

# Disability Living Allowance Reform

## Consultation Response

### From: The Hampshire Personalisation Expert Panel (PEP)

11<sup>th</sup> February 2011

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#### Introduction:

This is the response to the Governments consultation paper concerning Disability Living Allowance Reform from the **Hampshire PEP**.

Members of the PEP have submitted their comments on the DLA reform proposals to an elected co-ordinator and these responses have been collated to form this response.

The Personalisation Expert Panel (PEP) is a group of User Led Organisations (ULO's) and individual Disabled People. We meet regularly to advise Hampshire County Council on the progressive implementation of the personalisation agenda in Hampshire. The PEP was proposed and established by ULO's as a result to Hampshire's Personalisation Commission in 2008 to ensure that the views, opinions and experiences of users (experts in their own experiences of Independent Living) influenced the development of policy. Hampshire County Council highly values the input of the PEP in assisting the Council's officers to implement personalisation on a wide range of topics. Effective and meaningful **Co-production** is a central principle to the PEP's Terms of Reference.

The PEP is facilitated by Southampton Centre for Independent Living and Hampshire Centre for Independent Living; two of the oldest and most respected ULO's in the UK. Members of the PEP include:

- Southampton Centre for Independent Living
- Hampshire Centre for Independent Living
- Carers Together (User-led Carers organisation)
- All Inclusive Ltd
- Residential Care Users

Many of these organisations have been instrumental in the development of the now widely accepted principles such as the Social Model of Disability and Independent Living; and have been at the forefront of the development of Direct Payments since the early 1980's.

The PEP remains highly supportive of the Government's personalisation policy.

This response has also been informed by the Disability Advice and Information Network (DAIN), a ULO based in Southampton which provides expert benefits advice and tribunal support to Disabled People and their Carers. DAIN has over 20 years of experience of supporting users to gain access to the benefits to which they are entitled.

The PEP is committed to the development of progressive social policy, which enables Disabled People to live independently and have a life more comparable to that which non-Disabled People take for granted. The PEP welcomes the Government's request for ULO's specifically to respond to this consultation call.

This response focuses on the questions which we have the strongest views and experience of, and reflects the limited consultation period allowed and our capacity to respond to the very many consultation documents issued by the Government in recent months.

## **General comments on this consultation from the PEP:**

DLA evolved from recognition from successive Governments, that Disabled People face significant extra costs, which arise from the barriers resulting from society's inability to meet their needs.

Despite the undoubted advances over the last 30 years, Disabled People believe they remain one of the most oppressed and discriminated groups, and consequently experience inequality of opportunity, which affects all aspects of their lives; particularly, personal assistance, housing, transport, income and employment.

DLA therefore provides finance to Disabled People to offset **some** of these extra costs experienced through the discrimination they face. We emphasise the word **some**.

Recent research from the **Disability Alliance** records that 63% of Disabled People experience disability related costs higher than the current highest rate of DLA. We urge Government to consider very carefully, this evidence that DLA, in its current form, only meets **some** of the additional costs for many Disabled People.

We also draw the Government's attention to the many cuts and proposed cuts which Disabled People are currently experiencing from both national and local Government (including increased charges and reduced services and income).

The PEP is highly concerned that the Government does not appear to have conducted any holistic equality impact assessment into the cumulative impact of these cuts and reductions which undermine Disabled People's ability to live independently and to contribute positively to society.

Disabled People are willing to share equally in the pain of reinvigorating the nation's economy, but we have growing evidence that Disabled People are expected to shoulder an unfair proportion of the cuts being made.

The PEP is highly concerned that in this age of equality, Disabled People, recognised as one of the most disadvantaged groups in society, are experiencing innumerable attacks on their liberty through what appears to be a negligent disregard of the difficulties they experience. Disabled People are increasingly fearful of their ability to live independently in the future.

## The PEP's response to individual questions:

### 1. What are the problems or barriers that prevent Disabled People participating in society and leading independent, full and active lives?

The PEP considers that Disabled People experience barriers and discrimination in all aspects of their lives, every day of their lives.

