Received 19.1.11 025. Con. Res. Wr

DLA Reform Team
1st Floor
Caxton House
Tothill Street
London
SW1H 9NA

An Individual Feedback to the DLA Reform Consultation Exercise

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

Primary barriers include:

- the physical impact of impairment
- the way society is structured
- prejudice and discrimination
- paradoxically, the State's engagement with disabled people
- lack of incomes to meet the full cost of their disablement.

The last one is vital in terms of the DLA debate. Only disabled people have these costs to meet. The foregoing each constitute a cost upon the individual, as do reduced life span, overcoming pain, making the additional effort to do "normal" things etc.

These costs do not vary in accord with an individual's financial or social situation; they are fixed by the impairment and societies response to it. Some cost however, can be cancelled out through fiscal compensations.

DLA payments helps to reduce some of these barriers by meeting some of the costs associated with disablement and are therefore, vital to disabled people's freedom to participate in society.

Question 2. Is there anything about DLA that should stay the same?

Everything! There is little enough wrong with DLA as in operates now to justify the huge expenses of review and change. This seems to be far more about removing a potential complication to an across the board introduction of Universal credit. If this "odd" benefit can be removed then UC will be easier to assess electronically. (Odd in that it applies whether or not a person is in work or out of work)

I feel that those people who were in receipt of lifetime awards, assessed anytime prior to PIP, should NOT have their benefit reviewed. They were adequately and properly assessed at the time of their claim as having conditions that would last life long.

The argument that DLA is somehow flawed is disingenuous. Many will argue that DLA should stay just as it is, a lifetime award to help disabled people remain mobile

outside the home and contribute toward care cost inside the home. All early applicants for DLA had to prove absolutely that they met the terms and conditions for receipt by attending an independent medical. (This was the Mid 1990s). Nothing in their well-being has improved over that time. The fear of benefit loss already prevents many from seeking to further "prove" how much worse things are.

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

- Transport
- Care support
- Health / impairment / disablement support
- Getting to and from work, training or health support
- Other costs arising from impairment – e.g. heating, specialist care, carers, therapies, drugs, equipment, support workers such as handyman to keep garden tidy, household maintenance that the able bodied can carry out themselves, aids and adaptations etc.

Disabled people incur costs in a number of ways; these are costs that arise solely, wholly and exclusively on account of their disablement. Meeting those costs reduces the level of disablement associated with any given impairment but does NOT reduce costs arising from issues such as being discriminated against in the labour market, suffering pain, the risk of a foreshortened life span, making increased effort to move, get to and from work, acquire education or get about.

Costs that are impairment related include things such as additional heating requirements for those with reduced mobility or problems with circulation, the need to have private transport access rather than attempting to walk, wait for unsuitable buses, or get into low taxis, IT support, higher grade cars and other life equipment capable of helping to equalise disadvantage.

The current DLA payments work well because they help even out SOME of those costs upon the individual. Reducing welfare payments to disabled people in the hope it will encourage employment will not work unless these costs are met. Impoverishment and the inability to meet the cost of their impairment / disablement is a primary barrier to disabled people's engagement in work and society.

Question 4 No response

Question 5. Should some health conditions or impairments mean an automatic entitlement to the benefit .....?

Yes. Anyone who was given a life award should have that award honoured.

Equally, many would argue that one of the frustrations of being a disabled person in the 21st century is the amount of time, effort, cost and pain experienced simply by the need to "prove" entitlement to welfare payment. There ought to be a system that allows one medical for all welfare receipt.

Let's make an existing life time DLA award mean an existing life time PIP award, free of reviews – keeping the conditionality of reporting change. Anyone losing their

Motablity vehicles as a result of any such review will require EVERY further review to be done at home – resulting in further cost to the welfare State!!

Question 7. No response.

Question 8. Should the assessment take into account any aids and adaptations ……..?

No. The issue is where do you draw the line and how do you accommodate difference in factors such as motivation, force of personality, drive and determination? One individual may force themselves to manage as best they can with a stick – or morphine –whereas one less driven would maybe sit in a wheelchair? Is the person with more drive to be penalised or is the one with less motivation to obtain a greater welfare payment? Let's stick with the basic impairment. Of course it doesn't help if you lack the strength to power a wheelchair, move it about, get it in or out of a car – all of which would require payment to a carer. How do you accommodate such variance in circumstance fairly?

Question 9 – Making clear who will qualify?

Is anyone going to? Seems to be the aim.

Question - 10 Supporting evidence – who is best placed?

In order of importance

- The person
- Welfare Rights workers, carers, support workers, possibly close family members
- Their GP and their specialists
- The person's representatives – e.g. organisations OF disabled people

Recently the State has become obsessed with an assumption that "disabled people are at it". The simple truth is only able bodied people can make fraudulent claims to disability related benefits. Unless the benefit is poorly designed, disabled people by their very disablement must meet the conditions for receipt. Recent efforts to "catch" disabled people "at it" would be better directed toward the fraudulent able-bodied.

