

ILF response to the Public consultation on Disability Living Allowance reform

15 February 2011

Introduction

The Independent Living Fund is an Executive Non-Departmental Public Body of the Department for Work and Pensions. We currently make cash payments to over 20,000 disabled people with complex and high support needs to assist with meeting the cost of the support they require to achieve independent living. The purpose of the ILF is to enable those who face the greatest barriers to independent living to remain living in the community rather than in residential care and to play an active part in their community as full citizens.

The ILF occupies a distinct place within disability support arrangements and adult social care, bridging the support provided by local authorities and the benefits system. ILF funding is targeted at those who need the greatest support to live independently, determined by: the receipt of the highest rate care component of Disability Living Allowance (DLA) and a minimum level of local authority social care funding.

ILF and DLA are intrinsically linked, as an individual must receive the highest rate of the care component of DLA (HRDLA) before they can make an application for ILF funding. Continued receipt of HRDLA is necessary for a candidate to satisfy ongoing eligibility criteria.

An ILF award requires a user to contribute half of their DLA towards the cost of their ILF support. In any future system, it should be paramount that service users are enabled in a similar way, to channel their PIP award into their support plans, if there are truly efficiency savings to be made.

The current HRDLA rate of £71.40 a week, whilst making a substantial contribution towards assisting with additional costs of disability, is unlikely to be enough to meet the support needs of the most severely disabled in a way that promotes full inclusion and independent living to the extent that ILF support currently does.

The responses given here are based on the views of disabled people who receive ILF, gathered from our regular programme of user meetings across the UK and from our Advisory Group made up of ILF users, trustees and organisations of disabled people.

The consultation questions

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

Disabled people's ability to join in with others and to live full, active independent lives is restricted by a wide range of factors. These include: the ability to access transport and ordinary leisure facilities, poverty, non disabled people's attitudes towards them and access to suitable housing, to name a few.

DLA or PIP cannot on its own alleviate all these barriers, however, the extra financial support that DLA currently provides is highly valued by disabled people, for example accessing leisure facilities may cost double as service users have to pay for their PAs, which restricts social inclusion. Having weekly cash payments of DLA, without restrictions as to how it is spent, greatly helps to make these kinds of activities a reality.

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

DLA is currently recognition of the extra costs disabled people face, to be spent as the recipient sees fit, and this is highly valued by disabled people.

The ILF asks users to contribute half of their HRDLA care component towards their care. We do not ask users to contribute the full amount in recognition that there are additional disability related costs that users incur, such as those associated with having a PA, sometimes there are higher cleaning and home maintenance costs, and there are costs such as incontinence pads, equipment & medication (where not in receipt of Income support or equivalent).

Linked to that, because DLA is not means tested, all recipients have an amount available to meet the extra costs related to disability regardless of their financial circumstances, and there is therefore no disincentive to work.

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

There is a very wide range of disabilities and impairments and costs will vary from person to person depending on the nature of their impairment, however all individuals with a significant impairment are likely to face extra costs in comparison with their non-disabled peers. Examples include heating, wheelchair insurance, clothing, holidays, and travel costs, which tend to be double where service users have to pay for their PA to accompany them.

We welcome the intention to “prioritise support to individuals who face the greatest challenges and expense”, however, it may be very difficult to determine who faces the greatest expense, as it can vary even between two people with the same disability, depending on various factors such as interests of the individual and availability of unpaid assistance.

Many disabled people also have the added burden of being an employer, and whilst the Local Authority and the ILF usually cover employer costs, there are occasions where the user ends up meeting these additional costs.

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?**

Having two rates rather than three should be easier to understand and administer, but it risks being less nuanced. Not recognising a wide range of needs, and not supporting those with low needs could lead to increased costs elsewhere in the system.

If the rates payable change at the same time as moving from three to two rates, there is a high risk of dispute, appeal and perceptions of unfairness.

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?

There should be serious consideration given to extending automatic entitlement to the benefit beyond those with a limited life expectancy. For example, degenerative or life limiting conditions, severe learning disabilities or any condition where there is evidence that the user will never recover from. These may be the people who previously received a DLA award “for life”.

