

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

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14/2/11

11th February 2011

Dear Sirs,

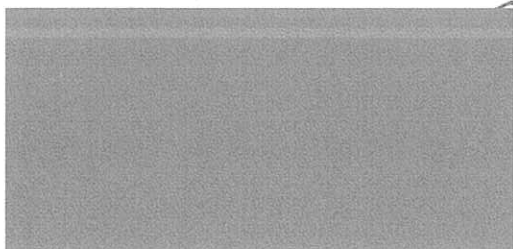
Re: Disability Living Allowance Consultation

I write as the father of a son with a mild/moderate learning disability (on the scale mild, moderate, severe, profound) who is 38 years old and living with my wife and me. Until recently I was the chairman of a Local Action Group for Adults with a Learning Disability. In that role I interfaced with the disabled, their carers, social workers, service providers, support workers, voluntary sector organisations, county councillors and officials, PCT officials, civil servants and government ministers.

From experience I have found that it cannot be taken for granted that those involved with people with a learning disability are sufficiently knowledgeable about the topic. I have taken the liberty of including a preamble that is intended, briefly, to help to explain this disability and its associated problems. The NHS and government have produced many documents on the subject.

A number of initiatives have been planned to improve the circumstances of people with a learning disability. This is a work in progress and much remains to be done to give those affected more control over their lives and circumstances. The availability of adequate and targeted benefits is the key to achieving this goal.

Yours faithfully,



Preamble

Comments are confined to the effect of learning disability on the person and exclude the effect of the additional disabilities that many have. These additional disabilities are usually apparent and their effect on someone's life more readily understood. In contrast, the effects of a learning disability are not readily understood – in part, because they will differ from person to person.

A Learning Disability (LD) is characterised by an inability to understand and to communicate. Complexity leads to confusion and there may be little memory retention. This affects every aspect of a person's life. The reason, of course, is that the brain of a person with LD is not functioning normally; early onset dementia is more likely. The causes include genetic defects, medical mishaps and traumatic incidents. The condition is usually apparent and diagnosed at birth or in infancy and is not curable. It is a life sentence.

Those on the Autistic/Asperger's Spectrum have been included within the provision for LD services. However, their condition may still allow for normal or even high performance in other areas. The successes of some of these individuals cannot be regarded as typical outcomes for the majority of those with a LD but are often regarded as so by the uninformed.

At least 80% of those with a LD are not employable. Many of those said to be in work will be working less than a full week and earning little more than the minimum hourly wage or may be doing unpaid work experience or volunteering. Specialist support workers are often needed in this process. All those with a LD will require support at times – for some it will be constant. Reaching retirement age has no significance unless the person qualifies for a pension. The overwhelming majority will not do so.

The majority of official documents that cover the field of disability do not reflect the problems associated with having a LD (this consultation is typical) and what is more many officials and professionals (including medical) have an inadequate understanding when confronted with a person with a learning disability. This leads to wrong decision making. Incidentally, the publishing of a document in an 'easy read' format is not, of itself, a sufficient means of communication. People with a LD do not understand issues if they cannot relate to them or they require a number of factors to be considered. A personal explanation may not help but not, in reality, suffice.

Finally, there appears never to have been an attempt to define the lifestyle (not really an appropriate word in this context) that a civilised society would want for people with a LD let alone a budget for making it possible. Whilst this exercise may be looking towards this objective, I fear that in a climate of cost reduction any conclusions reached now will lead to many living the whole of their lives in deprived circumstances.

Answers

Q1. What are the problems or barriers that prevent disabled people participating in society and leading independent, full and active lives?

A1. The intellectual differences between those with a LD and the rest of the population may be significant. With little common ground, mutual empathy is difficult and the potential for forming relationships limited. Understanding of the environment we live in is necessary to sort out what is happening and where and how to get somewhere and back – this is beyond most with a LD. People with a LD are not independent in this respect and often need continuing support. The acquisition of

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life skills often requires training and this may not be retained. People with LD often prefer routine and this has its limiting effect.

