

Disability Living Allowance reform consultation: a response from the Social Security Advisory Committee

1.1 The Social Security Advisory Committee (SSAC) welcomes the chance to comment on the Disability Living Allowance (DLA) reform consultation paper.

1.2 SSAC is an Independent Statutory Body funded by the Department for Work and Pensions (DWP). It is the main UK advisory body on social security and related matters. The Committee provides advice to the Secretary of State for Work and Pensions (and to the Department for Social Development in Northern Ireland) and performs a mandatory scrutiny of most proposals for secondary legislation that is the responsibility of DWP. The Committee responds to most of the Department's public consultation exercises and is also consulted separately by Ministers seeking views on specific issues. The Committee may, of its own volition, select issues to research and report upon, and it publishes the resulting 'Occasional Papers' on its website.¹

1.3 The Committee is independent of both Government and sectional interests. Members come from a variety of backgrounds, but collectively they have a considerable depth of knowledge of, and expertise in, both the specifics of policy and law and the wider social policy agenda.

1.4 DLA is an important benefit received by around 2.9 million people² and is intended to help to offset the increased costs of disability enabling people to actively participate in society. It has two components, one for mobility which can be received at higher or lower rate, and one for care, available in three rates. The benefit is non-contributory, non taxable and can be received by children and adults, including people in work. It is not taken into account as income for means-tested benefits. Research has shown that it has made a real difference in assisting disabled people to manage their daily activities and actively contribute to society.³

1.5 We are concerned that the aim of reducing the number of working age claimants of DLA by 20% appears to be driving the need for reform of the benefit. We would welcome some clarity about what the overall aims of the changes are: whether the aim is to reduce overall numbers in receipt of the benefit; and/or to reduce the length of time people receive the benefit and/or to ensure accurate targeting of support, or to achieve something else.

¹ www.ssac.org.uk

² February 2008 figures, DWP from Beatty C., Fothergill S., and Platts-Fowler D., (2009) *DLA claimants – a new assessment: The characteristics and aspirations of the Incapacity Benefit claimants who receive Disability Living Allowance*

³ Corden A., Sainsbury R., Irvine A. and Clarke S. (2010) *The impact of Disability Living Allowance and Attendance Allowance: Findings from exploratory qualitative research*, Department for Work and Pensions.

1.6 It is difficult to comment on the substance of the reform as no firm proposals are available at this stage but in general terms, notwithstanding our concern about the drivers for reform, we welcome the Government's commitment to support disabled people in exerting more choice and control so that they can lead independent lives. We are pleased that this reform envisages greater simplification and less subjectivity in decision making.

1.7 We support the continuation of the use of the social model of disability in the assessment process for the proposed Personal Independence Payment (PIP), and we agree that the benefit should include elements of personalisation and a continuing recognition of the extra costs that disabled people face.

1.8 Turning now to the consultation questions, our responses are detailed below.

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

The problems and barriers that people with disabilities face are many and varied: two people with the same disability may face very different issues. However, it is possible to draw out broad themes in respect to people's needs. The barriers can be practical, physical and/or cultural. Disabled people need:

- to be able to ensure a reasonable standard of cleanliness, nutrition and clothing: healthy food, washing, dressing, and toileting, which are currently covered in the DLA assessment. In addition, adults may need assistance with shopping and cleaning, both of which are currently not included in the assessment of DLA. However, if a social model of disability is to be used all of these needs should be taken into account.
- to have access to a range of goods and services, activities and venues: including safe physical access and the support needed to use it
- to be able to communicate with other people: this includes support with speech, communication and language and literacy problems to the extent they are linked to disability
- to be able to manage their condition effectively: including being able to participate in treatment, and being compliant with medication
- to be able to call on help and support and to be able to acquire necessary aids and adaptations
- to be able to actively participate in the communities in which they live and make full use of the facilities that they provide, which may include support to overcome mobility and communication difficulties.

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

SSAC agrees that the special rules, and the status of the benefit as non means-tested, non taxable and non-contributory, should continue. We would like to see the benefit continue to be exempt from being counted as income

for the purposes of means-tested benefits and for it to continue to act as a passport to higher rates of means-tested benefits.

