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national association of
welfare rights advisers

Consultation Response

Disability Living Allowance reform

February 2011

National Association of Welfare Rights Advisers

The National Association of Welfare Rights Advisers was established in 1992 and represents advisers from local authorities, the voluntary sector, trade unions, solicitors and other organisations who provide legal advice on social security and tax credits.

We strive to challenge, influence and improve welfare rights policy and legislation, as well as identifying and sharing good practice amongst our members.

NAWRA holds a number of conferences throughout the year across the UK, attended by members from all sectors of the industry. An integral part of these events are workshops that help to develop and lead good practice.

Our members have much experience in providing both front line legal advice on benefits and in providing training and information as well as policy support and development. As such NAWRA is able to bring much knowledge and insight to this consultation exercise.

The response has been put together from evidence collated through an email consultation with members. It is a representation of views from frontline advisers and their clients from across the UK.

Response

General Comments

For most NAWRA member organisations, disability benefits work is a significant element of their practice, including helping disabled children and adults with DLA claims, and providing representation with appeals to First Tier and Upper Tribunals.

The then Conservative Government deserves praise for introducing Disability Living Allowance in 1992 to replace the previous paternalistic and medicalised Attendance Allowance and Mobility Allowance schemes. DLA made and continues to make such a difference because:

- brought in a more social model of disability and a voice for people living with a disability in the decision making process. It would be deeply regrettable if its successor were effectively to return to a primacy of snap shot medicalised views of disability.
- DLA has made a profound difference to the lives of recipients, extending the scope of the previous allowances and making a real difference to their lives, choices and potential for social inclusion s. It is not just the additional money, but the choices and opportunities that it opens up, for the individual their families and the services they access. As clients often put it: “It makes the difference between living and merely existing”.
- DLA promotes independence from traditional social care support and is an important part of the mix in funding innovative supported living schemes.

There is of course much that could be done to improve the workings of DLA, but there are also real risks. It is then vital that there is a strong case for any change and improvement, given the huge potential for harm and disruption to the lives of vulnerable people and their support arrangements.

Any merit in the Government’s proposals may be undermined by the limited thought to date and the primary objective of achieving a 20% cut - some £2.4 billion – at the expense of people with long term illnesses or health problems, with the threat of a double cut for the poorest.

The current consultation document gives very little detail about the proposed changes, yet proposes a massive change; not the reform of DLA but its abolition. It is stated that the legal framework for PIP will only be given when a Bill is introduced, and detailed draft regulations for the secondary legislation will only be published ”where possible”, thus giving no guarantee for adequate future consultations. NAWRA is deeply concerned that proper consultation once the Government has worked out the details of the scheme will not be undertaken.

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

One of the main reasons given in the consultation document for replacing DLA with PIP is the view that society has changed greatly since the introduction of DLA in 1992, particularly because of equalities legislation. Legislative changes may have imposed some new duties on access and discrimination on e.g. employers and providers of service, but does not alter the fact that many disabled people remain excluded from such opportunities. Levels of financial poverty, and unemployment, remain far higher for disabled than for non-disabled people (see under Question 3).

People with disabilities still face considerable additional barriers to participation whether in the economy, community or decisions affecting their lives. Some with additional support networks and inner resourcefulness, may, with the help of adaptations, legislation and opportunities not curtailed by prejudice, be able to fully participate in economy and society. But many others - either because of the nature of their disability, or lack of support or resources, still find themselves excluded from work, social activity and even basic decisions about their life.

Economically, people with disabilities will tend to have lower incomes. The annual Households Below Average Income figures show that 29% of adults with disabilities will be in income poverty compared to 19% of working age adults and 38% of households with one disabled adult and one disabled child. DLA makes a significant difference, with the risk of poverty falling to 24% where there is one disabled adult and 26% where there is a disabled adult and a disabled child when DLA is claimed. DLA then has an important effect on the risk of poverty and child poverty in particular. These figures show reduced incomes and do not allow for the additional costs of living with a disability, which, if factored in, would significantly increase the poverty risks.

DLA certainly helps with these costs even if it does not fully cover them, but together with means tested top ups makes a real and significant difference to people’s ability to participate in society and to promote independent living.

Paid employment is an important way to participate in society, but not the only way, and the focus on welfare to work and individualised assessments has led both to despair for claimants not work ready and JobCentre staff faced with the yawning gap between ‘limited capability for work’ and employability identified by the technical working group working on the revised WCA.

Welfare reform agendas and poor assessment criteria can have the unfortunate effect of further labelling and excluding people. There may be lessons to be learned in the objectivity of assessments and the longer term costs of short term savings in excluding people from support that they need.

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

Social model of disability: It will be important to retain principles of self assessment and a social model of disability, especially in the face of a determination in these proposals to extend the role of medical assessments, which have always proved problematic in determining benefit entitlement. Snap-shot opinions from a medicalised viewpoint not always informed by full knowledge of the disability or even medical history often lie at the heart of poor DLA decision making.

Case law principles: Principles of reasonableness established in case law over the year have clarified and improved the benefit and its ability to be an effective mechanism for promoting independence and social inclusion. A new benefit means the clock is reset, but it would be a serious loss to people with a disability if the intention were to push back progress, reasonableness and fairness.

Help with mobility in residential care: This is already evident from the government's decision to stop, from October 2012, payments of DLA Mobility Component to adults in residential care after 28 days (unless they are fully self-funding).