Disabled People have collectively listed **12 Basic Rights** which if met would enable them to live independently and fully participate in society:

- Full **ACCESS** to our environment
- A fully accessible **TRANSPORT** system
- **TECHNICAL AIDS/EQUIPMENT**
- Accessible / adapted **HOUSING**
- **PERSONAL ASSISTANCE**
- Inclusive **EDUCATION** and **TRAINING**
- An adequate **INCOME**
- Equal opportunities for **EMPLOYMENT**
- Appropriate and accessible **INFORMATION**
- **ADVOCACY** (towards self advocacy)
- **COUNSELLING**
- Appropriate and accessible **HEALTH CARE** provision

Barriers sadly still exist in all these 12 areas; however, detailing all of the barriers in all these areas is outside of the remit of this response.

The Independent Living Strategy (ILS) recognised these barrier categories, and provides a range of commitments to addressing these barriers. The PEP endorses the ILS

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

The PEP believes the name should stay the same; it is an accurate description of the purpose of the benefit. We believe that changing the name would be for political purposes only and serve to confuse whilst providing no benefit at all to Disabled People.

We are already seeing many jargonistic name changes to services and benefits which serve little but to confuse people who already struggle to find knowledge about what they are entitled to.

## 3. What are the main extra costs that Disabled People face?

The PEP endorses the recent research conducted by **Disability Alliance**, which featured in their 'Interim Consultation Response' on this subject in January 2011.

These findings demonstrate that DLA currently helps Disabled People with the full range of their living needs. In the survey, people told Disability Alliance that they used DLA to help with the following items:

- Transport (89%)
- Heating/laundry bills (69%)
- Attending medical appointments (58%)
- Aids and equipment (57%)
- Home help (48%)
- Replacing furniture/household goods (39%)
- Leisure/holiday costs (37%)
- Home adaptations (33%)
- Special diet (30%)
- Special clothing (25%)
- Safety equipment (20%)

#### 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?**

The PEP believes that this proposal will result in inappropriate benefit levels being awarded.

The PEP supports measures to make DLA easier for people to understand, easier to decide if people are eligible, and easier to apply for. The PEP also supports attempts to reduce administration costs, as this will maximise resources available to meet assessed needs.

However, statements relating to *'prioritise support on those individuals who face the greatest day-to-day challenges and who are therefore likely to experience higher costs'* clearly suggests that Government will be, in effect, raising the 'Eligibility Criteria' from a 'Medical Model' assumption that the *'greatest day-to-day challenges'* relate to people's medical conditions, rather than needs. It is often the case that what is perceived medically as 'insignificant' can have a major impact on Disabled Peoples' ability to live independently.

However, it is widely accepted that every Disabled Person is different and therefore the extra costs of their impairment will be different. We are concerned that by reducing benefit to two levels per component will result in an inability to accurately assess Disabled People's benefit needs, which will result in two possible outcomes:

- a) Higher benefit costs for Government as a result of more accurate (and lower) rate bands being unavailable with recipients therefore receiving higher benefits than via the current DLA
- b) Inappropriately low benefit levels for Disabled People (or people just not receiving anything at all), simply because the two rate system does not provide enough options to accurately measure their genuine needs.

**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?**

The PEP believes that benefits should be based on need, rather than medical labels.

However, Government should accept that for many Disabled People, their impairments are permanent, life limiting or progressive; and that proper consideration should be given to the need for pointless (and costly) reassessments for Disabled People, whose impairments are obviously permanent.

If automatic entitlements are removed then far more people would have to go through the regular assessment process which would add to increased administrative costs for the Department and extra stress and worry for the Disabled Person.

**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?**

The PEP recognises that the current criteria for DLA care component only includes 'bodily functions', and therefore a totally different approach is needed to look at needs from a Social Model perspective. If the Government is serious about progressive social policy, then a radical assessment overhaul would be warmly welcomed by the PEP.

The aim of the benefit is to provide income to offset some of the extra costs which Disabled People experience, these needs will be different for everyone, and what is important to one person, may be less important to others.

It would be impossible in practice to judge a prioritised set of activities which are 'most essential' for Disabled People, in the same way as it would be impossible to do this for non-disabled people.

The PEP therefore recommends that any assessment process should be based on what the individual needs to be able to live independently. Assessments must be based on the Social Model of

Disability, addressing the barriers people face, rather than some medical assessment which simply cannot provide personalised solutions for Disabled People.

The most effective assessment process would revolve around an empowering assessment where Disabled People considered what they wish to do with their lives, what barriers prevent achievement of potential; and what solutions would best enable a Disabled Person to reach their potential.

