Consultation: Disability Living Allowance Reform

Response from NAT (National AIDS Trust)

NAT welcomes the opportunity to respond to the Department for Work and Pensions (DWP) public consultation on Disability Living Allowance reform (DLA).

NAT is the UK's leading independent policy and campaigning charity on HIV. We develop policies and campaign to halt the spread of HIV and improve the quality of life of people living with HIV. Policy and advocacy related to the needs of socially disadvantaged communities in the UK forms an important element of our work, and this includes people living with HIV who rely on benefits.

NAT is also a member of the Disability Benefits Consortium (DBC), and we support the DBC's submission to this consultation.

NAT supports the principle of reforming DLA in order to make the system less confusing and better able to support people with disabilities to do everything they want to. However, we are very concerned that the reform process is being driven by a 'reduction target' of 20%, as set out in the Budget Report in June 2010. The consultation document states the Government's commitment to breaking down barriers and supporting disabled people to exercise choice and lead independent lives, but this cost-cutting approach to reform will have the opposite effect for many people living with HIV.

Between 2006 and 2009, one in six people being treated for HIV in the UK were living in such poverty that they applied for charity assistance of emergency cash payments. Among those who received this assistance, the second most cited reason for their financial hardship was that they were reliant on benefits.[1] For any of these individuals, losing access to DLA would have a dramatic impact on their health and ability to manage day-to-day activities.

Individual experiences of living with HIV vary greatly, and there is an equally broad spectrum of ways in which HIV-related health issues can mean some people need a bit of extra support. Some will experience serious HIV-related illness, while others find that side-effects of treatment can be a set back. However, all benefit from a regular payment to help with the extra costs they face, and it is vital that anyone living with HIV who needs extra support will continue to have access to it. This should not be undermined by any attempt to meet arbitrary cost targets.

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[1] NAT and THT. "Poverty and HIV: 2006 to 2009". www.nat.org.uk

Executive summary

- People living with HIV can experience a variety of barriers related to the interaction of their physical symptoms with their environment, and with social attitudes and stigma related to HIV.
- It is essential that DLA/PIP continues to give people living with HIV the freedom to spend their benefit flexibly as needs arise.
- NAT is concerned that moving from three to two levels of the care/daily living component will adversely affect some people living with HIV who currently claim the lowest rate of care under DLA.
- DWP should not assume that DLA/PIP paid at higher rates has a greater positive impact on the lives of those with greater disability-related challenges, than lower rates of DLA/PIP has for those whose disability creates comparatively fewer barriers.
- The fundamental design of the proposed assessment will struggle to account for the needs of people with fluctuating conditions.
- Strengthening obligations to report changed circumstances will put individual claimants and HIV specific welfare advisers in a vulnerable position.
- There should not be an increase in the type of aids and adaptations which are considered by the DLA/PIP assessment, especially as access to aids and adaptations is likely to reduce with funding cuts.
- The new DLA/PIP application process must reduce the burden of proof upon the applicant, not increase it.
- NAT strongly urges DWP to consider the lessons learnt from the Work Capability Assessment to date, and not to repeat the same mistakes with this new benefits assessment.
- Claimants should be provided with information about HIV support and advice services, social care and health services. However, these services should not be considered as ‘alternatives’ to DLA/PIP.
- There are some specific sensitivities around assessing children with HIV, especially around disclosure of HIV positive status and caring responsibilities.
- If DLA/PIP did not provide a passport to other benefits, people living with HIV may not be as well linked to other benefits and services which can have a significant impact on their ability to lead independent lives.
- Any plan to combine assessments for different disability benefits or share relevant information must adhere to data protection and confidentiality, including ensuring that the claimant has given full, informed consent for the information to be shared.
- DWP has not yet provided sufficient information about how the proposed changes may affect ethnic minorities, in particular migrants. More information is needed on the switch from the of ‘ordinary residence’ test to the ‘habitual residence’ test.

Questions

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

People living with HIV can experience a variety of barriers related to the interaction of their physical symptoms with their environment and with social attitudes and stigma related to their HIV.

NAT can only provide comments around some of the barriers experienced by people living with HIV. Even within this group, there is significant variation in the impacts of HIV on individuals' lives.

Some people with HIV live with serious ill-health, related directly to their HIV or in some cases to their treatment. At present, these individuals will be receiving higher rates of both care and mobility DLA, reflecting their need for significant support in their daily lives. This is the situation for the majority of people with HIV who are currently receiving DLA. The most recent DLA caseloads figures NAT has seen indicate that of the 7,500 individuals receiving DLA on the basis of their HIV, 57% receive the highest rate of care, and 79% receive the highest rate of mobility.[2]

This is not the situation for most people living with HIV, owing to significant advances in treatment over the past decade and a half. However, while highly effective treatment means that people with HIV can live long, active lives, they may still experience illness related to their HIV. Many also experience significant side-effects from their treatment, including fatigue; stomach upset and diarrhoea; night sweats and sleeplessness; and in some cases nerve damage. People living with HIV are also more affected by mental health issues such as depression and anxiety.[3]

These physical problems can clearly create barriers, but just as important is the social context of these issues. The consultation document outlines the need to employ a social model of disability in providing support through DLA/PIP, and the support needs of people living with HIV is a good illustration of this. HIV remains a stigmatised condition and the social attitudes towards people living with HIV add to physical and mental symptoms to create social isolation and barriers to participation. DLA/PIP[4], and the new assessment for the benefit, needs to take into account both health-related barriers and the social dimensions of these.

