

# Response by Learning Disability Wales to the Public Consultation on Disability Living Allowance Reform

## Information about Learning Disability Wales

Our mission is to 'Create a Wales that values and includes every child and adult with a learning disability.'

We have 104 voluntary sector organisations that are members and have voting rights. We also have 42 individuals, 19 statutory organisations and 7 commercial organisations that receive our services as members, but do not have voting rights.

Our members are active in all aspects of the lives of children and adults with learning disability, from birth through to old age. They include self advocacy and advocacy organisations, children and adult service providers, parent and carer organisations, social service departments, statutory agencies and generic organisations.

We are a company limited by guarantee and a registered charity.

We provide 6 services to our members and partners:

- **Information:** A comprehensive service via newsletter, magazine, e-bulletins and website.
- **Training and events:** An extensive programme.
- **Policy and campaigning activity:** Extensive activity is undertaken to influence policies that affect children, young people and adults.
- **Network facilitation:** Convening and supporting important networks across Wales.
- **Consultancy services**
- **Hosting of projects:** Project activity is undertaken that will benefit children, young people and adults.

We believe that the child, the young person and the adult with a learning disability has a right to:

- Be valued and respected
- Services and support to live a meaningful life
- Education and training
- Be seen, heard and informed
- Plan their own life as they grow up and mature
- Friendships, relationships and a good social life
- Employment

We fully support and seek to promote, through our activities, the principles that have guided Welsh government policy since 1983. These state that people with a learning disability have the right to:

- An ordinary pattern of life within the community
- Be treated as an individual
- Additional help and support in developing their maximum potential

We also believe that people should be assisted to:

- Participate in all decisions and service planning that affects them.
- Learning Disability Wales

Our response to this consultation is informed by our members and by our values.

**1. What are the problems or barriers that prevent disabled people participating in society and leading independent, full and active lives?**

Our starting point is that the UK is a signatory to the UN Convention on the Rights of Disabled Persons. Therefore disabled people have a right to a life in the community and to have the same access to services and opportunities as other citizens. The many barriers that exist to disabled people exercising these rights have been very well evidenced by the UK Office for Disability Issues and the Office for National Statistics in their 'Life Opportunities Survey, Interim Report', Dec. 2010.

People with learning disabilities are particularly disadvantaged, with less than 10% of the working age population in any form of employment.

**2. Is there anything else about Disability Living Allowance (DLA) that should stay the same?**

We welcome the government's commitment to ensuring that the new Personal Independence Payment will remain an extra costs benefit, will not be means tested and will be free for disabled people to spend as they wish.

**3. What are the main extra costs that disabled people face?**

The Dept. of Work and Pensions own research shows that DLA helps individuals meet key expenses like healthcare and transport.

**4. The new benefit will have two rates for each component:**

- Will having two rates per component make the benefit easier to understand and administer, while ensuring appropriate levels of support?
- What, if any, disadvantages or problems could having two rates per component cause?

An important survey recently carried out by Mencap produced evidence on how adults with learning disabilities use their Disability Living Allowance. The findings, from 900 respondents were that the cash was used for:

- higher laundry costs and higher spend on cleaning products
- higher than average heating, electricity and phone bills due to medical, physical and personal care needs
- specialist food as a result of dietary requirements or purchasing of ready meals due to difficulty with cooking
- higher transport costs
- paying for help around the home (e.g. cooking meals, sorting bills) and with shopping
- help to access leisure activities and support with transport.

**5. Should some health conditions or impairments mean an automatic entitlement to the benefit, or should all claims be based on the needs and circumstances of the individual applying?**

We note the Governments intention to simplify the process and reduce bureaucracy. While we welcome the principle of looking with an individual at their needs through a personal assessment process, there will be a significant number of individuals whose needs are so substantial and unchanging that repeated interviews may serve little use, may be difficult if the individual has limited communication and will wastefully run up administration costs.

**6 How do we prioritise support to those people least able to live full and active lives? Which activities are most essential for everyday life?**

This a perverse question in the context of the decision already taken to removed the mobility element of DLA from those children and adults who have the most substantial needs and are furthest away from living an independent life, those adults living in residential care for more than 28 days. They are in most need of the financial support that will enable them to make trips out of their home.

**7. How can we best ensure that the new assessment appropriately takes account of variable and fluctuating conditions?**

We accept that the new benefit should be subject to review, where the individual claimants condition or circumstances may change.

**8. Should the assessment of a disabled person's ability take into account any aids and adaptations they use?**

- **What aids and adaptations should be included?**
- **Should the assessment only take into account aids and adaptations where the person already has them or should**

**we consider those that the person might be eligible for and can easily obtain?**

We find this suggestion to be particularly mean spirited and indicates a lack of understanding as to the challenges that disabled people face. Aids and adaptations will, if used, only assist with certain aspects of daily life or only be useful in certain locations, like the family home. As the Mencap survey indicates DLA has many uses. Calculating the extent to which any aid assists the individual to more fully take part in an aspect of daily life, and then seeking to put a monetary value on this as the basis for a cash deduction from the new PIP, would be a wholly subjective and arbitrary exercise, the very assertions that the consultation document makes as to weaknesses with the current DLA benefit.

Are disabled people to be penalized for having use of a simple gadget or Device, or will a sliding scale of cash figures be identified for each and every gadget, based on their usefulness? In such a scenario will disabled people be deterred from accepting aids or adaptations lest it affect the level at which their PIP is paid?

