



A joint response to the public
consultation on Disability Living
Allowance reform
from
Surrey Coalition of Disabled
People
and
Action for Carers Surrey

14th February 2011

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Introduction and background

The aim of the Surrey Coalition is to campaign and promote the rights of disabled people to have equality of opportunity and to live independently. This means influencing the policies, strategies and services which impact on the lives of disabled people to make them better and more accessible for everyone.

Action for Carers Surrey's main aim is to raise awareness of carers' needs in Surrey and to work in partnership with statutory services and voluntary sector colleagues to promote how best to support carers in Surrey.

Disability Living Allowance (DLA) is essential to many disabled people in order to be as independent as possible. For this reason we welcome the opportunity to be consulted on the proposals for reform of this benefit, which will impact on so many disabled people in Surrey and nationally.

We are also pleased to see the Coalition Government commitment to making sure that welfare reform plans "...protect the people in the most vulnerable situations, including disabled people."¹ Based on this commitment, we look forward to the Government's response to the concerns raised by these proposals.

Our consultation

Our response to this consultation comes from a diverse range of individuals: disabled people, carers, or people who are both.

This response incorporates the views of those who attended a dedicated meeting held on 7th February 2011 including also representatives of the five local Empowerment Boards for people with physical, sensory and cognitive impairments and representatives from Surrey Learning Disability Partnership board. It also includes the

¹ Ministerial Foreword – Public consultation Disability Living Allowance reform

views of many other disabled people in Surrey, and their carers, in letters which raise concerns about the proposals.

Executive Summary of our response

Members of the Surrey Coalition of Disabled People and Action for Carers Surrey believe that a number of elements of the current DLA system are positive and should be retained.

Not least, is that DLA Mobility should be retained for people who live in residential care and are state funded. The effect of removing this will be profound for many individuals and their families and carers. Many will see their quality of life, independence and choice eroded, should this change go ahead. This will include an inability to engage in the community, go to work and maintain links with their family.

Given the Government's commitment to independence, personal choice and control, and the 'Big Society' agenda, we very much hope that our concerns will be translated into actions.

In our response we have also highlighted potential negative effects resulting from the proposed changes to DLA bands. We would welcome further detailed information on the proposed changes so that we can consider these more fully.

We would ask that the Government carry out further analysis on how the proposed changes will affect disabled people, families and carers. Attention needs to be paid to the preventative value of DLA. This is particularly the case in terms of carers. If they are denied support to continue their caring role the impact would be significant for the quality of life of all concerned and increased financial pressures on the state.

Response to the questions posed in the consultation paper

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

Disabled People have identified twelve basic rights, which, if met, would enable them to live independently and fully participate in society. Anything that gets in the way of achieving these rights will be barriers to leading full and independent lives. These rights are:

- Full Access to buildings and our environment.
- A fully accessible Transport system.
- Technical Aids and Equipment
- Accessible/adapted Housing
- Personal Assistance and Support
- Inclusive Education and Training
- An adequate Income
- Equal opportunities for Employment
- Appropriate and accessible Information
- Advocacy (towards self-advocacy)
- Counseling
- Appropriate and Accessible Health Care Provision

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

Although not consulted on, we believe that DLA Mobility (DLAM) allowance should not be removed from people living in residential care, including children in residential schools for over 84 days. This would have a very detrimental effect on disabled people and their carers. This is illustrated by the case study below.

My 13 year old son has cerebral palsy, hydrocephalus and other complex needs including double incontinence and learning disabilities. He is a power wheelchair user. Surrey LA Education fund his placement at an independent special school in Hampshire as this is the only school where ALL his SEN can be provided for. The Mobility Component of his DLA funds a wheelchair accessible vehicle (WAV) through the Motability scheme. My son cannot transfer himself, he has to be hoisted into and out of his wheelchair therefore he has to travel in his wheelchair. I use the car to take him to school on Mondays and collect him on Fridays, term time only, thus saving the LA transport costs. When he is sick or has a hospital appointment he stays at home and I take him in the car to the doctor or hospital. If the car is taken away how would he get to school? How would he get to regular hospital and doctor appointments? How would he pursue social activities such as horse riding for disabled on weekends? What about the lengthy school holidays – 8 weeks during the summer? I cannot lift him as he is heavier than me. It would cost Surrey more as I would have to ask for direct payments for transport, we have no provision from social services, his case was closed when he started this school a year and a half ago. How can a young teenager be left with no transport? I am really worried, this is adding to the stress of caring for him.