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[2] Disability Living Allowance - all entitled cases Caseload (Thousands) : Main Disabling Condition by Care Award Type. 2008. Information provided following an FOI request.

[3] NAT. 2010. Psychological support for people living with HIV'. www.nat.org.uk

[4] For simplicity, both terms 'DLA/PIP' will be used throughout this submission to refer to the benefit that meets the need currently met by DLA, both at present and following the reforms.

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

NAT welcomes the commitment to retain the key features of DLA: an extra-costs cash benefit, that is not dependent on whether someone works, and is not means-tested or taxable.

In addition, it is important that DLA/PIP continues to offer varying levels of support dependent on individual circumstances. An additional £18.95 a week for someone living with HIV with relatively minor care needs can have just as great an impact on their quality of life as £121.25 per week has for someone with high needs for both care and mobility support (see also our responses to questions 4 and 6).

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

It is essential the DLA/PIP continues to give people living with HIV the freedom to spend their benefit flexibly as needs arise.

In a recent survey of people who accessed disability benefits, respondents were asked what the top uses for their DLA was – these responses can be taken as a proxy for what their main extra costs are. Among respondents living with HIV, the chief uses of DLA were paying bills, buying food, transport, buying essentials, paying for help or support, and the motability scheme. These are likely to be high on the list of many disabled people, though for people with HIV there may be particular reasons why these are extra costs. For example, particular nutritional needs can make food shopping expensive, and essential personal care needs such as continence pad also add to grocery bills. The need to keep a home well-heated because of susceptibility to respiratory problems can drive up utilities bills. Living with pain, fatigue and specific HIV-related conditions such as neuropathy increase the need for help with transport such as taxis or motability vehicles.

What is most important, though, is that DLA/PIP recipients remain free to use their benefits flexibly as needs arise. NAT supports the introduction of a 'daily living' component in place of the 'care' component, in order to reflect the breadth of needs among individuals with the same disability and condition, as well as across these groups. However, DWP must ensure that the assessment process is not so prescriptive in its approach to need, as to undermine the potential for flexibility in the payment.

4. The new benefit will have two rates for each component:

NAT welcomes the continuation of multiple rates of each component of DLA/PIP, but is concerned that moving from three to two levels of the care/daily living

component will adversely affect some people living with HIV who currently claim the lowest rate of the benefit.

Will having two rates per component make the benefit easier to understand and administer, while ensuring appropriate levels of support?

NAT is concerned that reducing the three rates of the care component under DLA to two rates of the daily living component under PIP will mean that those who currently receive the lowest rate of the care component will lose access to DLA/PIP. This impression is also given by the stated intention to prioritise DLA/PIP for those who “face the greatest challenges”.

In setting these priorities, DWP is assuming that DLA/PIP paid at higher rates has a greater positive impact on the lives of those with greater disability-related challenges than lower rates of DLA/PIP has for those whose disability creates comparatively fewer barriers. This is not necessarily the case, as we elaborate upon in our response to Question 6.

What, if any, disadvantages or problems could having two rates per component cause?

NAT supports the proposal to continue having multiple rates of payment for each component to reflect differing support needs. However, we are concerned that communication between DWP and claimants is not always clear, and some may not be sure what rate of DLA/PIP they have received, and why. There is room for improvement in communicating the purpose of DLA/PIP to claimants, the purpose of the different components and rates, and why they receive the components and rates they do.

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?

With respect to HIV, NAT does not think that an HIV positive diagnosis should lead to automatic entitlement to DLA. We agree with the current special rules provision to provide automatic entitlement for those who are terminally ill. We do not have any comments to make with regard to other conditions.

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?

NAT agree with the general categories of everyday activity nominated in the consultation document. However, we are concerned that under a new prioritisation of essential activities, DLA/PIP claimants with less severe physical and mental health barriers will lose their support.

NAT agrees with the general categories of key activity nominated in the consultation document, namely the ability to:

- get around
- interact with others
- manage personal care and treatment needs
- access food and drink

However, we are concerned by the question of how differing abilities in these categories of activity may be used to 'prioritise' need. Clearly, there will DLA/PIP claimants who have quantitatively and qualitatively greater barriers than others to carrying out these activities. However, it is important that those who face comparatively lesser barriers do not lose access to DLA/PIP support because they fall below an arbitrary cut-off point. The positive impact of extra support on these individuals' capacity to be active and independent can be just as great as for those who face multiple or severe disability-related barriers. Moreover, as noted earlier, providing support to those with less severe barriers can have an important preventive effect on their future health and wellbeing.

