

**Advice NI response to
Disability Living Allowance reform
February 2011**

Background

Advice NI is a membership organisation that exists to provide leadership, representation and support for independent advice organisations to facilitate the delivery of high quality, sustainable advice services. Advice NI exists to provide its members with the capacity and tools to ensure effective advice services delivery. This includes: advice and information management systems, funding and planning, quality assurance support, NVQs in advice and guidance, social policy co-ordination and ICT development.

Membership of Advice NI is normally for organisations that provide significant advice and information services to the public. Advice NI has over 65 member organisations operating throughout Northern Ireland and providing information and advocacy services to over 100,000 people each year dealing with almost 250,000 enquiries on an extensive range of matters including: social security, housing, debt, consumer and employment issues. For further information, please visit www.adviceni.net.

Context

Advice NI finds it difficult to accept that Government is genuinely interested in 'protecting' people with disabilities and those people with work limiting health conditions who are reliant upon the benefits system, and Disability Living Allowance in particular, when one considers the raft of welfare cuts that have been proposed as a result of the June and October announcements. Worryingly in the current economic climate many of these cuts appear to be purely punitive in nature given the job opportunities that exist in Northern Ireland.

The Budget 2010 Policy Costings document highlights the following:

“Drawing on the evidence of the impact of the WCA, the central assumption for this policy is that it will result in a 20 per cent reduction in caseload and expenditure once fully rolled out.”

Advice NI believes that ultimately the driver behind the Personal Independence Payment is cutting expenditure, regardless of how this may be dressed up in the consultation document, and our fear is that the needs of the disabled will become a victim of financial expediency.

Advice NI has already made the point that we are very concerned about how people with work limiting health conditions are currently treated and will be treated under Universal Credit. Advice NI is very concerned about the thinly veiled threat contained within the consultation document to potentially withdraw additional premiums in respect of disability from Universal Credit. There is potential for people to lose out not only by being refused the new Personal Independence Payment but even where they do secure entitlement there is the potential for them to lose out on additional premiums. Additionally we are already seeing more people failing the Work Capability Assessment (which is the medical test for Employment and Support Allowance). Undoubtedly more people with moderate to severe work limiting health conditions are finding themselves claiming JSA and so may well be subjected to an inappropriate level of conditionality within the proposed Universal Credit regime, this direction of travel is undoubtedly set to continue. We believe that there needs to be a fundamental review of the needs of people with work limiting health conditions and how they can be properly supported within the benefits system.

There is a real potential for the proposal to introduce the Personal Independence Payment as a replacement for Disability Living Allowance to have a significant differential impact in Northern Ireland. In terms of numbers, over 100 people per thousand receive Disability Living Allowance in comparison with over 50 people per thousand in Britain. Taken together with additional payments included within other benefits due to Disability Living Allowance being in payment (for example Severe Disability Premiums) we would fear that claimants in Northern Ireland will disproportionately suffer as a result of these proposals. Advice NI would draw attention to the unique circumstances of Northern Ireland, a society emerging from forty years of conflict with many people still suffering as a result, which need to be factored into the implementation of Disability Living Allowance reform.

These uptake figures would lead Advice NI to question the clear implication contained within the consultation document that Disability Living Allowance is not targeted and not understood by those who need it. It is our view that whilst the rules governing entitlement to Disability Living Allowance are complex and the application form is lengthy and complex, people do understand that eligibility is based not on their particular illness or medical condition but the impact this has on their daily living. The caseload and expenditure figures suggest that Disability Living Allowance is a benefit which is well understood and accessed by people who meet the qualifying criteria. In Northern Ireland the Disability Living Allowance caseload is regularly 'churned' and claimants are already subjected to a periodic review process.