Q2. Is there anything else about Disability Living Allowance (DLA) that should stay the same?

A2. No comment

Q3. What are the main extra costs that disabled people face?

A3. Caring and support would be the main extra cost for those who cannot adequately look after themselves. For those who are nominally independent additional costs would arise from poor budgeting, unwise decision making, inability to access goods cheaply, wastage of food, spoilage of food, need to purchase ready-made meals, breakages, inability to understand instructions, use of taxis where public transport is not accessible.

Q4. 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?*

A4. People's circumstances differ (e.g. their location) and this affects their cost of living. Having a LD affects people differently. Unless the intention is to award the higher rate in most instances then many will be deprived. People with a LD are dependent for life. Having a variable rate is best for the individual.

Q5. 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?

A5. Having a LD is an unchanging, lifetime, condition, mitigated only where training may have had an effect. Qualification should be automatic for those who are on the social services registers.

Q6. How do we prioritise support to those people least able to live full and active lives? Which activities are most essential for everyday life?

A6. Assuming that people with LD have the independence they have been assured is their right, then they need to be provided with appropriate accommodation and support, as necessary. Suitable transport will enable access to such as work, shopping and leisure activities. Living close to others with similar outlooks will promote companionship and the sharing of interests. Basically, the same requirements as the rest of the population.

Q7. How can we best ensure that the new assessment appropriately takes account of variable and fluctuating conditions?

A7. LD is largely invariant but the person may have proportionately more medical crises than the general population.

Q8. 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?*

A8. People with a LD will use their devices less effectively than the average.

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Q9. 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?*

A9. Without support the majority of people with LD are unable to properly understand forms or complete them. An 'easy read' version might help but would not replace the support.

Q10. What supporting evidence will help provide a clear assessment of ability and who is best placed to provide this?

A10. An extraordinarily difficult task, the results of which may vary with the person's mood. The person may not realise to what degree of success they are able to undertake activities. Yes/no answers are not helpful and there should be scope for qualification. A carer, family member or support worker should be involved.

Q11. 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?*

A11. It is not to be taken for granted that 'a healthcare-professional' knows sufficient about LD to make any useful input. Persons with LD will have a long medical history. Many do not respond to strangers. Only in exceptional circumstances should this sort of meeting be deemed necessary.

Q12. 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?*

A12. The conditions of LD are essentially invariant. Reviews are unlikely to be productive unless a person's medical condition has changed – in that case a review could be requested. This could involve the GP, social or other worker.

Q13. 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?

A13. Persons with LD are expected always to have a local point of reference for obtaining help and support and changes could be identified via this route. Their initial qualification for receipt of payments implies that monitoring and support is in place, although its frequency and quality is not assuredly high. Their income is likely to be little above subsistence level (seemingly) so recovering overpayments is likely to be inappropriate.

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Q14. 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?

A14. Someone who knows the person sufficiently well needs to be involved – as covered in other answers. Support organisations should make themselves informed about the benefits available. Of course the forms need to be understandable and explained.

Q15. 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?

A15. No comment

Q16. 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?

A16. Aids and adaptations will require frequent replacement during a person's lifetime.

Q17. What are the key differences that we should take into account when assessing children?

A17. No comment.

Q18. 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?

A18. It is important that there are few assessments.

Q19. 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?

A19. Increased work for all concerned. However, the conclusions of a single assessment regarding a person's disability must not be driven by financial restraints.

Q20. 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?

A20. In principle a good idea, in practice there are barriers – e.g. incompatible computer systems.

Q21. 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?

A21. No comment

Q22. Is there anything else you would like to tell us about the proposals in this public consultation?

A22. The comments in the preamble also form part of this submission.

Please take into account at least the following referenced document to put into context the lives experienced by and expected for people with a learning disability. The new payments system should promote fulfilment of the needs that are identified therein.

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Valuing People Now: A new three-year strategy for people with learning disabilities. Published by DoH 2009

