an incomplete definition. The word “Overwhelming” is a subjective word and we would prefer it to be “disabling distress” as anxiety and panic attacks can arise not just from mental health conditions or cognitive and intellectual impairments but as a side effect of both a physical condition and also medication.

“Social support” it is unclear whether this trained or experienced person can be a professional or someone who is an informal carer (in our view it should be both)

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

Children in Wales is concerned that the PIP benefit has not been based on the Social Model of Disability and recommend that DWP should engage with disabled people's organisations to consider how the recommendations made in the paper "The Future of PIP: a social model-based approach" can be incorporated into the PIP assessment criteria and procedures.

The minimum period for notification of an interview should be 4 weeks to enable suitable advocacy or other advice and support to be obtained.

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