The Disability Benefits Consortium (DBC), which is a group of 27 organisations representing disabled people, has heavily criticised this change in regulations. It has, for example, said that this will have a "huge and regressive impact" on the independence of thousands of disabled people, including people with profound and multiple learning difficulties.

Also, in its recent report, published in January 2011, "Don't Limit Mobility", the DBC details research which counteracts the government's argument that mobility needs are already being met by local authorities providing the residential care. Such budgets have focused on provision of care in the home, and are unlikely to be able to fill the gap by this cut. It is based on an out of date and condescending Government view which appears to assume that people living in residential care will no longer be involved in the community, when in fact many will participate fully in society and even go to work, facing all the additional costs of Mobility this may involve.

The DLA Budget: The document suggests that DLA spending is "out of control and is being paid to people for whom it was not intended. However, the DWP's own research suggests that DLA is significantly underclaimed while DLA came in at the beginning of a period of massive expansion in community care and significant improvement in social attitudes around integration and aspirations for people living with disability. This may explain why initial expectations of likely claimant numbers were so out of line with actual outcomes and at odds with the DWP's own research into underclaiming.

Proposals to tackle real problems and issues with this key benefit can rightly be viewed with suspicion if their primary purpose is to cut 2.4 billion a year from people with disabilities or a long term illness. We would ask the Government to retain the budget if there is an honest intention to reform and improve the benefit. The proposed spending cuts have also attracted criticism in the recent Joseph Rowntree Foundation report, published by the Institute of Fiscal Studies in December 2010.

The report concludes that the government's "Tax and Benefit Reforms" will increase both child and working age poverty, and calculates that there will be an increase in "relative poverty" of 800,000 and 900,000 in "Absolute Poverty" when comparing figures from 2010-2011 with the figures for 2013-2014.

Additional benefits: NAWRA is very concerned by throwaway comments that in developing the new Universal Credit, consideration will be given to what - if any - additional support will be included for PIP claimants. DLA is very useful in being non-means tested and payable on top of other benefits or earnings, but does not begin to fully cover the full additional costs of disability. Additional amounts within means tested benefits help bridge this gap for those on the lowest incomes and in particular help with the additional household costs not intended to be covered by DLA.

Qualifying period: The proposal to increase the Qualifying Period for benefit from three to six months is, in our view, another unjust cut. The sudden onset/ deterioration in people's illness/ impairment, for example, often causes them severe problems in many areas of their lives, and we think they should start to receive financial help as soon as possible.

The current "forward test" provision - that there is an expectation that difficulties are likely to last 6 months – more than deals with the intention of targeting the benefit on long term illnesses and disabilities. Indeed there is a strong case for dropping the 3 month qualifying period altogether.

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

This will vary considerably with the nature of the disability. Research suggests that they can be grouped into additional costs relating to mobility and getting around, personal care and support at home, additional household costs (such as adaptions, clothing, food, heating, extra wear and tear) and additional support to participate fully in the economy and society.

Of course these vary hugely with both the nature of the disability and the extent to which society deems it appropriate to allow people with disabilities to fulfil their potential. The mistaken and wrongful assumption that a person needing to live in a care home does not and need not go out lies behind Government proposals to remove entitlement to Mobility Component or to refuse help for those aged over 65.

In 1998, the Joseph Rowntree Foundation found that it cost three times as much to bring up a child with a severe disability than one without a disability, at a then cost of £7,335 a year.

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?

The gains of simplification from reducing care from 3 to 2 rates seems somewhat overstated: It is unlikely that the potential for 11 different rate combinations lies at the heart of inconsistency or problematic decision making. These have been looked at extensively in DWP reports.

No detail is given as to the criteria for these new rates, and the devil will indeed lie therein.

The move to put mobility on a continuum of needs around ability to mobilise seems a potential improvement. However, if implemented fairly this may point to an additional cost, as people with significant difficulties mobilising through mental health or sensory impairment will justifiably access the higher rate. It is assumed that the Government anticipates savings from those who while physically restricted in walking, can enjoy a greater level of ability to mobilise.

However that is often only possible because of the current help to meet the significant additional costs of mobility, so it is unlikely that savings can be fairly generated.

The consultation document suggests as an example that a disabled person's ability to get about in a wheelchair should be considered, instead of ignoring the wheelchair. *(Chapter 2, Paragraph 27).*

We believe that this shows a high degree of naivety regarding the reality of disabled people's daily lives, and a lack of understanding of the social model of disability.

Even if a disabled person is independently mobile using a wheelchair, for example, he/she will still be denied access to many buildings/parts of buildings due to physical barriers (despite current equalities legislation), which will have a financially adverse knock-on effect on many aspects of his/her daily life. Disabled people may have to use certain more expensive cafes or shops, for instance, simply because they are more accessible than cheaper ones.

On the care side In paragraph 14 of Chapter 1, it is seen as a negative that today 880,000 people receive DLA lowest rate Care Component, instead of the estimated 140,000 people when DLA was introduced in 1992. It seems clear that the intention is to remove the current Lower Rate of Care. These smaller awards of under £20 a week can make a significant impact on the quality of life for people experiencing real extra costs and barriers, so its potential removal is a serious concern. NAWRA completely disagree with this cut, which would cause increased financial hardship for many thousands of disabled people, and may lead to greater cost to the public purse in the future.