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

We consider that some of the main extra costs faced by disabled people are as follows:

- personal support and assistance, including to keep safe and/or participate in the communities in which they live
- transportation
- help with housework, food preparation, bathing and shopping
- special diets for people with certain conditions, e.g. diabetes, Coeliac disease, phenylketonuria
- fuel costs for heating – particularly for those people with a condition which is aggravated by being cold – and for washing (over and above a non-disabled person's costs)
- aids and adaptations
- the cost of paying for personal, domiciliary, respite and/or residential care
- telecommunication and internet costs, particularly for those with mobility or communication difficulties, or who are at risk of needing urgent access to assistance

This list is supported by DWP research which has shown that people in receipt of DLA used the money for: personal care; transport; food; fuel; home maintenance, including cleaning, gardening and small jobs; health care, medical equipment and supplies; telephones and computers; and social activities.⁴

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?**

It is difficult for us to answer these questions definitively without more detailed information about what the two rates will represent, or whether there will be any reduction in the amount of DLA paid.

Anecdotal evidence suggests that there is widespread confusion at present about what the two rates of the Mobility component are for, with many people assuming that the lower rate is for people who have difficulty walking but are less disabled than those in receipt of the higher rate. The care component appears to be less problematic at present in that it is better understood by claimants and their advisers. However we would be concerned if the change to two rates of care component meant that eligibility criteria were to be tightened with the result that the rate of benefit received by those on the

⁴ *ibid.*

higher rate was reduced to the current middle rate and the middle rate to the lowest rate.

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?

As mentioned above, we consider that the special rules, whereby a terminally ill person (under the meaning of the legislation) is automatically entitled to DLA, should continue. In addition there are some conditions which we think should trigger automatic entitlement, including tetraplegia and being deaf-blind.

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?

We are unable to provide an answer to this question without a definition of what is meant by 'support' or 'full and active life' in this context. We do, however, consider that all the points we have noted in response to Question 1 are essential.

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

It is essential to ensure any new assessment takes proper account of the complexities of fluctuating conditions. Many medical conditions vary from day to day, and individuals with the same condition can react very differently. We suggest that there is a need to:

- ascertain good medical advice about which conditions are prone to variability and fluctuation, and the range of patterns that are experienced
- check this advice with user groups, to seek their input
- seek information about the pattern of the disability from claimants and their medical advisers and other professionals, for example, community psychiatric nurses, occupational therapists, social workers, and support workers, at the pre- assessment stage.
- ensure that there are mechanisms for updating assessments to take account of fluctuations over time, but bearing in mind that it would serve little practicable purpose to repeatedly reassess an individual when a condition is considered to be lifelong, permanent and with little realistic prospect of improvement.
- understand the implications of the fluctuations for the needs of the individual concerned

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?**

IB and ESA already take some aids into account and we would be concerned if the new DLA would go beyond that.

We think that aids which a person is eligible for but does not have should not be taken into account. There can be a very long wait for an occupational therapy assessment, or for a grant or loan to purchase an adaptation and it would be unreasonable to take into account something a person did not have or had no idea was available, or could not afford.

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?**

The key is to keep the claim process as simple as possible. If the two rates of each component are for different levels of disability then the proposed change may remove a level of complexity. The form should ask only for information that is necessary to assess eligibility and avoid repetition. We also suggest that the questions should be much better focused than those on the present claim form and rendered as clear and as simple as possible.

Telephone applications could be used to make the application process easier for claimants. A member of our secretariat with experience as a Decision Maker working on DLA and AA claims found that the best way to ensure that all the relevant information was captured when assessing claims was to talk to the individual on the telephone. The issue here may be that some people may not be able to explain the consequences of their illness or disability, and some people try to put the best light on their ability to manage day to day life: some delicate questioning may be necessary to draw out a true picture of a person's needs.

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

Few people with disabilities are unlikely to have regular home visits from their GPs, and their main day-to-day contact may be with a physiotherapist, a CPN, a support worker or keyworker, a social worker, or a family carer; or they may manage unsupported, other than by their GP, who sees them in their surgery. Therefore, we consider that GPs are not always best placed to provide

supporting evidence. In most cases, the claimant should be asked to nominate the most relevant health or social care professional.

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?**

It will be crucial for the assessor to be appropriately qualified, with awareness of the particular needs of people with a learning disability and/or a mental ill health problem. We would also point out that there are questions of definition that need to be considered, for example in the context of Scottish legislation there are three discrete types of mental disorders: learning disability, personality disorder and mental illness.