Many ILF users were awarded “DLA for life” and are now concerned about what these changes mean for them, and whether they can challenge the decision if they are not awarded an automatic benefit. These concerns are magnified due to all the other changes to their support they are currently experiencing, leading to uncertainty over the whole of their future provision and the fear of dependency.

It would be undesirable to incur the considerable costs involved in assessing people already on the highest rates where there is already clear evidence that the need is stable or increasing.

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?

People with the highest support needs are those at risk of being unable to live independently in their own homes if the right support is not in place. These are the people who should receive priority of support to ensure they do not end up institutionalised.

The ILF provides support for those personal and domestic tasks that have been considered by DWP as vital to enable a person to lead an independent life. These are:

- Cleaning and other domestic duties
- Cooking and preparing food and drink
- Laundering and ironing
- Shopping
- Personal hygiene and grooming
- Dressing
- Eating
- Drinking
- Physical movement such as turning and walking
- Supervision in order to avoid substantial danger to him or herself or others

In practice the award combination of ILF, social care and DLA monies funds personal assistance that enables the individual to live at home, leave the house, and engage in community activities like anyone else.

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

Any new assessment should require supporting evidence & should be carried out by a person who fully understands the nature of the conditions they are assessing.

A 'social model' approach is essential, as the DLA/PIP award needs to help to remove the barriers that face people with different impairments and conditions.

Service Users are also becoming increasingly skilled in understanding and assessing their own needs. Their own expertise should not be lost from the assessment process.

Ideally the PIP assessment should be part of a single or coordinated assessment process to avoid extra duplication in the system.

The Government's Right to Control program aims to develop a single support plan, which should identify all the funding available to the user and the outcomes this will achieve. Assessment for PIP might usefully be drawn into this process.

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?**

Aids and adaptations are designed to lessen the effect of disability, make caring easier and make people less reliant on support. However they are unlikely to reduce the added expenditure associated with disability, other than in situations where slightly less care is required.

If adaptations are taken into account then it must be ensured that people are able and supported to use them. Some users report being issued with aids that they didn't know how to use. To reduce the amount of PIP awarded because they have an aid, without being sure that the aid is reducing the cost of care, would be counterproductive to the service user.

People with wheelchairs have maintenance costs such as insurance for which they may use mobility allowance. Having an adaptation may make day-to-day living easier but does not necessarily reduce the extra cost of disability.

9. 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?

Every opportunity should be taken to help people to secure the best possible life, including signposting to the available aids and adaptations. A funding regime that too crudely reduced awards or set them at a lower level would risk perverse behaviour in response.

10. 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?**

Applying for any benefit, grant, aid or social care funding can be a very stressful and disjointed process for the recipient, leaving them confused as to what they receive and why.

Anything public bodies can do to ensure people are correctly informed and sign posted by whichever agency they first contact would help greatly. Advocacy support should ideally be available. Very many ILF users would wish to have a single point of contact to advise on all the information they need relating to their disability or impairment.

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

Evidence of the extent and impact of the disability / impairment and the effect this has on a person's life should be provided principally by the person themselves and by people who know them and professionals previously involved.

This evidence would best be captured in a joint or single assessment with a social model perspective and all the relevant people present, as outlined above.

12. 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 individual should have the opportunity to self assess, as it may be difficult to understand or get a full picture during a short interview. Some disabilities are more complex or fluctuating than others and therefore there are some questions about the assessment process that should be addressed:

- Is carrying out periodical assessments where we know that someone's disability is likely to remain the same, the best use of public funding?
- Can a periodical meeting judge needs that are complex and needs that arise in all circumstances?

- A face-to-face meeting may be intrusive, seen as “justifying” the need for a benefit – if professionals who have known someone for a period of time concur then what is the added value of a separate assessment?

The assessment process is likely to add cost, complexity and time lag to the process, not least when appeals are taken into account, so we must be sure it is carried out in the best possible way and that a separate assessment is truly necessary.

13. 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?**

Evidence should be gathered of the extent of disability caused by the condition and the reasonable likelihood that the condition will change; The assessment should be streamlined with Local Authority/Right to Control and other assessments of disability; and see above regarding awards “for life”. Some conditions may need reviewing less frequently, if at all, as otherwise it is just an extra process that is unlikely to add extra value.