Of particular concern is the fact that one of the criteria for DLA lowest rate Care Component is the inability to cook main meals, due to illness/impairment. Should we therefore draw the conclusion that being able to eat cooked food is not an essential part of life?

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?

The proposals envisage a reduction in automatic entitlements to just one for people falling under the Special Rules, on the basis that all people are individuals. NAWRA however sees that there is scope to free up resources by increasing rather than reducing the number of automatic entitlements.

We do not agree with the proposal to remove automatic benefit qualification for everyone except people who are terminally ill.

The experience of NAWRA members with similar approaches in the move from Incapacity Benefit to ESA is that this can mean people being unnecessarily hauled in to sometimes problematic and rushed assessments in defiance of common sense and at additional cost to the DWP. Thus in the name of individualised assessments, people with severe mental health problems, in a persistent vegetative state, already assessed by the department as needing extensive day and night care or with profound learning disabilities can now all be required to attend a medical to see if they will score the points to stay on ESA. It may well be right to offer individual support so that no-one is written off, but it defies common sense to consider that they will not have limited capability for work. Sadly this has not prevented ATOS Origin assessors reaching this conclusion in all too many cases.

It would be regrettable if this confusion in thinking by the last Government was continued by the current administration. The list of exemptions for DLA is fairly limited. It is likely that someone with no legs is likely to have problems with mobility however redefined.

The DWP has a huge amount of data in relation to awards and diagnoses. Some conditions will vary considerably in the impacts they have, but others may very clearly show a common trend in awards, especially when moderated at appeal. In fact there may well be a case for *extending* automatic entitlements in many cases.

We think that the current automatic entitlements for specific groups of disabled people under DLA should remain, as those groups of disabled people clearly have substantial and long-term mobility and/or care needs. In addition, we believe that there is a strong case that several other groups of disabled people should be automatically entitled to benefit, including:

- People with severe learning difficulties;
- People with severe mental health problems;
- People with severe sight or hearing impairments.

We also think that some groups of disabled people should automatically qualify for a short-term award of benefit, including people with cancer undergoing intravenous chemotherapy treatment.

DLA is meant to be a long term benefit - hence the 3 months back and 6 months forward test. However this can be problematic in situations of real need where they may be significant, variable and changing needs within the qualifying period. For example, those receiving chemotherapy or who have experienced a stroke. There may be a real prospect of significant improvement. Currently it depends on common sense being applied and a short term award being made, where a rigid application of the law may lead to refusal of benefit. There may be a case for automatic entitlements in these situations (as for example can apply under ESA), until such time as it is realistic to apply an ordinary assessment.

The Special Rules definition of reasonable likelihood of death within 6 months is problematic in the light of improvements in palliative care prolonging life even in the face of extreme illness . Evidence also shows that recipients of disability benefits under the Special Rules receive them for an average of *just 12 weeks* before death; clearly the current arrangements are not enabling people to access benefit early enough. We believe there is a strong case to extend the 'likelihood' period to 12 months.

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?

Prioritisation is reflected in the current system by eligibility for higher rates. There can though be problems with the current emphasis on day and night care, beyond a certain threshold. There may be such significant and complex care needs that a higher rate might otherwise be justified, but may not be payable

The House of Lords quite rightly warned against an undue concern with the latter part of this question in the Fairy/Halliday case, suggesting it was wrong to confine help merely to those activities that are essential to maintain basic bodily functions.

Instead they suggested the more ambitious and inclusive yardstick of considering help that as far as possible enables the claimant to lead a normal life. By asking how to prioritise support to those people least able to live full and active lives, we think the clear intention is to cut benefit for all but the most severely disabled people.

We are very concerned that the consultation document does not give any detail at all on this matter, yet it seems clear that there is an underlying intention to change the criteria for the Mobility and Daily Living components radically in order to meet the government's wish for significant expenditure cuts.

We completely disagree with the proposal to devise a list of the most essential activities for everyday life. It seems that such a proposal would mirror current benefit rules, such as the scoring activities used for Employment and Support Allowance assessments, which have rightly been criticised as being narrow, very medicalised, unfair, and not fit for purpose in identifying those with limited employability.

Currently, we welcome the fact that the criteria for DLA mobility and care components in many ways offer a broad framework for assessing mobility problems and care needs, which can be looked at in accordance with an individual disabled person's needs and circumstances arising from their illness/ impairment.

The consultation document states that*: "The benefit (PIP) will continue to take account of the social model of disability"*, and will *"make sure they (disabled people) are treated as individuals".* (Chapter 2, paragraph 3).

In contrast to these statements, restricting criteria to a list of only the most essential activities for daily life would inevitably lead to assessments being based on the "Medical Model" of disability, and would not be designed to assess disabled people as individuals.

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

The current system has particular problems with such conditions and most especially when a Decision Maker relies on the snapshot one off medical assessment. While the assessment criteria are not yet determined it seems highly likely that the problem will increase significantly if all claims are subject to such assessments. In these cases the evidence of the claimant (if consistent with the disabling conditions), carers, support workers and medical practitioners involved in the patient's care can give a much better basis for a decision than the results of a one-off assessment.

We do find that many of our disabled clients have impairments/illnesses which fluctuate, including people with mental health problems and chronic physical illnesses such as ME, arthritis and fibromyalgia, to name but a few.

These clients still face many problems in coping with everyday life and employment, and we don't think that current DLA regulations and assessments give them enough help or recognition.