Although there are advantages to a face-to-face assessment they can be potentially misleading both for people with fluctuating conditions, (for example, whether they are seen on a good day or a bad day), and for those with no insight into their condition (including some people with mental ill health issues or learning disabilities). For some people where the documentary evidence is clear cut a face-to-face assessment may be unnecessary. We are aware that the need for a face-to-face meeting can lead to long delays, as can occur in ESA assessments. If such meetings are to be introduced for DLA then there will need to be provision for a provisional payment to be made, similar to that in ESA, while the claim is assessed.

We are concerned about how face-to-face assessments would be resourced. We are aware that many ESA claimants are having their assessment phase extended beyond the intended 13 weeks because of delays in the assessment process. To extend assessments to the new benefit will vastly increase the workload. To target them at an appropriate group, where a decision cannot readily be made from the available information, including previous assessments, would be proportionate.

We are also concerned that changes to DLA are being made while ESA is still bedding in. The level of dissatisfaction with the quality of assessments has at least in part been confirmed at least in part by the Harrington review.⁵ There is a need to learn lessons from the ESA experience when preparing for PIP as there is likely to be some resonance between the approaches taken to the two benefits.

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?**

⁵ Professor M. Harrington , *An Independent Review of the Work Capability Assessment*, Department for Work and Pensions, 2010

In all cases the primary source of information to determine the point at which an award of DLA is reviewed is the prognosis of a particular condition, which may require evidence to be provided by a consultant with some knowledge of the history of the condition (especially in fluctuating conditions). If someone satisfies the requirements for an award and their condition is likely to continue to deteriorate we think that there would be little to gain from reviewing that award any more frequently than every five years. If improvement or adaptation is possible, then a more frequent review may be indicated, but this must be a genuinely informed decision based on medical evidence.

It should be a condition of a longer-term award that claimants notify any new diagnosis or new treatment that could bring about substantial changes and thereby trigger a review.

There may be some people whose awards will need to be reviewed regularly; but for anyone with a genuinely long term condition it should not be usual to review their awards more often than once a year.

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 key here is the provision of good information and clear communication. People will need to be informed that they must report changes in their needs that would be expected to trigger a change in entitlement. A clear list of the changes that customers need to notify should be provided to them in the information they receive about their benefit. This communication should include information about changes of circumstance where there is a potential risk of an overpayment to the customer.

One approach would be to send a short enquiry form (one page) annually to ask if anything has changed, highlighting a list of reportable circumstances. An advantage of this to claimants is that if their condition has deteriorated the reply could be used to trigger a review. Similarly it may prompt someone whose condition has improved to inform the department.

We would be concerned if changes in circumstance are only reportable using the internet, as many people do not have access to computers. It will be essential to provide diverse channels for communication including via the telephone and face-to-face.

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?

See our response to question 15 which considers questions 14 and 15 together.

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?

We would like to offer our response to these two questions together. We have some difficulty with the suggestion of making it a requirement to access support and advice. Variations in the availability of public services means that, for many people there is little realistic prospect of help and support being available. Anecdotal evidence suggests that waiting lists for occupational therapy appointments, for cognitive behavioural therapy, for drug and alcohol rehabilitation courses and for all types of help from the NHS and social services are very long in some parts of the country and are likely to increase. Provision also varies widely between NHS trusts and local authorities. We are also worried about how Decision Makers will know what advice is available in different localities. We note reports that some Citizens Advice Bureaux are being forced to close because of withdrawal of local funding, including all five offering drop-in services in the Birmingham area.

The question suggests the possibility of some sort of conditionality being imposed on some claimants: a “requirement to access advice and support to encourage the minority of claimants who might otherwise not take action.” We would like to see a more precise definition of what is meant by “advice and support” and how the DWP will be able to guarantee that advice and support will be available on demand across the country.

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?

Our experience shows that disabled people use their benefits to help them meet a variety of costs such as heating, housework, and transportation. The Motability scheme is hugely popular because it enables even non-drivers to have transport. We are aware that one cause of appeals in DLA is the award of the higher rate mobility for less than three years⁶, which is the minimum period needed for a Motability car (that rule may need to be changed, if awards generally move to shorter periods).

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

Children’s awards are currently governed by comparison with a child of the same age without a disability and we consider that this is the right approach. As children get older, some may partly outgrow their disability, or learn to manage it themselves. Others may become progressively more disabled relative to their peers. This suggests that awards of DLA to children may need to be reviewed more regularly than those of adults.