- 9. How could we improve the process of applying for the benefit for individuals and make it a more positive experience? For example:**
- **How could we make the claim form easier to fill in?**
  - **How can we improve information about the new benefit so that people are clear about what it is for and who is likely to qualify?**

Information should be provided in easy read and in other formats so that people with a learning disability are not disadvantaged.

- 10. What supporting evidence will help provide a clear assessment of ability and who is best placed to provide this?**

We believe that the assessment process will benefit from the claimant being able to present evidence from social care staff and other professionals that they come into contact with regularly. Using an individuals social care plan or person- centred plan could also be very helpful.

- 11. An important part of the new process is likely to be a face-to-face discussion with a healthcare professional.**
- **What benefits or difficulties might this bring?**
  - **Are there any circumstances in which it may be inappropriate to require a face-to-face meeting with a healthcare professional – either in an individual's own home or another location?**

We are not clear why such prominence is given in the proposed reforms to involving a health care professional, particularly when at other points in the document there are claims that the reforms will ensure that the new benefit is rooted in a social model of disability. People with a

learning disability do not have an illness, and their condition is not susceptible to medical treatment. In many cases the factors at work in an individual's life that would mean they will benefit from the Personal Independence Payment have nothing to do with their physical health.

This continuing and uninformed emphasis in the document on the contribution of healthcare professionals seems to flow from the Treasury. The October 2010 UK budget statement referred to the new benefit containing an 'objective medical assessment'.

The flaws in this approach have been highlighted by the substantial negative feedback generated by the new Work Capability Assessment introduced for the Employment and Support Allowance. Individuals leading these assessments have had a low awareness of learning disability and lack knowledge about how to communicate with people with learning disability.

- 12. How should the reviews be carried out? For example:**
- **What evidence and/or criteria should be used to set the frequency of reviews?**
  - **Should there be different types of review depending on the needs of the individual and their impairment/condition?**

Any review should use the input from professionals and plans that we have referred to in our response to Question 10.

As we indicated in our response to Question 5, automatically reviewing the claims of some individuals with unchanging conditions or circumstances may introduce pointless activity.

- 13. The system for Personal Independence Payment will be easier for individuals to understand, so we expect people to be able to identify and report changes in their needs. However, we know that some people do not currently keep the Department informed. How can we encourage people to report changes in circumstances?**

We note that the DWP has estimated the level of fraud as running at 0.5%. We also note that some claimant's condition and circumstances will change and do not oppose appropriate review activity, structured as we suggest in our response to Questions 10 and 12.

- 14. What types of advice and information are people applying for Personal Independence Payment likely to need and would it be helpful to provide this as part of the benefit claiming process?**

If face- to face interviews become part of the assessment process adults with a learning disability may well need to be supported by advocates or friends, particularly if they may become stressed in this situation or

communicate in an untypical manner.

- 15. Could some form of requirement to access advice and support, where appropriate, help encourage the minority of claimants who might otherwise not take action? If so, what would be the key features of such a system, and what would need to be avoided?**

In the case of people with learning disability the obvious step would be to give individuals access to advocacy assistance should they want or need it.

- 16. How do disabled people currently fund their aids and adaptations? Should there be an option to use Personal Independence Payment to meet a one-off cost?**

Please see our response to Question 8.

- 17. What are the key differences that we should take into account when assessing children?**

We would oppose the qualifying period increasing from 3 to 6 months for disabled children and would wish to see any payment made from the date of diagnosis. Extra costs will be incurred by parents from Day 1. Delaying qualifying is a crude cost limiting device.

We completely oppose the suggestion that a disabled child should be penalised financially for receiving education services that are a universal right for all children. DLA and the new PIP are 'extra costs' benefits. It would be counter to Article 31 of the UN Convention on the Rights of the Child.

- 18. How important or useful has DLA been at getting disabled people access to other services or entitlements? Are there things we can do to improve these pass-porting arrangements?**

We are concerned, see above, that a proportion of adults with learning disability who are identified as having lower level need will have their income cut in the move from DLA to PIP. It would be doubly unfair for them to lose pass-porting to other benefits.

- 19. What would be the implications for disabled people and service providers if it was not possible for Personal Independence Payment to be used as a passport to other benefits and services?**

See our response to Question 18.

- 20. What different assessments for disability benefits or services could be combined and what information about the disabled person could be shared to minimise bureaucracy and duplication?**

Subject to appropriate safeguards regarding confidentiality, we do not disagree with the principle of this suggestion. The practicalities of pooling assessments conducted for very different purposes may be challenging.

**21. What impact could our proposals have on the different equality groups (our initial assessment of which is on page 28) and what else should be considered in developing the policy?**

The initial impact assessment in the consultation document is partial, subjective and tendentious. Despite the very strong evidential basis for a link between poverty and disability, no evidence is provided for the assumption that 'less disabled' people no longer need additional financial support by way of PIP.

**22. Is there anything else you would like to tell us about the proposals in this public consultation?**

We are very concerned that while the UK Government's June 2010 budget anticipated a 20% reduction in expenditure through reform of DLA and this target clearly informs much of the content of the consultation, it is not referred to anywhere in the Consultation document.

The target directly leads to an emphasis in the document in focusing on disabled people with the 'greatest need'. The principle of DLA was that all disabled people needed assistance to meet the extra costs inherent in having a disability, albeit paid at different levels. No evidence has been provided that these extra costs have diminished.

The consultation document emphasizes that people with disabilities and relevant organisations are being consulted as reform proceeds. We are not aware of any Welsh organization being involved and, given the higher prevalence of disability in Wales, and therefore the proportionately greater impact of any changes, believe it essential that this omission be remedied.

**Learning Disability Wales  
17. 02.11.**