Impact of reduction in help provided via the Personal Independence Payment

The 20% reduction in caseload and expenditure will have a wide-ranging impact beyond the immediate impact of withdrawing the benefit itself. People may also see the removal of additions in terms of additional premiums included in other benefits, including Housing Benefit; impact on the psychological well-being of the individual who may well have mild to severe health conditions who are barred from accessing the benefit they feel they need and should be entitled to; potentially very significant impact on carers and their ability to claim Carers Allowance and ultimately their ability to carry out their caring role; impact on parents looking after children with disabilities, in terms of making up the shortfall if deprived of this financial support; potential impact on older people if the scope of the reform is broadened to include those aged over 65 who receive Disability Living Allowance; the removal of access to non-benefit related passported support, for example car tax and the Motability Scheme. These knock-on consequences of achieving a 20% reduction in the Personal Independence Payment caseload and expenditure would lead us to question whether these additional savings have been factored into the projected savings.

Uptake of the Personal Independence Payment

Despite the focus on efficiencies and reducing expenditure, Advice NI would urge Government not to lose sight of the fact that this benefit will be for 'those with the greatest need.' With that in mind, Advice NI would urge that thought be given to the issue of uptake so that those most vulnerable people actually get the support to which they are entitled.

Proposals: General comments

Advice NI believes that the consultation document is economic with the truth in terms of not addressing the central policy intent behind the proposed reforms, namely a reduction in caseload and expenditure. The consultation document, either intentionally or unintentionally, also sets out mixed messages by frequently referring to Disability Living Allowance and work. The word 'work' or a derivative of it appears at least 50 times in the document; and whilst it is made clear that the reformed benefit will continue to be paid to people in and out of work, we believe that the direction of travel is undoubtedly towards restricting access to the Personal Independence Payment. The focus is on targeting payments towards those needing greatest help – in others words the most severely disabled – so obviously those least able to work. In our view the Personal Independence Payment will have less people engaged in work as a proportion of the overall total (in comparison to Disability Living Allowance). Indeed moving into work could well be considered one of those changes in circumstances that, if not disclosed, might trigger a benefit penalty or prosecution. We would be interested in exploring further the whole area of a person's work limiting health conditions and the Personal Independence Payment.

Questions

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

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

Advice NI is surprised that this question is included in the consultation document. If Government does not know the answer this would be unthinkable given the strides that have been taken in this area in the last twenty years and in terms of research into this whole area including disability discrimination and on equality issues. If meaningful information is required, arguably there should be a specific consultation exercise aimed at eliciting this information.

Advice NI would assert, for the record that physical and mental health-related conditions act as a key barrier to participating in society and leading independent lives; closely followed by the financial limitations that people with physical and mental health-related conditions live with on a daily basis. Additional costs impact on all aspects of life including home

adaptations, heating, transport, dietary and generally the need for additional care and support.

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

In terms of administration in Northern Ireland, the current situation is that decisions on eligibility for Disability Living Allowance and the amount of allowance to be paid are made by decision makers in the Social Security Agency, based on evidence provided by the claimant and any additional corroborative medical evidence sought by the Agency (whether from the claimant's GP or from an Examining Medical Practitioner). Successful claims are subject to regular review.

In terms of the Personal Independence Payment, the main focus for change appears to be on implementing the 20% cut in caseload and expenditure by: (i) introducing a new, arguably harsher, medical test; and (ii) reducing the number of rates to two for each component.

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?**

Advice NI would require more information in relation to the criteria to be introduced in respect of the two rates per component. Obviously the intention will be that not everyone currently entitled to Disability Living Allowance will be entitled to the Personal Independence Payment. The main problem will be faced by those who are unable to access support under the new Personal Independence Payment. Advice NI would recommend that Government profile the type of current claimant who will be negatively affected and publish this information.

Secondly no information has been provided in relation to the amounts payable in respect of the two rates per component. Again this information will inform what disadvantages or problems could exist within the new Personal Independence Payment regime.

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?

Advice NI has examined the list of conditions that currently provide automatic entitlement, namely the severely mentally impaired; double amputees; deaf/blind; severely visually impaired; haemodialysis and terminally ill. We fail to see what positive outcome can be achieved by abandoning automatic entitlement in such cases, other than increasing costs in terms of requiring medical assessments and generating nugatory work which does not alter the decision making process.