Surrey resident (mother and carer)

We have also received ten letters from Surrey residents whose lives will suffer if this change is implemented. An extract from one letter is shown below.

“I have a severe learning disability and I live in a residential care home. I am being supported to write my disagreement to the government’s proposed withdrawal of my DLA, as this will greatly reduce my Quality of Life.

My weekly personal allowance is £18.95 and this has to pay for my toiletries, clothes, outings, holidays, day trips with my day centre, community activities, shoes, birthday and Christmas gifts for my family, subscriptions to leisure groups or clubs I belong to, visits to the coffee shop or pub, and treats for myself.

My DLA money helps to subsidise the above plus also pays for the taxis to my leisure activities, as they are not on a bus route. I also like to travel to visit my family. I would love to do more leisure activities and cannot afford them; but if my DLA was taken away I would have to stop going to the current ones, some of which I have been attending for many years, and have made lots of friends there. I would not be able to visit my family.”

It is our own experience that the assumption of double funding, that has been used to justify this change, is incorrect. We believe that social care assessments take into account where people receive DLAM and do not fund mobility needs in those circumstances. It is estimated that in Surrey there are 1603 adults receiving DLAM and in residential care funded by the Local Authority. The removal of DLAM would result in a total loss of income of £2,697,929 per annum for these 1603 adults.

It is rare that residential homes have their own transport, but where this is the case, without DLAM a person cannot exercise real choice over where they go, when, or who with. This affords very little control to people and does not support the personalisation of services.

DLA is currently being paid as a form of recognition that the disabled person has needs, which may or may not be met in other ways. It is up to the disabled person to spend it as they feel that they need to -

this is an area where they can have some sort of control, freedom and independence. If this is taken away as is being suggested, that this would be contrary to the stated aims of the government to increase a disabled person's right to control, freedom and independence.

DLA is currently flexible in what it can be used for and this should continue. It can be used for heating, leisure activities or anything else that the disabled person wants to spend the money on to help meet their additional disability related costs. DLA is used towards the cost of maintenance of equipment, or replacement. DLA is also used to help towards the costs of higher utility bills. The disabled person is the best person to decide what to spend their DLA on, if they are capable of doing so, or be able to help decide how to spend the benefit on. It should not be for the DWP to decide what the money is spent on, as every disabled person is different, and their needs will be different.

We believe that the current 'passporting' system to other benefits should remain the same.

There are some very positive elements to the current application form, which has evolved over the years with the input of disabled people. This should be retained.

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

There are many, and include:

- Transport is a big extra cost to disabled people.
 - Where there is community transport this is not accessible to all. Not all can take certain types of wheelchair for example. Often people need to hire private transport.
 - Community transport is also generally only available during weekdays and ends in the early evening.
- Continence can also present a significant expense.
- Home maintenance such as decorating, mowing the lawn etc.
- Clothes and clothing alteration

- Accessible holidays
- Heating
- Special diets
- Interpreters
- Assistance dogs
- Prescriptions
- Water bills
- Internet – to maintain contact with friends, family and the community and to order on-line e.g. food. It is also a vital communication tool for people with sensory impairment.

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?

We would like clarification of what the two rates would be and what level of need would fall into each.

The rates need to be able to take account of the fact that some people have impairments which have 'hidden' or fluctuating and variable effects on their lives, e.g. those with mental health issues, brain injury and autism etc. There is a huge variation in impairments and the needs of individual disabled people.

We feel that DLA works well at the moment, without reform, and that the Government should look closely at the additional costs of reforming and cutting this benefit.

We do not believe that the lower rate of DLA Care should be removed. Three rates should be maintained. The majority of people who receive this would not be eligible for social care services and so would receive no support. If the lower rate were removed it would be contrary to the reason that DLA was developed: to help people with care needs who receive no other service.

Clearly, at the lower rate of only £19.50 per week this payment is a 'recognition' of people's unmet needs, but goes a long way in allowing access to preventative, inclusive services. If these could no longer be accessed it is likely that the unmet needs would increase to a point where more intensive and costly services would need to be provided.

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?

Automatic entitlement should be a simple and an open system for people with certain conditions that will not improve e.g. those with learning difficulties, severe sensory impairment, brain injury and amputees.

The current automatic entitlement works well and should be kept.