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

The PEP knows that fluctuating conditions are, by their nature, very difficult to assess. Currently DLA criteria require Disabled People to show that they have the need for the 'majority of the time', which misses the point.

Fluctuating and variable needs must be accounted for when carrying out assessments. Disabled People are the experts on how fluctuating conditions affect their lives. Disabled People need to know that they will receive a consistent and reliable assessment which properly accounts for their needs, fluctuating or not.

Disabled People can then exercise control over how to proportion the use of their benefit to accommodate these fluctuating needs.

## **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?**

The PEP agrees that aids and adaptations should be taken account of, but **only** if the individual has genuine, real access to the equipment, and they agree that it is appropriate to their needs and

how they want to live. It would be wholly wrong to judge benefits of any equipment unless the individual has access to it. (There is a world of difference between being eligible and actually receiving it)

Any assessment based on generalised assumptions about suitability of aids and adaptations will not be workable as everyone is different, and what works for one person may be inappropriate to others.

Assessments need to account for maintenance and periodic replacement of aids and adaptations to ensure benefit levels take proper account of these costs; if we are to avoid health and safety issues or accidents caused through faulty equipment, which will be far more expensive to sort out.

The PEP points out that aids and adaptations are already taken into account when assessing DLA entitlement (at Tribunals for instance, they often ask about Occupational Therapy assessments).

**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?**

An 'on-line' completion option would make the form easier and more accessible for many Disabled People to complete (many currently have to rely on others to fill in forms for them, due to difficulty in handwriting).

Disabled People often state that the current DLA form appears to be designed specifically to discourage applications; as it looks extremely daunting when it arrives, and it is accompanied by lots of additional pieces of paper which make it look even worse, it is very long and seems to them to be very repetitive.

The PEP believes that making a claim should be much easier. Claim forms should include the minimum of questions that are clear, and concise to determine if Disabled People meet eligibility as opposed to

the current form which has broad questions that are open to interpretation and can be misleading or off-putting.

Current application forms mainly focus on the negative aspects of living with impairment rather than focusing on the support Disabled People need to live independently.

The PEP therefore welcomes the new style DLA claim forms for children which are being trialled in some areas. These include more 'yes' or 'no' answers, but still give room for explanation. They also look far clearer and more user friendly.

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

Whilst there is an important role for healthcare professionals, they are often not well placed to understand the impact of impairment and other circumstances and the lifestyles of Disabled People.

Many Disabled People report that Doctors fail to have any real understanding of their lives. Therefore any value placed on healthcare evidence should be validated by the claimant to ensure that it presents an accurate assessment (*'Nothing about us, without us'*).

Medical assessments are usually very focused on what the individual cannot do. The PEP believes that a progressive, Social Model of Disability assessment which focuses on barriers, needs and aspirations, would be far more appropriate for 21<sup>st</sup> Century benefits systems.

Current DLA claims assessors are most likely to contact the GP for evidence rather than the consultant. However, advisory services that help claimants, report that assessors appear to twist reports to suit their own ends. For example, if they have a GP report that is supportive, but a report prepared by one of their doctors which is not, they tend to prefer the latter, stating that it is likely to be *'more objective and impartial'*. However, if the case is reversed, they then prefer the GP report stating that it is based upon *'the GP's ongoing knowledge and opinion of the client'*. We therefore feel that there should be a defined procedure which deals with any evidence in exactly the same manner – and it should be obtained from those who

knows the Disabled Person's condition the best, and the effects that it has on their day to day life.

**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?**

See response to Q10 above.

Any assessment should be made in the environment the individual has to function within, ensuring that environmental and other considerations are properly taken into account. This approach would be compatible with the Social Model of Disability (which understands that it is the environment and society that we live in which disables us, rather than individual impairments).

Healthcare professionals often simply do not understand these issues and we consider this method of assessment to be very badly considered.

The PEP does have concerns about the costs of regularly reviewing everyone, only to find the majority of benefit levels remain the same. This money should be better spent on supporting more disabled people.

Disabled People find attending 'medicals' to be extremely daunting and stressful. Many people have said that they have underplayed their condition because they feel too embarrassed to admit the true extent of their difficulties to someone they do not know. This then leads to a lengthy and consequently very expensive appeals process.

**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?**

No comments

**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?**

The PEP considers that the best way to encourage individuals to report changes, is by developing an honest, accessible and transparent system for reporting changing needs and for benefits to be adjusted accordingly (upwards and downwards).

