Response from Scottish Spina Bifida Association to Public Consultation Document on Disability Living Allowance Reform.

Background on SSBA

MISSION STATEMENT;

“The SSBA seeks to increase public awareness and understanding of individuals with Spina Bifida and/or Hydrocephalus and allied conditions. It aims to support all those affected to identify their needs and to empower them to make informed choices and decisions.”

The Scottish Spina Bifida Association is the only voluntary sector organisation in Scotland that supports children, families and adults affected by spina bifida and/or Hydrocephalus.

Many of our service users are affected by the condition to varying degrees and these can range from severe and complex needs to those more mildly affected. Many go on to attend mainstream school and have no significant learning disability. Mobility issues and bladder and bowel management affects a large number of our service users and this can have a huge impact on forming and maintaining relationships, gaining meaningful employment, accessing further education and can lead to social isolation and poor self esteem. Hydrocephalus can have an impact on communication, learning and behaviour which affects social interaction skills and educational achievement.

A high percentage of our service users are in receipt of Disability Living Allowance and we currently provide a trained Benefits Finance Coordinator to support our service users to apply for any benefits that they may be entitled to as a result of the impact of their disability.

The Scottish Spina Bifida has prepared this response to the DLA reform on behalf of our service users following consultation with service users and carers.

Executive Summary Response

The Scottish Spina Bifida Association welcomes the opportunity to respond to this consultation.

It is regrettable, however, that the planned reconfiguration of this piece of welfare reform coincides with a period of government austerity measures. It is therefore unavoidable that many current recipients of DLA are fearful that the objective of the exercise is one of efficiency savings rather than modernising the current benefit to make it more “fit for purpose”.

It welcomes the government’s intent to develop the new Benefit as a non means tested benefit with a clear focus on helping people with the additional costs of disability.

It is concerned about the proposal to cut DLA for people in residential care. Individuals who by virtue of them being assessed for residential care will have significant and often progressive conditions demanding increased support at all levels.

It is concerned about the lack of clarity for children both in terms of eligibility and assessment.

It welcomes the view that there should be a shift away from assessing the functional aspects of disability to a more person centred approach where the needs and aspirations of individuals are taken into consideration and support is offered in order to promote active citizenship.

It is concerned about the proposal for new objective face to face tests by healthcare professionals. Any assessment should be person centred and take the individual’s self assessment of the impact of their disability as central to the assessment process. Supporting evidence from professionals who know the individual claimant should also be sourced and utilised in the process.

It is concerned about the proposal to review all awards. This is both unnecessary in terms of cost and potentially distressing to individuals who have long term progressive conditions. It is reasonable to expect that such individuals should be responsible for intimating any change with a view to reassessment.

Response to Question 1

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

Our service users and carers tell us that mainstream schools and further education resources are often ill equipped to cater for their mobility needs resulting in exclusion from sports and gym sessions and having adapted transport to take part in residential camps and activity based excursions with their able bodied peers etc. Lack of appropriate educational support relating to more subtle learning difficulties can affect young people’s ability to attain their educational potential and prevent them from gaining meaningful employment. This can lead to feelings of social isolation, poor self esteem, lack of confidence and poor motivation can be a barrier to leading a full and active live. Ongoing health issues and the challenges relating to bladder and bowel management can disadvantage people with disabilities when applying for jobs or even voluntary work. Restrictions on appropriate resources available to overcome these barriers, such as accessible public transport, adapted vehicles, accessible buildings and better disabled toilet facilities prevent many people with disabilities from accessing educational, social and leisure opportunities.
Response to Question 2
Is there anything else about DLA that should stay the same?

Maintaining the new benefit as a non means-tested, non-taxable, non NI contributions dependent benefit is vital, as is recognising its role as a passport to many other public funded services. Claiming this benefit means at the moment filling out a very long, complex form. Whist agreeing that the current form does need simplified, the answer is not a whole new process of interviews, which many disabled people could find intimidating. The proposals to replace this with an objective test will surely result in more time and expense on the part of the claimant and the department.

Entitlement at 3 months old should remain, as children with essential medical interventions/invasive procedures such as urinary catheterisation, oxygen administration, suction, peg feeding etc. require these to sustain life.

Being perceived as an out of work benefit will apply to the new benefit too, and rather than reforming the whole system, providing more information and advice would be less expensive.