Question 11. Face to face interviews with a healthcare professional.

The issue here is how well suited and well qualified the "health care individual" is for the task. Many staff at Social Worker, NHS Staff Nurse type of grade tend to have a poor understanding of disability issues. Occupational Health specialists tend to be better suited – they work all day everyday enabling disabled people to cope with their environments. The difficulty is many are called in only when further specialist advice and adaptations to the house pre and post surgery are needed. They however, are always very busy, have huge caseloads and access to precious little fiscal resource.

What we need for a "fair" assessment is:

- To be listened to, heard and understood – the 1st time and once
- To have access to independent, state funded advocates who can speak for us at such interviews
- To have empathetic ears making the assessment; someone well qualified and capable of recognising the soft issues in disablement such as pain, effort, and endeavour; alongside the impact of disablement itself upon an individual (as against the impact of disability/ impairment) – and anyone who fails to understand the difference has no business making any such assessments
- Access to assessment in the home as a right – getting to and from these places, waiting around, worry, concern, unexpected closures all add up to making this a very stressful process. Many disabled people are constantly close to ending it all simply because of the amount of pain and suffering they put up with getting "treatment" without being painted as "scroungers by the State and it's representatives in the media; and put through to ten types of hell every time someone wants to check upon – not impairment – but integrity.

Question 12 – How should reviews be carried out?

- If a lifetime award was made it should NOT be reviewed; things are tough enough as they are.
- There should be reviews only for conditions that might vary over time e.g. depression, autoimmune diseases BEFORE they do permanent harm
- When there is any suggestion the applicant is otherwise able-bodied raised by the GP, specialists etc.

Question 13 – How should reporting change be encouraged?

- First and foremost obtain the trust of disabled people that change reported typically has a positive outcome. Many disabled people do not trust the impact of political whim upon the decision making process to produce a fair outcome
- Secondly make it as simple as sending off an email with no negative repercussions unless there is a clear and obvious improvement being reported.

Question 14 – What advice and information should applicants have access to as part of the application process?

- The advice line as it currently stands – very helpful people in the main
- Access to independent impartial advice on how to complete the process – since the introduction of recent process changes applying has become more and more about saying the right things than saying what's right. I know too many people who failed until they took advice. Their impairment was the same, it's impact the same but not ticking things apropo the guidance lost them access to DLA funding.
- An ability / freedom to apply on line with technology that allows the applicant to download the form, complete it electronically and then email it back for acceptance is crucial. Many disabled people use voice recognition software to

draft documents, others use Zoomtext and other adaptive technologies, they need that freedom as well.

Question 15 – Forced requirement to access advice prior to claiming?

- The issues here are who provides such advice, and who funds it? The state funding of such advice implies partiality. The state not funding the advice means it might never become available across the Board.
- Making such an interview a requirement of applying makes it mandatory? Another "forced" hurdle to jump through.
- It should be like the passport system – access to advocates to give advice on a "free to all callers" basis, then the form being filled in, but before being submitted there could either be – like the passport system – someone independent to check the form is complete and / or an electronic pre-application scoring check, a bit like some of the newer benefit assessments. For example applicants could use advice to fill in the form, then take further advice making sure they had done so correctly but then "score" the application BEFORE it is officially submitted. They would then know if proceeding was worth the effort or not. If you put "scoring" before anything else it might encourage too many people to just tinker at it until they got the "right" result.

Question 16 – Funding Aids and Adaptations

Presently many fund as individuals. Walking sticks, powered tricycle, specialist IT and software packages are all currently funded privately, using money from DLA alongside wages. The best approach would be to ensure DLA / PIP or whatever, is sufficient to pay for all the additional costs a disabled person meets. The trouble is this will INCREASE the unit cost per applicant and there seems no wish from Government for that. The next best case is to leave it all well alone and let those who qualify chose how best to use the money. Those choices vary over time whereas impairment / disablement do not.

Question 17 – No response.

Question 18. – Passporting Arrangements.

It should be the case that if you get DLA all the other benefits should be deemed met in terms of the role of impairment / disablement. This would not automatically passport every benefit to every person getting DLA / PIP, but would mean just one medical assessment covered all. Criteria such as income etc. would still need to be assessed.

Question 22 – Anything else.

Just recognise once and for all that:

- Disabled people DO NOT and CAN NOT commit disability related fraud – that is only within the purview of the able-bodied.
- Disabled people do have additional costs to meet as a result of their disablement – these costs are not simply about heating, transport but include

pain, being disenfranchised from the labour market, being used only as a reserve pool of labour, being denied equal access to participation across society, including education. Those costs should be met by the state for as long as the participation rates of disabled people continue well below those of the able-bodied.

- Back off and leave disabled people alone. You have no idea of the abject misery, fear and suffering you create with attempts to intimidate people who are already greatly disadvantaged by society – without any choice or say in the matter – no one goes out of their way to acquire disabling conditions!