This is because in an over-simplistic DLA medical assessment, a medicalised view is taken on simply whether a personal care task can or cannot be performed without help. EMP report forms and less experienced Decision Makers get this wrong. The current case law also allows for situations where tiredness, pain, difficulty, lack of motivation or ability to concentrate means the task cannot be performed, within the range of living a normal life. It can take the more experienced Decision Makers or a Tribunals to get these decisions right.

We do think that time needs to be taken to ensure more adequate account is taken of variable and fluctuating conditions, but this can all be done within the current DLA framework. The experience of the shift to assessment interviews/examinations under ESA is that there is an even stronger emphasis on "snap shot" reports and the problem significantly worsens rather than improves. It does though establish a mechanism for achieving significant cuts.

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?

The current position seems reasonable in this regard: that account should be taken of adaptations and aids that are fitted or that could be readily afforded by those on a minimal income. There may be a whole range of adaptations and technical support which if fitted and if the person with disabilities is supported in their effective use, could make a real difference.

However at a time when the main funders (NHS, social services, charities etc) of both the adaptations and support to use them are under increasing financial pressure, waiting lists are likely to become longer and more expensive options or full support even less forthcoming.

There can also be a lack of awareness and a patronising assumption amongst observers of people with disabilities that if only they would use their aids or medication as directed and show the proper amount of pluck and fortitude then all would be well. There may be a real lack of awareness of difficulties in their use.

If potential for adaptations is to be a bigger feature who will decide what will meet the disabled persons needs and the appropriateness of any such adaptations? Similarly who will decide if support within a household is adequate to meet the claimants needs.

Based on what disabled people tell us in the course of our Welfare Rights work, we believe that it is important to maintain the current DLA assessment structure and regulations. It is very important to continue to assess disabled people as individuals, based on the difficulties they face, rather than wrongly assuming that certain adaptations and equipment are in place and/ or can be used without help.

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?

DLA forms are by no means without problems – they can be too long and can inadvertently lead people into understating their difficulties or assuming that having expressed the difficulties in one area, there may be no need to repeat it. The consultation document describes disabled people being concerned that: *"The claim form for DLA is too long and complex, and can require them to talk about their disability in a negative way, focusing on what they cannot do rather than what they can do."* (Chapter 2, paragraph 29).

In our experience, although we recognise that the DLA criteria are to some extent based on what disabled people can't do, being paid this benefit does play an essential role in enabling our clients to maximise their independence and participation in society, including in many cases enhancing their ability to do paid work.

There is already a tendency for people to understate difficulties relevant to the benefit, so care has to be taken in any more positive rewording. The issue of the complex claim form could be rectified by providing more help and information for disabled people.

Removal of unnecessary questions (or the use of follow up forms for specific information) could reduce the size of the claim form considerably. There can be a tendency for claimants to focus on actual help received or the physical aspects of care tasks, and so to feel that the benefit does not apply to them because somehow they manage (despite pain, difficulty and fatigue) or because their problems are more about motivation, reminding and guidance through tasks.

A return to the days when claim forms came in two sections – the first covering just 'name rank and serial number' type information and the second dealing with information relating to health or disability associated difficulties – could, with specific 'Section 2's for various illnesses/ disabilities enable shorter claim forms with condition-specific prompts and tick boxes.

Whilst recognising the impracticality of producing forms specific to *every* condition, claimants could for example be offered the 'asthma and breathing problems' form / 'mental health' form/ 'deafness and hearing impairment' form/ 'arthritis and rheumatism' form/ 'cancer' form...

Some other forms currently used by the DWP to collect further information for DLA can be narrow if not potentially misleading - e.g. factual statements with limited questions around help needed or report forms for Examining Medical Practitioners conducting medicals which remain rooted in the medicalised view of pre-1992 Attendance Allowance, to the point where they no longer reflect the case law relating to benefit.

Ultimately though there is no getting away from the fact that a proper individualised assessment is complex and it is important to offer the opportunity for self assessment for clients backed up by the availability of support and advice.

Any such provision would, however, require an increase in funding – indeed the government's aspirations for "The Big Society" are being undermined by their own budgetary policy. DLA is an enabling benefit, promoting independence and choice: cuts to both the benefit and to the support and advice resources which help people deal with the complexities of claiming and the problems of poor decision making will reduce its reach and impact.

The advice sector can be a powerful advocate and support for the individual, across a range of issues, bringing together paid staff and volunteers to empower people. The plan to abolish all civil legal aid for welfare rights advice, and cuts to budgets for the main funders of local advice services means that there will be a significant reduction in “Big Society” support from the advice sector or support from within the DWP, as ancillary information roles are cut back.

Greater awareness of the conditions for benefit (be it DLA or PIP) among professionals can help encourage people to make claims or help people understand that a diagnosis in itself does not mean an award.

Other positive methods which could be used to improve the claiming process for benefit, and for providing better information to disabled people about the criteria include:

- Publicity, for example radio and television adverts;
- Take-up campaigns, in conjunction with both the Department for Work and Pensions, and welfare rights agencies;
- The provision of adequate levels of advice, advocacy and help with the claims process.

Again the availability of independent advice is crucial in a partnership to spread information about an empowering benefit. However many NAWRA members, from both the voluntary and statutory sectors have already experience cutbacks in their funding.

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

The current DLA procedures already provide a range of possibilities to help the DWP’s decision makers compile supporting evidence for their assessments.