Surely a better use of financial resources would be in the present benefit being administered with improvements in processing time and relevant DWP staff being trained in disability issues or better still using highly trained staff from the voluntary sector who specialise in disabilities and could be more objective.

Response to Question 3
What are the main extra costs that disabled people face?

Transport costs, more specialised aids and adaptations, extra laundry costs, higher heating costs, health insurance, contribution to housing adaptations, accessible holidays are just some of the main extra costs that most people with disabilities face on a daily basis.

Response to Question 4

Will having 2 rates per component make the benefit easier to understand and administer while ensuring appropriate levels of support? What are the disadvantages or problems with having 2 rates per component?

It is widely understood that 3 levels for the care component i.e. High, Middle and Low Rate would more accurately reflect the levels of care required for people with a huge spectrum of care needs relating to the wide and diverse range of disabilities. If this is reduced to only 2 levels this could result in those currently receiving middle rate care being downgraded affecting their level of need and also carers entitlement to carers allowance. It could also result in more people being awarded high rate care which would have additional costs implications to the government.
It could result in more administration through people appealing against the decision to award low rate who were previously on middle rate.

**Response to Question 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?**

In order to implement a fair system, exceptions to the rules should always be considered. It would be very difficult to decide which conditions should have automatic entitlement but if strict criteria were adhered to it would enable those people with the most severe and complex disabilities to avoid an often demeaning and intrusive assessment process when the impact of their disabilities is very clear. Where there is any doubt claims should be based on individual needs.

**Response to Question 6**

**How do we prioritise support to those people least able to lead full and active lives and which activities are most essential for everyday lives?**

If a person centred approach is taken then an assessment of each individual’s needs and aspirations is crucial in order to identify the level of support they require. In order to respond positively to questions relating to “activities essential to everyday life” we need to set a criterion which defines such activities. This could be such activities as bathing, using the toilet, dressing, cooking, eating, drinking, walking, ability to carry out domestic chores, communicating, making choices, self medicating, socialising, being employed, accessing education.

**Response to Question 7**

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

The assessment process should firstly identify which conditions or disabilities are variable and fluctuating. This should alert the assessor to conclude that regular reviews are required in these cases. Conversely those people with stable and life long conditions should not require frequent reviews which can be intrusive, time consuming and humiliating when their condition is not going to improve. The 6 month rule could have a significant impact when/if children’s DLA is reassessed could be detrimental to delay to 6 months as costs high during early months due to surgery/hospital stays/travel etc. For adults, there can be significant and rapid changes in health/mobility and if payment delayed individuals could suffer significant financial hardship over 6 month period – could cause knock on effect of housing problems and significant stress if payment delayed by 6 months.
Response to Question 8

Should the Assessment of a disabled persons ability take into account any aids and adaptations they use?

It is a positive step to look at people’s mobility from a wider perspective ie. Not just can/cannot walk, however, we are concerned that discussion implies that if someone is independently using a wheelchair that this reduces the extra costs to them currently compensated by DLA. Simply looking at the mobility does not assess the cost implications to the individual (particularly in remote and rural areas of Scotland) imposed by accessibility restrictions…..eg. reduced accessibility to public transport meaning that many people have the expense of taxis to get to events, also choice is limited for shopping/social events due to inaccessibility of older buildings etc. narrow pavements in small towns/villages. Whilst legislation is in place to radically improve accessibility, there are still difficulties posed in reality. Time is also a great cost that may not be factored in i.e. time taken to access day to day tasks compared with ambulant person, or person without Hydrocephalus for example Similarly not all work environments can adequately cater for accessibility and also fluctuations in health/capacity to work, limiting choice of employment –earning potential etc.

Assessment needs to take into account the context of where a person lives and the realistic accessibility of local infrastructure as this determines the additional cost to the individual rather than the bare facts of their mobility.

Response to Question 9

How could we improve the process of applying for the individuals and make it a more positive experience?

Personal Independence Payment (PIP) is supposed to be simpler than DLA, but as stated much of the perceived complexity is due to a wider lack of understanding of the nature of disability and its wider impact, so again provision of better and up to date information would be more cost effective than changing the whole system. Short case studies may be more effective than repetitive questions e.g. “a day in my life” where someone (with support from professionals or carers if required) can provide an account of the impact of their disability on everyday life. This could show the positive outcomes and the level of effort required on the part of the person with the disability to overcome some of the challenges they face as well as the support they need.