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?

This process is about reforming and cutting the support currently available via Disability Living Allowance. We believe that the current criteria used to assess claimants for Disability Living Allowance (and the caselaw which has grown up around the current criteria) provide clear guidance as to the areas where people need support to live full and active lives. To cut support in any of these areas will serve to disadvantage people with disabilities, whose work limiting health conditions will severely curtail how this shortfall can be overcome.

Quoting from the Minister's foreword, *'this is our opportunity to improve the support for disabled people'*, Advice NI fails to see how these cuts serve to improve the support for older people.

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

Advice NI would call on Government to resist the temptation to simply use variable or fluctuating conditions as a potential barrier to making a successful claim for the new Personal Independence Payment.

Many extremely debilitating disabilities and health problems are variable in nature, with 'bad' days and 'less bad' days difficult to predict. Advice NI believes that a reasonable starting point on the issue of variable and fluctuating conditions would be to take the 'more often than not' benchmark. Medical assessors and decision makers should not pre-judge

claims, decide each case on its merits and in particular listen to the claimant's views on how their disability affects them.

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?**

There is an issue that claimants might be penalised in terms of the existence of aids, but those aids might not in fact be available to them. For example, lengthy delays in accessing Occupational Therapist assessments and in obtaining the aid or adaptation are a reality for many people, there may also be issues in terms of stigma and affordability. Government cannot have it both ways: if people are to be penalised based on aids or adaptations; these must be readily available to people that need them.

Advice NI would also be concerned that the focus of this question is on the existence of aids and adaptations, not on the extent to which aids and adaptations may help someone play a full and active part in society. The implication of the consultation document might be that the existence of an aid (whether used or not) will lead to the claimant being penalised. It is our view that the focus must be on assessing need on an individual basis, with care taken not to pre-judge a case on the basis of the existence or not of aids and adaptations.

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?**

Advice NI is an advocate of the Systems Thinking approach and would encourage Government to use this methodology to improve service provision to Personal Independence Payment claimants.

Advice NI firmly believes that there is an as yet untapped opportunity to reduce bureaucracy, improve staff morale and improve efficiency within public services using the

Systems Thinking methodology. Advice NI's work in this area to date builds on Systems Thinking work in GB and demonstrates the immense contribution advice services can make to improving public service delivery and minimising waste and how gaining absolute knowledge of systems is the key to unlocking cost and waste. A systems thinking methodology, whereby customer demand and service purpose is clearly understood and work-flow is analysed with front-line staff taking the lead is essential for service improvement. It provides the key to the absolute knowledge that is needed to reduce cost and waste and deliver what customers really want. We would commend this approach to Government.

The following quotation from Professor John Seddon reflects the Systems Thinking ideology:

“At the highest level there are two types of customer demand: ‘value’ and ‘failure’ demand. Value demands are those you want customers to place on the system; they are the reason you are in business. Failure demands are those you don’t want: demands caused by a failure to do something or do something right for the customer. It follows that failure demand, being created by the organisation, is entirely under the organisation’s control. Turning off the causes of failure demand is one of the most powerful economic levers available to managers; it has an immediate impact on capacity.”

Advice NI would be keen to engage with Government on how to release the opportunities presented by Systems Thinking to streamline the claims process and improve service to claimants.

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

Advice NI's reading of the consultation document would suggest that the decision has already been taken to introduce a *‘new, fairer, objective assessment of individual need ... in most cases we envisage the individual having a face-to-face meeting with a healthcare professional.’*

In Northern Ireland, an independent healthcare provider (ATOS) has been appointed by the Social Security Agency to undertake medicals for social security benefits commencing June

2011. There is a concern therefore that this added layer of change could negatively impact on social security benefit claimants in Northern Ireland.