These include the information on the claim-form, and information from healthcare and other professionals. Indeed the introduction of self assessment was a welcome feature of the new system in 1992, giving disabled people the opportunity to describe in detail their illnesses/impairments and how these affect their ability to get around and care for themselves. We believe that this self-assessment should continue to be an integral part of assessing claims.

In paragraph 29, Chapter 2 of the consultation document, it is stated that: "disabled people are experts in their own lives and information they provide will continue to be vital".

This would seem to concur with our positive view of self-assessment, but the consultation then goes on to describe how face-to-face interviews with a healthcare professional will be an important part of PIP. Our concern is that from our experience of the undue weight on EMP reports in DLA cases and the tests for incapacity/limited capability, that these will become the only factor in decision making. For the reasons given in our response to question 11 below, we think this would be a backwards move.

There can be an over reliance by hard pressed decision makers on the medical snapshots commissioned by the Department or factual statements from GPs. Often the failure to assess all the evidence effectively lies at the root of poor decisions, which sometimes only seem to be properly made at the appeal stage.

There is a need for common sense and discretion in determining the need for and sources of, further evidence. Sometimes the GP knows matters in detail, but in many cases the best person may be a key worker in a specialist team or a support worker, a carer, formal or informal enablers , of course the claimant themselves, especially when their account seems reliable and consistent with what is known about the medical condition.

Care should also be taken with reports produced for other purposes: ESA medicals are applying a very different test, care assessments are looking at needs which should be accepted as statutorily bound to be met, school reports may focus positive success for the child, and may omit day to day issues or the additional support and structures in place.

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?

As stated above, NAWRA members have frequently found that it is such healthcare assessments that lie at the heart of problems in DLA decision making.

It is though a welcome feature of DLA that decision makers do have discretion to seek the most appropriate further evidence or none where it seems quite clear from available information, the problem is not that too few medicals are conducted but that too many are sought inappropriately.

It is wishful thinking to assume that simply by choosing a selection of sometimes arbitrary descriptors and attaching numbers to them, somehow assessments become more objective and consistent.

NAWRA members and tribunals have certainly not found this to be the case with incapacity benefit or ESA, with clear evidence of inconsistency and subjectivity being applied in a rushed assessment. At other times assessors or decision makers can be frustrated when real accepted difficulties do not appear on the current list of descriptors. There is a lot to be said for the model of well trained and experienced Adjudication Officers weighing up all the evidence in detailed decisions.

In June 2010, the government commissioned an independent review of the points-based Work Capability Assessment for ESA. In the research's findings, Professor Harrington describes how there are clear and consistent criticisms of the whole system and much negativity surrounding the process. His findings included:

- There is strong evidence that the system can be impersonal and mechanistic;
- The process lacks transparency;
- Lack of communication between the various parties involved contributes to poor decision-making and a high rate of appeals;
- Jobcentre plus decision-makers do not in practice make decisions, but instead "rubber stamp" advice provided through the ATOS assessment.

The government has stated that it fully accepts Professor Harrington's series of recommendations regarding the Work Capability Assessment, and it is hard to understand why the government would then want to introduce the same system of independent medical assessments for DLA claimants, when the experience of ESA has clearly shown that these assessments are seriously flawed.

The idea of a descriptor-based approach has been piloted before in a DWP project to look at improved consistency in decision making, rather than being cuts driven. The conclusion was that the Activities of Managing Life descriptors did not broadly affect decisions, would be costly and disruptive to implement and narrowed room for common sense and discretion in cases which did not fit within the AML list. It was felt that improving training, better feedback from reviews and appeals and a tiered approach to decision making would improve consistency.

The case for a descriptor-based alternative to DLA assessment then has already been explored and rejected by the Department. The experience of incapacity and ESA do not give any confidence in claims for their potential for a more individualised assessment or increased objectivity, but do reveal their potential for masking significant cuts and disallowance of benefit.

The creation of an expensive and unnecessary individualised assessment structure, replacing the more flexible criteria and cost effective structure of DLA does not seem to make sense in any policy or practical terms and has been rejected by the Department. It's only virtue is its ability to deliver significant levels of benefit disallowance and cuts, targeted at the poorest and most vulnerable in our society.

- 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?

Particular problems are faced with the many conditions where it is not really possible to get a full assessment from external examination. This may be where other test results are needed or where diagnosis is based on an in-depth assessment of symptoms, as in mental health.

It is not clear what is meant by complex barriers which may exempt people from a medical assessment. It would seem better as now for medicals to be sought only where it is needed than assume they will occur in all bar a few cases.

Fluctuating and variable conditions of all types are problematic, along with rarer conditions or childhood illnesses and disabilities:

- People with learning difficulties;
- People with mental health problems;
- People with autistic spectrum disorders;
- People who have cancer;
- People who are profoundly deaf.

However, NAWRA has significant concerns over the ability for necessarily arbitrary descriptor bases to deliver effective individualised assessments in all but the most straightforward, clear-cut cases. There is scope for improvement in the current system, but these proposals point in the opposite direction.

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?

The document is highly disingenuous in suggesting that there is no review procedure at the moment. Most awards are time limited and even indefinite awards are subject to periodic reviews.

As now, discretion should be applied based on the reasonable time before improvement (or deterioration) might be expected. It may be that the longer term picture only becomes clear after a year or so (e.g. after a stroke or a cancer diagnosis.) Sometimes it is clear that this is a lifelong disability and care needs will remain the same. Where awards are made for too short a time then it can create unnecessary anxiety, financial insecurity for both recipient and carer and undermine the potential of the benefit to be an effective support for long term care, social inclusion or progress into work.