There needs to be an improvement in the standards and consistency of those professionals who assess DLA entitlement in general, but especially when deciding whether to award the benefit periodically.

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 new benefit must ensure there is some focus on people who have additional costs as this may be the only way in which they can get support. With the tightening of eligibility criteria for social services support, it will be harder for a disabled person to be able to access that area of support. The payment of DLA/PIP is in recognition, and this should remain so, that the disabled person has additional needs which need to be met.

Activities which are most essential for everyday life include interaction and communication, getting around, not only their house

but also outside, being able to get dressed, feed oneself and look after personal care. These are needed regardless if a person works or not. If DLA is taken away from someone, who is deemed not to be disabled enough to merit social services help, then they may have to stop paying for someone to help them with getting dressed, getting around, interacting, joining social activities etc.

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

There should be an opportunity for people to refer themselves for reassessment if their condition changes or deteriorates.

The application form should expressly encourage people to explain the variable nature of their impairment and its effects. There should be the opportunity to give an overview of a week or a month.

Those that are currently carrying out assessments need to work to much clearer and consistent criteria.

People completing DLA forms should be encouraged to get help from somebody who knows them or from an independent advocate. By nature, people often describe themselves as able to do more than they usually can.

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?

The majority of the group do not believe that aids and adaptations should be taken into account in the assessment. One person thought that they should but only if people actually used them.

However, it would be helpful to have a definition of 'aids and adaptations' as used here.

Most people felt that successfully using a mobility aid, for example, doesn't take away the additional costs incurred by the disabled person. For example being able to use a wheelchair doesn't mean the need or the significant extra cost of accessible transport has gone away.

Assessments should concentrate on the need of the disabled person rather than aids and adaptations that may be available but not necessarily affordable. Needs will still exist despite the use of aids. This should also be driven by the Government's own choice agenda. For example, whilst a commode may aid people unable to get to the toilet, people may choose not to have the commode in their living room. Personal dignity and quality of life also need to be considered.

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?

A lot of work has gone into re-designing the claim form in recent years, in partnership with disabled people, and it is much easier to complete now. This should not be lost. There can always be improvements though, for example different formats for people who are visually impaired are needed.

There are a number of multiple-choice questions on the form with extra space available for further explanation. This is helpful. The current form is far less repetitive than the previous form. The form needs to be comprehensive so that people's needs can be fairly and accurately assessed.

We know that when applying for any benefit there will be an overlap in the questions and sometimes this can't be avoided.

We would like to recommend help for disabled people to complete the form from advocates and or independent information and advice services.

There is a need to continue to ensure that DLA staff are well trained.

Government ministers should not refer to DLA as an 'out of work benefit' as many disabled people receiving it also work.

There should be a publicity campaign, including television and accessible leaflets.

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

This needs to be decided on an individual basis. The individual themselves should decide who can provide the best evidence based on who they have most contact with e.g. doctor, physiotherapist, or a non-health care professional, if appropriate.

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?

The difficulty in having a face-to-face discussion with a healthcare professional is that they may not understand what the disabled person is saying. If the disabled person is deaf and uses sign language, or they have a speech impairment, or they have a learning difficulty, then they may not be able to communicate with the healthcare professional. These problems may be made worse if the disabled person is not allowed to have their carer or a representative in the room with them.

The healthcare professional may not have any knowledge or expertise about the disabled person's specific impairment or condition and its impact on their life. They may not understand that a person with a learning difficulty or a speech impairment needs to have plenty of time to think and to answer the questions. This again could result in a withdrawal of benefit, and a loss of entitlements to other benefits or services.

Where English is not the professional's first language it may make it difficult for them to be understood.

The disabled person may be vulnerable for a range of reasons, and therefore it may not be appropriate for them to have a face-to-face meeting with a healthcare professional. This would be regardless of whether the meeting took place in their home or at another location.

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?

If there are to be periodic reviews, then they should be as now, every three or five years. Some conditions do change over time, and needs sometimes change.

However, if a person has been assessed as being entitled to DLA – for example higher rate mobility due to being blind or severely sight impaired, or they have speech impairment or a learning difficulty or brain injury, then these should not be reviewed periodically. Their needs will not have changed since the first time they were assessed. The costs that these people face will be the same or greater; they may need an interpreter or someone to support them to interact within society.