⁶ although in some circumstances Motability cars are accessible to people in receipt of awards with 12 months or more remaining

With any face-to-face assessment, particularly of younger children, or those with cognitive/intellectual impairment, it will be essential to have a parent/carer not only present but also able to give information and answer on behalf of the child.

At present, the need for extra support at school can and should be taken into account when assessing entitlement to benefit. We are concerned that the need for such support might not be taken into consideration in deciding whether a child is entitled to PIP.

We would have no problem with the continuation of the principle that DLA is not payable to residents in residential accommodation of whatever type but that entitlement remains. However, if it were to be extended to children attending day schools, we consider that this would impact on families. Having a disabled child in a family puts the family under stress, especially if the disability has behavioural consequences. It can lead to the break up of relationships and to emotional and psychological trauma for other children in the family. If, as is the case at present, the underlying entitlement to the benefit remains even whilst it is not actually payable, there could be added complexity in making payments when the child is not physically in school, such as weekends, holidays, or when ill.

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?

DLA has been useful in providing additional help with transport costs via passporting arrangements. People who receive DLA at the higher rate for mobility are exempt from paying road tax and we agree that this should continue. We also feel that people in receipt of the highest rate for mobility should continue to be passported to the Blue Badge scheme, Warm Front grants and the VAT exemption on certain vehicle adaptations.

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?

At present DLA is disregarded income for Income Support/Income Based Jobseekers Allowance/Income Related Employment and Support Allowance/State Pension Credit/Housing Benefit and Council Tax Benefit, and an award of DLA can also lead to higher rates of these benefits. An award of the care component means that non-dependent deductions for people living in the claimant's household do not apply to housing benefit, council tax benefit and mortgage interest support. Additional elements of working tax credit can be added-in for workers getting DLA, including a special high rate for the most severely disabled workers on the highest rate of the care component.

Passporting is simple and easy to understand. The absence of passporting is likely to affect take-up and increase administration costs.

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?

ESA and DLA are not the same and the considerations are not the same. We do not think that PIP should share the same assessment basis as ESA: the latter is or should be based on occupational health principles, the former on a social model of disability. We think it is right that ESA uses a disability-based rather than diagnosis-based test.

The work activity tests of ESA, such as the ability to move safely around a work place and to be able to communicate simple messages to other workers, are not relevant to the ability to access a full and active daily life. So we think that there is nothing to be gained by combining the two assessments. It may be the case that results from one *may* contain information which could be used to supplement the assessment of the other. Overall, we see no harm in sharing information as long as claimants are informed about it and the information being shared is accurate.

We would welcome better integration of the various services available to disabled people, particularly with social care services, and we would support moves for DWP to work more closely with other departments, including the Department of Health.

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 consider that there would be a greater impact on women. Women tend to be the primary carers for children as well as for disabled relatives. For this reason women are likely to feel a disproportionate impact from any reductions or cuts in the move to PIP.

An impact that has not been considered is the effect on people living in rural areas with, for example, limited transport links and fewer shopping options. It is likely that people in rural areas will find it harder to access the services they need.

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

We have some concerns about the qualifying period for entitlement to PIP, which we understand may be extended to six months. Combined with the potential delay inherent in a new face-to-face assessment this would mean that people would wait a long time for the financial support that they need. We would also like to see the qualifying period maintained at three months for children.

We would like to see more detail about how people over 65 will be dealt with, for example, will they be moved onto Attendance Allowance, or will they remain entitled to PIP post 65 as at present with DLA; and how will transition points be managed. We would suggest that the current age limit is re-

examined. We consider that in light of the moves towards a more flexible retirement age, where people will be working longer, making the age of 65 a cut off point for the benefit seems arbitrary and could be discriminatory.

Given the potential for impacts on people over 65, and on children, we suggest that the Department runs separate consultations on the plans to reform DLA for both these groups.

We consider that the proposal to remove the mobility component from people in residential care should not go ahead. This measure will substantially reduce the independence of disabled people who are being cared for in residential accommodation, which goes against the stated aim of the reform of DLA to support “disabled people to lead independent and active lives”⁷.

⁷ Department for Work and Pensions, *Public Consultation: Disability Living Allowance reform* (2010), p3