15. 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 PIP award would require very clear criteria, and it must be easy to understand the type and extent of changes that would require reporting.

Streamlining the PIP assessment with other assessments and providing ongoing advocacy will help users understand where they need to report changes. Otherwise PIP trigger questions included in other assessments would ensure changes are captured.

The ILF client group has a very high level of disability and users tend to lose track of all the different payments and benefits they have – no amount of clarity will help if they have too much to keep a handle on or if they rely on carers who do not fully understand it. Therefore it is also paramount that all the right people are given the necessary information.

Also key to keeping recipients engaged is to ensure as many barriers to communication as possible are removed, e.g.: making communication free such as freepost or free phone and having various methods for reporting changes such as internet, phone etc, available – ie make communication ‘comfortable’. Users report frustration at agencies that will only speak directly to the user rather than a carer or family member of their choice.

16. 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?

As mentioned above, users want to see public bodies working in a joined up way, and they want advisors to be able to provide support for any and all parts of their support plan.

Apart from clear information about the PIP application process, the rules surrounding the PIP and any changes they are expected to report, they would also benefit from advice about or signposting to, other services they may be entitled to or that PIP passports them to.

- 17. 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?**

There is definitely a need for more advice and support provided ideally by one point of contact and in a streamlined way as outlined above, but the real question may be how to identify those who are not claiming but are entitled, and why that might be? Are there communities and groups of people that we as a society are failing to reach?

- 18. 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?**

The NHS and Disabled Facilities Grant both fund some adaptations, as does Access to Work. However, a lot of people fund their own equipment where, for example, they find that the equipment offered by the NHS is not adequate for their needs, or where they find that the waiting time makes life prohibitive.

There could be a case for one off PIP payments where this clearly led to savings for the taxpayer without detriment to the recipient.

People will expect to continue to be able to use PIP for adaptations should they so choose. Changing this freedom may lead to a greater demand on other funding streams and consequently on the public purse.

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

ILF funding is available to working age adults and continues to be available to those over 65 who already receive ILF. Therefore this question has not been addressed.

20. 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?

Receipt of HRDLA is a requirement for receiving and continuing to receive ILF funding. Service users are expected to contribute half the care component of DLA towards their care package, thus ensuring DLA is channelled towards the purpose it was awarded for.

Any change to the current arrangements should ensure that current passporting arrangements are addressed and that where these arrangements channel government funding in the right direction, these efficiencies are retained. There could be even greater efficiencies to be made in the system if awards and benefits were even more closely linked.

21. 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 ILF system for its 20,000 users would become unworkable as it stands and would need complete revision at considerable cost.

To sever links between PIP and other forms of support might risk further disjointing a system that is moving towards synchronisation and may cause more confusion to benefit recipients and service users making them less efficient in collaborating with the state in providing correct up to date information, and in truly understanding what each payment is for.

People may lose out on the support that they need if certain passporting arrangements are lost and the information provided in the process, is lost with them.

22. 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 possible in theory at least, to combine the PIP assessment with the regular care assessment carried out by Local Authorities.

ILF and Local Authorities are beginning to work more closely together and intend to test out how assessments can be streamlined as part of the Right to Control. This could be extended to include assessment of certain benefits, including an assessment of need such as that proposed for the PIP.

Secure data sharing is a vital part of making a coordinated assessment process work and reduces bureaucracy within different processes. For example, if ILF had direct access to information on the DLA our users receive, it would enable ILF to check ongoing eligibility rather than finding out after the event that circumstances had changed, and expecting users to return large overpayments.

23. 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?

There is potentially a significant disruption to the lives of disabled people by the introduction of another periodical needs assessment and the added uncertainty of the benefit changing from 'a lifetime award' to an award that will require ongoing needs to be periodically demonstrated.

Particular care needs to be taken to ensure the needs of people with learning disabilities, and those with mental health conditions, are fully recognised.

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

Local Authorities have told us that they believe any cost saving to the DWP as a result of the change from DLA to PIP will end up creating a parallel increase in cost to them. This is because they take DLA into account in their assessment of charge and where the PIP is less than the previous DLA, this will result in the LA charge decreasing. This needs to be fully explored before definitive conclusions are reached.

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