We would suggest it be mandatory to gather such information *before* deciding whether there is any real need for either an initial or review assessment by a healthcare professional

It may be helpful to review existing information from the previous award, rather than starting from scratch. It should for example be possible to have much shorter or condition-specific review forms. It would also be helpful for people to be able to sign a declaration simply stating that their pattern of difficulties and needs has not changed as was possible in the past.

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?

It is not clear in what way the Personal Independence Payment would be any intrinsically easier to understand than DLA. There is plenty of scope for improving the clarity of both award and rejection letters within the current system, so that claimants are clearer on why they have been awarded or turned down for benefit.

In paragraph 31 of Chapter 2 it is stated that*: "Within DLA, there is no systematic process for checking the ongoing accuracy of awards".* This assertion ignores the fact that usually, DLA is awarded for fixed periods. At the end of the award, claims are reviewed as a renewal.

While some awards are made indefinitely, these are subject to a periodic review system.

We therefore can see no need to change the current system. We also feel it is important to continue with a system of indefinite awards of benefit for those disabled people who clearly have a severe and life-long impairment/illness. Increasing the amount of reviews would be costly, and so would make it even more likely that the main "disability" criteria regarding mobility and daily living would have to be further tightened in order to meet the Government's stated targets for cutting expenditure.

In our experience, DLA renewal applications, as with any other review of their benefits, are very stressful for our disabled clients, bringing unnecessary uncertainty, especially when it is clear that they have a lifelong health or disability issue. The fear is increased when the review is carried out in a culture driven by cuts and a presumption of suspicion rather than sympathy.

If their impairment/illness worsen, they already have the opportunity under the current rules to request a DLA supersession.

This can then help them better understand when a change may be relevant, whether pointing to decreasing or increasing needs, remembering that research has shown that the overwhelming majority of claimants tend to understate rather than overstate difficulties.

Better information can help clarify understanding and responsibilities as well as broaden understanding of the benefit. For example that it may entitle the claimant to additional means tested benefits and the need to contact the relevant sections; too many claimants miss out. Or to make claimants more aware of how DLA can support a move into work, remaining payable in employment.

The issue is not just then one of claimants living up to responsibilities to report changes, but of Government tackling underclaiming. A broad view needs to be taken taking into account that for every claimant who may benefit from a reduction in care needs earlier than their anticipated review date, there may well be others who are missing out following deterioration.

At an individual level, there is a need to consider that some disabilities may affect ability to fully understand and discharge responsibilities, or that changes may be gradual and imperceptible. Government also needs to address the concern that responsibilities sometimes appear to be required in inverse proportion to the means and status of the individual.

NAWRA members are of course strongly opposed to deliberate fraud by any claimants, but in all the media excitement around such cases, it can be forgotten that significantly greater sums are not claimed by people in desperate need. Overblown fraud messages can actively deter people from claiming rightful entitlements whether of DLA or the proposed PIP.

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?

Independent advice is crucial, to help people access their entitlement to DLA and related benefits and there is likely to be a similar need under PIP. Better information from the Department can always help, but there may not be the time, resources or remit for the Department to provide this. Its core business remains the processing of benefits claims and getting much beyond improved information and signposting can get into areas of conflict of interest.

NAWRA is deeply concerned at the scale of potential cuts to the availability of advice just at a time of significant changes affecting some of the most vulnerable in society. Massive migration processes from Incapacity Benefit to ESA to be followed by one of a move from DLA to PIP will significantly increase demand.

The potential withdrawal of the Legal Services Commission from social welfare law and the significant pressure on local authority funding, mean that funding of advice provision is under considerable threat., However such services are valued as an extremely cost effective means of social inclusion and participation, there are only limited statutory duties around its provision, and advice services may well fall into the “nice to have but not essential” category when very difficult spending decisions are made.

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?

NAWRA is totally opposed to any form of requirement on people to seek advice, but would welcome signposting towards available advice and sufficient funding to ensure advice services were available. Advice services depend on trust built on being free, confidential and independent of the providers of services and the decision makers on benefits.

While the overwhelming majority of clients need support to tackle underclaiming or unfair decision making, there will be instances where we have to tell clients they may not have a case or that they are in an overpayment situation and corrective action they need to take. Any compulsion would undermine the trust essential to advice.

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?

Disabled people may have other income and savings, but would otherwise rely on grants such as Social Fund Community Care Grants or Disabled Facilities Grants. Other sources include the NHS, grants from central government, charities, voluntary organisations, as well as DLA payments themselves. The one thing they all have in common is that they face increasing financial pressures which will mean that grants will become harder to get and waiting lists lengthen.

DLA is intended to help meet additional day to day care and mobility costs, so there is a danger of a further hidden cut to resources for disabled people if PIP were used to substitute for other cuts in other resources.

On the other hand DLA and PIP recipients may well value additional choice and opportunities to convert some of their weekly income to meet the capital cost of ***additional*** items to supplement not replace those that should be provided by other sources. For example, extending the reach of schemes such as Motability. Alternatively support for Credit Unions and social enterprises may extend the choices and opportunities that DLA brings. Market solutions for many claimants on low incomes can be highly uncompetitive.