In terms of other sources of evidence, very often the claimant's GP is not best placed to comment on his/her health condition. Other healthcare professionals may provide ongoing support in respect of the person's physical or mental health problem. Advice NI would urge that (i) claimants are encouraged to provide information on any / all healthcare providers who are involved in their case; (ii) and that decision makers involved in adjudicating on Personal Independence Payment claims are encouraged to seek evidence from these sources.

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?**

Advice NI believes that the focus must be on making correct, timely Personal Independence Payment decisions. In our view decision makers must have the discretion to seek evidence from whatever source which will enable them to adjudicate in a correct and timely fashion. The implication within the consultation document would be that most claimants will be subjected to a face-to-face medical assessment, in our view that approach may be overly prescriptive, costly, bureaucratic and ultimately unnecessary.

In our view some claimants, in particular people with mental health problems, may find face to face scrutiny by a healthcare professional intimidating and stressful. Advice NI would urge that all healthcare professionals receive adequate training in relation to what might be called 'customer care' so that claimants are treated with respect and dignity at all times.

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?**

In Northern Ireland, all successful claimants to Disability Living Allowance are already subject to a Periodic Enquiry Process where cases are periodically reviewed on an ongoing basis.

It is our understanding that decision makers keep this approach under review, so for example if a case is reviewed and the award unaltered (with all the associated costs that this involves for the Social Security Agency and the stress for the client), an assessment would be made as to what learning might be applicable in terms of future reviews for that claimant; and all claimants who might have a similar disability or health problem.

Advice NI's view would be to delegate such matters to frontline decision makers, not set centralised, top-down, ill-informed policies that have to be slavishly followed at the frontline.

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?

This section of the consultation is worrying given that (i) it is related to penalties and fraud in relation to failure to disclose; and (ii) the consultation document already acknowledges that some people's condition gradually changes over time and that these changes can occur so gradually that the individual themselves may not notice.

Advice NI believes that an approach like the Periodic Enquiry Process is sufficient to protect the public purse and that it is unnecessary and indeed ill-judged to introduce the issue of fraud which will only serve to scare or at best unsettle potential claimants.

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?

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?

In Advice NI's experience people seek independent advice and support with the application process for Disability Living Allowance. We understand that the Social Security Agency in

Northern Ireland attempted to provide a support service for people seeking to claim Disability Living Allowance but the uptake of this service was under-whelming.

If the Government are serious about ensuring that people have access to advice and information, they will ensure that a service is available which is free, independent, confidential, effective and accessible.

The consultation document has already stated the importance of face-to-face engagement with respect to the Personal Independence Payment medical assessment and Advice NI would similarly urge that face-to-face provision be built in to any advice and information service that is being contemplated.

Lessons learned following the introduction of Employment & Support Allowance include the knock-on impact on appeal workloads. In the last year the tribunal representation workload of Advice NI members has increased dramatically by 43% to 1,329 hearings as more people have struggled to access their benefit entitlement. The information provided by The Appeals Service highlights the impact that representation has on outcomes – Advice NI representation generates a 38% success rate as opposed to an unrepresented success rate of 18%. Advice NI would urge that appeal tribunal representation be factored into any advice and information service that is being contemplated.

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?

The consultation paper states that the Personal Independence Payment will remain an extra-costs benefit, providing cash support and allowing disabled people to spend the benefit in the way which best meets their individual needs. There is at least some ambiguity and a lack of clarity as to how this statement squares with the consultation question.

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

Children are currently able to access Disability Living Allowance, and there are clear criteria that need to be satisfied, for example the child must require attention or supervision 'substantially in excess of the normal requirements' of a child the same age. If the thrust of

this question is around how the cuts agenda can be applied to children, Advice NI is unable to assist.

We would re-iterate that the current criteria used to assess children for Disability Living Allowance (and the caselaw which has grown up around the current criteria) provide clear guidance as to the areas where children need support to live full and active lives. To cut support in any of these areas will serve to disadvantage children with disabilities.