The current stance appears to be that reducing fraud is the principle focus (time and again, anti fraud measures have failed to show any major abuse, and cost more to administer than they save). If the Government placed the principle focus on meeting people's changing needs, rather than fraud, then we believe that people would respond appropriately.

There are times when what is perceived as fraud, is error or misunderstanding. By ensuring that Disabled People have adequate, impartial support from people they trust, much of this could be avoided.

Sadly, Disabled People's experience is that reviews are normally, in reality, an attempt to reduce the benefit people currently receive. It should not therefore be a surprise if people do not want to engage.

**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?**

The PEP considers that advice and information is imperative, and for it to be effective it should be independent, confidential, accessible and user led.

**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?**

It has been demonstrated that peer-based support systems are the most effective at ensuring that individuals consider their own circumstances and what they can strive to achieve. (e.g. *Prime Ministers Strategy Unit report "Promoting the Life Chances of Disabled People"*)

Such solutions will be more empowering and less likely to result in isolation or require expensive medical based solutions.

**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?**

The PEP believes that one-off payments should be encouraged. The provision of an electric wheelchair (if properly maintained/replaced) can have a radical impact on an individual's ability to live independently.

The PEP also makes the point that DLA already enables individuals to use the benefits they receive in a creative way and many use money to buy one-off equipment. Individuals should be allowed the trust and flexibility to make these judgements themselves, (with support if needed). The state does not know better than the individual.

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

Current DLA basic rules are the same for children, however, individuals also have to show that the needs of the child are 'substantially in excess of the usual requirements of a non-disabled child of the same age and sex'. High rate mobility is only applicable from 3 years and low rate mobility from 5 years. This can be extremely difficult to show in very young children as they all need care and supervision. It is easier as children get older as the differences are often easier to identify.

Assessments should be very carefully considered and individualistic, as all children develop at different rates (irrespective if Disabled or not). More regard should also be taken of the impact upon the family as a whole (e.g. taking time off work to attend hospital appointments, cost of getting there etc.)

**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 passporting arrangements?**

The mobility component of DLA has enabled Disabled People to lease a car through the Motability Scheme, which has a major positive impact on Disabled People's opportunities and independence. Without this, the vast majority would not be able to have access to their own vehicle.

The PEP understands that 'passporting' is a really big issue for those agencies supporting people to claim DLA. Specifically in relation to the low rate care component of DLA. (Which we believe to be the most under attack)

The PEP urges the Government to think very carefully before jeopardising passports to the following entitlements for those currently entitled to lower rate care component DLA.

DLA low rate care is currently worth £18.95 per week, and provides passports to the following:

- a) Working Tax Credit (means tested) – a single person or member of a couple who do not have dependent children have to be working

30 hours per week before they can claim WTC. A Disabled Person – in receipt of certain qualifying benefits (including low rate care component) only has to work 16 hours to be able to claim WTC. Many people approach support agencies to claim DLA low care purely for this reason as they want to be able to work but feel unable to cope with the full 30 hour requirement. Alternatively they are able to take a lower paid job in the knowledge that they will receive some additional top up.

- b) Job Seekers Allowance (means tested assessment) – if signing on for JSA and looking for work, receipt of the low rate care component also gives entitlement to the Disability Premium as part of the JSA assessment – worth another £28 per week for a single person or £39.85 for a couple.
- c) Housing Costs – Housing and Council Tax Benefit – entitlement to any rate of the care component of DLA means that non dependant deductions are not taken from benefit if non-dependants (eg grown up children etc) are still living at home. This can cause enormous difficulties within families where grown up children refuse to make any contribution or if they refuse to tell their parents how much they are earning.
- d) Entitlement to DLA also gives entitlement to a local city bus pass which can be used off peak – this enables Disabled People to attend work, training, interviews etc.
- e) Entitlement to DLA for children also gives additional premiums for the family if they are in receipt of means tested 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?**

No comments

**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?**

No comments

**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?**

There is potentially a significant disruption to the lives of disabled people by the introduction of yet another periodic needs assessment and the added uncertainty of the benefit changing from 'a lifetime award' to an award that will require ongoing static needs to be periodically demonstrated.

Disabled People already experience far too many assessments, which are often reported as having little regard to their impairments or needs. These uncertainties cause stress and severely limit the ability for Disabled People to plan for their futures.

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

No.