However NAWRA is concerned that the availability of such measures should not be accompanied by a requirement to self fund the capital cost of one-off costs of aids or adaptations, because to do so may well increase financial difficulties in meeting everyday living and mobility costs. It would be particularly cynical if such a requirement was then used to subsequently deny access to benefit.

We believe that gaps in current provision – which are likely to widen - should be identified and filled in other ways. Access to work, for example, (funded by central government) could very usefully be extended to help disabled people who are not in paid employment, particularly to help them to overcome barriers to work.

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

We are strongly opposed to any expenditure cuts in disability benefits for children, the most notable of which is DLA. Many of NAWRA's member organisations do a great deal of work helping disabled children to claim DLA. We have found that DLA is a vital source of income for families, to enable them to care for their disabled children. Often one or both parents are unable to take up paid employment because of being full-time carers, and they frequently have to care during the night as well as during the day, which in turn can lead to associated health problems for parents, including frequent cases of reactive depression.

We feel that any cuts to DLA for children would go against the government's own Child Poverty strategy. On 22/12/2010, the government launched a consultation, entitled "Tackling Child Poverty and Improving Life Chances: Consulting on a New Approach".

As part of this new strategy, the government states that tackling child poverty should include financial support to the most vulnerable families, and also agrees that the importance of family income levels is "indisputable".

The consultation document (Chapter two, paragraph forty), suggests that benefit may be cut for children if their support needs are being met from public funds by another institution, such as a school. We think that any such suggestions are both unfair and illogical: Even if a child is being given extra paid support at school, for example, this does not lessen the extra costs which have to be met by parents to cater for the needs of disabled children.

Research shows that underclaiming for children's DLA is particularly high. There are a number of reasons for this:

- There is probably a need to retain an additional test of comparison with an average child of that age without that disability which adds another level of complexity
- Forms need to take account of additional issues around developmental delay
- There are a number of specific childhood conditions which do not necessarily relate to Decision Makers accumulated experience of adult conditions.
- Many will also produce disabling effects which do not fit neatly into simplified can/cannot interpretations of DLA or PIP descriptors
- School reports will tend to concentrate on positive achievements for that child, within a structured and supported environment, and may not fully reflect difficulties or how the child copes without support.
- Similarly medical reports from doctors may reflect a focus on treatment and support plans rather than a Decision Maker's need for precise diagnoses
- Parents may feel very reluctant to label their child as disabled with a claim

DLA for children is then problematic in what can be more complex cases. However, there is scope for simplification of claims processes and forms and improvements in information and awareness amongst parents and professionals. Trials of tiered approaches to Decision Making, with more complex cases handled by more experienced Decision Makers, may well make a difference. In the experience of NAWRA members, resolutions of disputes rely on the application of flexibility, discretion and common sense whether by reviewing Decision Makers or appeals tribunals.

It would be extremely challenging to capture that in any replacement points system where flexibility will necessarily be constrained by the chosen descriptors. We feel that having more face-to-face medical assessments by independent healthcare professionals would be particularly inappropriate and detrimental to disabled children and their families.

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 is vital not just because it always offers extra income to help towards additional costs of disability but because it can also enable those on the lowest incomes to access additional amounts within means tested benefits. However, too many are not aware of these additional entitlements and the steps they need to take. There is scope for the Department to improve take up by sharing information across silos and ensuring that information already held by the Department is used to adjust related benefits/ highlight potential additional entitlement – e.g. a 'what additional benefits your DLA award might entitle you to ' leaflet sent out with decision notices .

For those who only become entitled to means tested benefit for the first time as a result of their DLA claim, better information and a simpler backdating process will prevent people being systematically denied their entitlement.

The Higher rate of DLA Care is only awarded after the Department assesses a need for significant levels of care day and night. It therefore seemed perverse to withdraw passporting through the ESA assessments, simply in the name of a dogmatic pursuit of the principle of individualised assessment. It may be that the value lies in individualised support around work readiness where appropriate.

Both older people and people with disabilities may need to spend more on fuel, both because of physical needs and tending to spend more time in the home. Awards of DLA are a welcome qualifier under the various heating measures grant schemes but there is a glaring inequity in Winter Fuel Payment arrangements where age qualifies for a payment regardless of income, whereas severe disability does not, even on minimal incomes.

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?

NAWRA is extremely concerned at throwaway remarks revealing that work on the new Universal Credit will consider "what if any, additional support, should be included" for DLA claimants. The current system of premiums sought to simplify the individualised and hard to administer system of Supplementary Benefit additional requirements (additional food, laundry, wear and tear on clothing and receipt of the then Attendance Allowance).

The then Government proposed a single Disability Premium, but it took the House of Lords intervention to allow an additional Severe Disability Premium for those who would have received much higher amounts under the old system. The Government accepted the additional Premium but then sought to constrain eligibility with seemingly irrelevant and limiting criteria.

Research shows that DLA alone does not cover the additional costs of disability and these premiums are vital additional support to those on the lowest incomes. Together with the DLA award they can promote independence and make the difference between “living and merely existing”. The combined benefits are vital resources for the provision of supported living.

NAWRA would strongly oppose any reduction in associated benefit entitlements as this would put the Government in the invidious position of cutting awards for all people with disabilities, by 20% while but singling out the poorest for additional cuts.

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?

It may be tempting to assume that a single assessment could be applied, but consideration must be given to the very different purposes.