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?

Advice NI believes that Disability Living Allowance provides an important passporting function to additional support and assistance. Advice NI would advocate that, as the Personal Independence Payment is actually going to be focussed on those with greatest need, presumably with the severest disabilities and health problems, that the passporting function actually be enhanced. Presumably with the 20% savings to be achieved with the move to Personal Independence Payments, there will be less people accessing the passporting facility so again it follows that there will be scope to enhance the support available.

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?

Advice NI is very concerned about the threat to withdraw additional premiums that are currently paid within means-tested benefits, where Disability Living Allowance is in payment. Advice NI would seek further clarification as to why the Government feels it is necessary to take this punitive approach, effectively penalising people who will have actually 'passed' the new, objective (arguably harsher medical test) in respect of the Personal Independence Payment. Advice NI believes that this effectively would amount to a 'double whammy' of direct financial cuts: (i) withdrawal of help which would have been available under Disability Living Allowance; (ii) withdrawal of additional premiums payable within means tested benefits in recognition of the existence of disability or illness.

Advice NI would urge Government to clarify this position as a matter of urgency.

Similarly withdrawal of other types of passported assistance would amount to a cut in help available to enable people with disabilities and health problems live full and active lives.

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?

Whilst it would appear attractive to combine and streamline assessments for disability benefits and services, Advice NI believes that care should be taken to ensure that people with disabilities are not disadvantaged by such changes. For example different benefits and services will have different qualifying conditions. The concern would be, in a climate of cuts, that streamlining would lead to uniform criteria being set for a range of benefits and services which would serve to reduce access and produce savings for the Exchequer.

The consultation document provides little detail about how streamlining might work in practice; Advice NI would wish to see the further detail in order that the above concerns could be allayed or confirmed.

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?

Given that no information has been provided in relation to the qualifying conditions of the two rates per each component, it is not possible to have a clear view on who may be negatively impacted by the introduction of the new Personal Independence Payment regime.

'It is likely that some disabled people with lesser barriers to leading independent lives will receive reduced support' is a worrying statement. Advice NI would like to see the information behind this statement which makes it *'likely'* that some people will be negatively impacted: only then can an assessment be made as to the likely impact on different equality groups.

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

Advice NI is very concerned about how people with work limiting health conditions are currently treated and will be treated under the new Personal Independence Payment.

Undoubtedly more people are failing the Work Capability Assessment (which is the medical test for Employment and Support Allowance). Undoubtedly more people with moderate to severe work limiting health conditions are finding themselves claiming JSA and so may well be subjected to an inappropriate level of conditionality within the Universal Credit regime. We believe that this trend will continue with the introduction of the Personal Independence Payment. We believe that there needs to be a fundamental review of the needs of people with work limiting health conditions and how they can be properly supported within the benefits system.

Advice NI notes the focus on work in the consultation document. However we would point out that a fundamental factor in the equation of 'welfare to work' is the availability of employment opportunities. In terms of timing, Advice NI notes a recent forecast which estimates that at least one in 10 people will be unemployed in half of UK regions by 2015, according to the Centre for Economics and Business Research (CEBR). Even the most optimistic of forecasts question the strength of the economic recovery over the short to medium term. This would tend to cast doubt on the ability of any reformed system to support people to make the move into employment, if there are no employment opportunities available. Specifically in relation to Northern Ireland there is a growing problem of unemployment, for example over the year (2010), the Northern Ireland claimant count increased by 8.9% (4,800), compared to a decrease of 10% in the UK as a whole.

Advice NI would further draw attention to the unique circumstances of Northern Ireland which need to be factored into the Personal Independence Payment equation; the undoubted potential for Northern Ireland to be negatively impacted to a significantly greater degree than any other UK region due to the higher numbers receiving Disability Living Allowance; and the fact that society in Northern Ireland is emerging from a period of conflict and many people are still suffering as a result (for example post traumatic stress, trauma to limbs, addiction rates, mental health issues).

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