Response to Question 10

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

There is often a misconception that the persons GP is best placed to provide this evidence but often GP’s are not involved in the day to day support of someone with a disability. Many people with disabilities that are life long and stable do not see their GP on a regular basis. Sometimes teachers are asked to provide this evidence but
can often provide a very biased view of the child or young persons ability in a structured school environment and they are often under some pressure to provide a very positive view. In general the person should be assessed in their home environment which can often be chaotic or they may not have the appropriate aids or adaptations or support from carers who are exhausted. Evidence from professionals or carers who are involved in the persons life and can see the impact that their disability has on their ability to access services, self manage their condition and communicate their needs would be the most realistic.

Response to Question 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 where it may be inappropriate to require a face to face meeting with a healthcare professional either at an individual’s home or another location?

See response to Question 10. It would be inappropriate where the person's level of need is so great that automatic entitlement to the payment should be awarded.

Response to Question 12

How should reviews be carried out?

See response to Question 7

Response to Question 13

How can we encourage people to report changes in circumstances?

See Response to Question 7 Many people currently in receipt of DLA who have a long term condition and life long disability cannot understand the need for reviews and often feel embarrassed at having to respond to the same questions over and over again. However the reality for many people with relatively stable conditions is often a deterioration in their condition as they get older and this should be highlighted as a change rather than the current process which seems to focus on improvements in the persons condition. The current system causes anxiety about losing the award if there are any positive reports. It should be made clear that only changes that would increase the persons independence would have an adverse affect on entitlement to benefits.

Response to Question 14

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

It is the experience of SSBA that a very high percentage of our service users and carers require assistance to fill in benefits claim forms either from ourselves, citizens
advice or welfare rights officers. Waiting times for the latter two can be long and most voluntary sector organisations including ourselves can respond much faster and provide home visits and telephone support which relieves anxieties and provides emotional support as well as advice and information. Providing information leaflets with the claiming process can be confusing and service users often need to contact us for clarification. Providing trained workers who can deal with these enquiries swiftly and have knowledge about the person's condition/disability would be very helpful. This could be an ideal opportunity for joint working between the statutory sector and the voluntary sector.

Response to Question 15

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

Providing a contact list of approved organisations that specialise in different conditions and disabilities would save time and effort on the part of the claimant in getting advice and information and may identify support that they could access. Options rather than requirements to access advice and support would be more appropriate. Working in partnership with voluntary organisations and health should be a key feature of this system in order to provide a comprehensive one stop information service. Bombarding people with too much information would have to be avoided.

Response to Question 16

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

Disabled people fund their aids and adaptations in a variety of different ways including through community OT services, social work, health and through grants and trusts in some cases. Aids and adaptations are also privately funded especially when more specialised equipment is needed. PIP should not be used where entitlement to funding is already in place from health or social services.

Response to Question 17

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

Consulting with parents and carers when assessing children should be paramount as they are the people caring for the child on a daily basis. Children’s needs can change quickly as they grow and develop and there is often more potential, so early intervention is essential so that the appropriate support is in place to help the child realise their full potential. Children often adapt and respond to change better than adults and may be more receptive to new ideas, services and activities.
Response to Question 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?

Passporting is an efficient mechanism for securing additional relevant support based on an agreed assessment. Most notable are links to Motability and the Blue Badge Scheme. In addition there are other State Benefit links for example to Disabled Child Premium or Enhanced Disability Premium.

Response to Question 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?

The major issue would be lack of awareness of currently passported benefits and additional administration in accessing these.

Response to Question 20
What different assessments for disability services could be combined and what information about disabled person could be shared to minimise bureaucracy and duplication?

Basic demographic information would be useful to be shared along with relevant benefit awards.

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

Ironically, the proposals are likely to impact adversely on those for whom the benefit is specifically intended to support. Those currently eligible for DLA may find that their entitlement is reduced or removed. A new mechanism should be put in place to assess the impact on other equality groups.

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

There is, at the very least, a moral obligation on government to ensure that current recipients of DLA are not financially disadvantaged both now and in the future. Individuals who currently rely on DLA to assist in maintaining their current standard of living should not be disadvantaged by the introduction of a replacement benefit which may be less financially beneficial. New arrangements should apply to new claimants only or to DLA claimants whose condition improves such that their circumstances change for eligibility.

February 2011