An ESA assessment is focussed on whether a person has sufficient difficulties to be categorised as having “limited capability for work”, whereas DLA takes a much wider view of disability and long term illness and may be payable to someone in full time work. It is a different threshold, and it is the experience of NAWRA members that assessors have enough difficulty dealing with complex issues within the ESA test, without having to address the different requirements of a very different benefit.

Social services departments are having enough difficulty agreeing a common assessment framework with health, let alone bringing in benefit assessment criteria. These assessments are around rationing increasingly scarce resources, with considerable pressure to consider only priority needs. Any need assessed has then to be met from a cash limited and decreasing budget. This may tend to skew assessments around the most urgent priorities rather than the full assessment needed to assess entitlement to DLA

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?

DLA has a powerful overall anti-poverty effect. As people with disabilities face a generally lower income earning potential and increased costs.

Other inequalities can interact and exacerbate those caused by disability alone. Additional barriers around gender, race, age, location, caring responsibilities, and just the presence or otherwise of effective support networks can all make a difference to the experience of long term illness and disability.

The HBAI statistics show a number of increased risk factors for poverty and in combination these can make a toxic cocktail of deprivation.

It is likely then that DLA and associated benefits matter most to claimants who experience the most deprivation and that a significant cut built into these plans, especially if combined with an additional cut for the poorest will have a disproportionate impact on equality groups

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

In the part of the consultation document referring to children, there are also brief references to carers (Chapter 2, paragraph 38), and to people aged over 65 (paragraphs 41 and 42 of Chapter 2).

Regarding carers, the document states that: "*We recognise the important role that carers play in supporting disabled people*"*.* However, NAWRA believes that the current benefits system only gives token financial recognition to carers through Carer's Allowance, much of which is clawed back in means-tested benefits. This is despite the fact that, in numerous cases, carers save local authorities hundreds of pounds each week, by caring for disabled family-members who would otherwise need to go into residential care, which is a very expensive resource.

We would urge the government to increase the financial support available for carers, as part of its current welfare reforms.

As far as disabled people aged 65 and over are concerned, NAWRA has long believed that the current DLA rules are ageist in that people have to claim DLA for the first time before reaching the age of 65. Therefore, they miss out on any entitlement to DLA lowest rate Care Component, as well as on the Mobility Component.

This is despite the fact that many people in this age-group only start to have care-needs which would meet the criteria for an award of lowest rate Care Component, and/or mobility problems, when they are already too old to apply for DLA.

We understand that the reason for this has been financial, but we do think that such blatant age discrimination is no longer acceptable, given recent equalities legislation regarding age.

Conclusion

NAWRA would like to re-iterate its total opposition to the abolition of DLA and replacing it with PIP, with the resultant very large cuts in benefit expenditure targeted at people with disabilities and long term health problems, who often experience social exclusion and poverty.

In paragraph 4 of Chapter 1, it is claimed that the proposals for DLA reform, (as well as other welfare reform plans), will tackle the root causes of poverty and social exclusion. Despite this, the whole consultation document is led by cuts, summed up in paragraph 13 of Chapter 1, when it is stated that: "*Caseload and expenditure (regarding DLA) is increasing at a rate never envisaged".*

The document is set to promote myths of an out of control benefit, which is negatively described as "subjective" and "complex" to seek to justify the abolition of DLA and its replacement with a more limited new benefit.

The proposals outline a benefit which will, at considerable additional administrative expense, replace flexibility and common sense with a rigid arbitrary descriptor / points based system. Experience has shown that this produces assessments which are neither more objective, simpler nor more consistent and the case for such a system has already been rejected in DWP pilots.

The case for change appears to us to be at best ill informed and poorly made, at worst disingenuous and dishonest. It is not based on any concern to address failings within DLA or reform it to make a benefit more suited to the needs of people with disabilities. It is then a short term ill thought out cover for savage cuts.

DLA – with all its faults – makes a huge difference to the lives and life chances of people who receive it, the poverty they experience, their ability to participate in society and to influence and shape support they need. Cuts in this area do not make sense as DLA is a classic case of an investment where the Government can "spend to save".

Reducing the incomes of disabled people can only lead to increased financial poverty, and a decrease in their independence, including ability to take up paid employment (with associated National Insurance and income tax payments).

We note with concern that these proposals will come hot on the heels of cuts in benefits for sickness and incapacity from work and that the proposals also contain a specific additional threat to the incomes of the poorest, those on means tested benefit.

NAWRA strongly urges the government not to abolish DLA and not to target these cuts at some of the poorest and most vulnerable in our society.

Whilst we are happy to engage with serious discussions on DLA reform, these proposals are not such a discussion. We have nevertheless tried to make constructive responses, while seeing very little evidence of a serious thought out case for change. It would seem that the radical step of abolishing DLA is motivated less by a thought out approach for a modernised fit for purpose benefit, and more to achieve a saving of £2.4 billion to the Treasury. .

These savings will not though be achieved without significant financial costs, as hard pressed voluntary and statutory social care budgets face additional demands as benefit ceases to be available, support arrangements break down or health situations deteriorate after the withdrawal of benefit.

This is of course as nothing to the human cost not only for those eventually disallowed, but in additional anxiety for all DLA claimants as they face both the process and uncertainty around another migration production line. We are concerned that some claimants just will not be able to take it - lives will be lost.

Whatever the economic case for public sector reductions, we simply do not understand why people facing pain, disadvantage and social exclusion should be so directly targeted.