It would not be cost-effective for the government to insist that people with permanent impairments or health conditions that will not

improve have to go through repeated assessments or reviews when there is a clear entitlement to the benefit on an ongoing basis. The stress and exertion caused by repeated assessments may make someone's condition worse. A person with chronic depression will not have their condition helped by the stress and worry that they may lose their benefit.

By expecting a disabled person to constantly report minor changes to their condition, may make the situation very onerous, stressful and burdensome. It would not just be disabled person would find a situation very stressful; it could also be the DWP staff.

The DWP staff may end up spending more time on the phone noting any changes than actually assessing a new application or a renewal application. It is adding another layer of bureaucracy when the government should be making it easier for disabled people to claim their entitlements.

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?

A disabled person should not be penalised for not informing the department about change in their needs or condition. The change is not always very significant. By my introducing the possibility of penalties, the DWP may have an extra level of bureaucracy, which is costly in these financial tight times.

There should be clear easy to understand guidance on what changes should be reported. In the past where changes in circumstances have not been reported, they have not been viewed as 'fraud' by the DWP. This should still be the case.

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?

And

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?

Individuals should be given a choice on where to seek advice and information and we would like to see local independent providers and services maintained and improved, particularly those in the voluntary sector.

We do not agree with some form of requirement to access advice and information, or being conditionally referred to certain providers.

We do not think that the DLA Service should be the providers of this advice and information. It is unlikely that they would have the capacity to administer this and the advice and information should be independent, or there could be a conflict of interest.

In order to deliver this Surrey has developed Citizens Hubs, which are run by and for Disabled People. The first of these Hubs has opened in Epsom; situated in a key high street location and offers a drop in service. As well as offering information and advice the hub also offers peer support. Further information can be found on www.epsomhub.org.uk.

We feel this type of initiative offers more value than people approaching statutory bodies for information and advice.

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?

In line with the Government's agenda of Choice and Control it should be an individual choice as to how Personal Independence Payment is used.

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

One of the key differences is that needs can change very rapidly in children, and communication can be difficult.

Face to face medical assessments may be difficult and frightening for children.

Often, special needs funding awarded to a school that a child is attending, is not used for the education of the specific child that needs it, as these payments are not ring fenced.

The current system of the care component of DLA for children in residential schools, where parent submits details of days spent at home to the DWP, is very fair. The DLA is apportioned between time spent at home and school.

Changes to this system would not benefit the individual or the family.

When children are assessed they should have an adult with them.

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?

This has been very important.

For example: if an individual is in receipt of DLA middle or higher rate this enables parents / carers to receive carers allowance.

At this time there are three disability premiums. There have been improvements in recent years in the DLA and Job Centre plus automatically paying these premiums as part of means tested benefits.

These three different premiums reflect three different situations:

- Being in receipt of DLA
- Being in receipt of higher rate DLA (Care)
- Living alone, middle or higher rate DLA (Care) where no one is receiving carers allowance.

It is a complex system but not overly so. We would be very concerned if there was a loss of any of these entitlements just to simplify the situation and would be opposed to any cuts in disability related payments in the Universal Credit. More disabled people currently live in poverty than non-disabled people and this would only serve to increase the inequality.

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?

This would cause delay in processing other benefits and require individuals to undergo multiple assessments.

It would cause a duplication of work and would create an extra cost for services.

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?

It would be extremely difficult to bring assessments together. We would disagree with any proposals for a universal assessment.

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?

We believe that further work needs to be carried out in order to scope the degree to which disabled people may be disadvantaged by these proposals.

There also needs to be greater focus on the impact the changes will have on carers and families.

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

Moves to remove any part of DLA, or reduce it, are contrary to the current Government's policy of promoting independence, which, is mentioned several times in this consultation. We believe that promoting independence now, will produce longer-term savings.

These proposals could also act as a disincentive for disabled people to work, as they may not be able to afford to travel there.

In our opinion, the assumption that the numbers of people claiming DLA have 'mushroomed' because it is no longer supporting the people who need it most is not true. More disabled people are surviving into adulthood and old age due to medical advances and improved social conditions. The numbers will also have increased due to the year on year increase in new applicants with long term entitlements.

We believe that there is a misconception that DLA is an overcomplicated benefit. This is not the case. Many aspects of it work very well and have helped many people to enjoy a better quality of life.

We also think there is a very real public misconception that DLA is an 'out of work benefit' and that Government should raise awareness that this is not the case.