Just as important as identifying the key areas of day-to-day activities is how these are operationalised for the assessment. A good example of this is the ability to "manage personal care and treatment needs". For people living with HIV, managing their treatment is a key challenge and also a key determinant of how well they are. HIV treatment regimes can be complex and must be adhered to strictly. Medication must be taken at the correct time, sometimes with food, and must be stored correctly. If treatment is not adhered to correctly, the individual may become ill, but may also develop drug resistance. This reduces the options available to that individual and their clinician for future treatment regimes. As noted earlier, some people with HIV may experience significant side-effects as a result of their treatment, which may make them less likely to adhere correctly.

In the case of someone living with HIV, then, managing treatment needs may be as much about social and psychological support as the practical aspects of taking their medication. DLA/PIP may help them access formal counselling, or pay for travel to in informal peer-to-peer support group, or simply keep them in touch with an individual support network. People living with HIV may also have special nutritional needs, as the success of treatment is undermined by being poorly nourished - DLA/PIP can help pay for this, especially when living on a low income. An extra £18 a week can really make a difference when shopping for fresh, nutritious food.

Most individuals in these circumstances would not be considered to have severe disability-related barriers; HIV treatment is highly effective when taking correctly. However, without the extra support of DLA/PIP, the chances of disrupted treatment increases, which may result in serious ill health and greater support needs. DLA/PIP can be an important intervention against future illness for people living with HIV, and will increasingly be so as other sources of support, such as social care, decrease.

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

The fundamental design of the proposed assessment will struggle to account for the needs of people with fluctuating conditions.

This is a particular area of concern for NAT. In a recent survey of disabled people accessing benefits, 95% of those with HIV reported that they experience fluctuating symptoms.

We would caution against simplistic approaches such as that taken in the Work Capability Assessment for Employment and Support Allowance, which asks about the physical and mental symptoms experienced a *majority* of the time. Even experienced a minority of the time, problems around continence, fatigue, pain, nausea and loss of appetite, depression and anxiety can present significant barriers to participation and create a real support need. Information about fluctuating symptoms should be sought as part of the medical evidence provided by clinicians.

In addition to these ongoing fluctuations in health, some people living with HIV may experience episodic poor health or deterioration of health over time. While NAT appreciates that DLA/PIP should be directed to those with current support needs, we are concerned that the DLA/PIP system will not be responsive enough to provide support when it is needed.

The consultation document puts a lot of focus on improving the review system for DLA/PIP, with the intention of “recognising an individual’s changing needs over time”. However, for fluctuating conditions like HIV, these needs may change significantly and rapidly, and sometimes without warning. We are concerned that if a review takes place that reduces or ceases DLA/PIP payment, and the claimant subsequently becomes ill, the system will not be responsive enough to reinstate payment in time to be of assistance. In the meantime, the health of the individual living with HIV could further deteriorate.

NAT suggests that there should be special rules for reporting changes in circumstances for those with fluctuating conditions, especially those that involve a life-long diagnosis. In addition, those with symptoms that are significant but fluctuating should receive a moderate rate of DLA/PIP at all times, with the option to increase if needed in times of serious ill-health.

8. **Should the assessment of a disabled person’s ability take into account any aids and adaptations they use?**

NAT is concerned about the intention to increase the type of aids and adaptations which are considered by the DLA/PIP assessment, especially as access to aids and adaptations is likely to reduce with funding cuts.

As noted in the consultation document, some individuals currently use their DLA to pay for their essential aids and adaptations - an obvious example is the motability car, which requires ongoing funding. But also even if aids are only replaced periodically, the individual may need to save up to pay for them. These are precisely the ‘extra costs’ that

disability may incur for some people.

There is already significant pressure on alternative sources of funding for this help. The consultation document does not suggest any additional sources of funding to replace this self-funded option, if DLA/PIP is reduced for those using aids and adaptations.

• What aids and adaptations should be included?

None to suggest owing to concerns raised above.

• 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?

NAT is particularly concerned by this aspect of the proposal to take into account aids and adaptations, owing to the reasons given above: sometimes DLA is an essential means to gaining access to these, and where alternative sources exist these may involve prohibitive waiting lists. Moreover, with respect to assessing eligibility, we are not convinced that the phrase "the person might be eligible for and can easily obtain" would be in practice interpreted as intended. It is possible that disabled people will be rejected for benefit (or given a lower rate) on the basis of aids or adaptations, yet still not have access to the very aids and adaptations considered in making this decision.

9. How could we improve the process of applying for the benefit for individuals and make it a more positive experience? For example:

The new DLA/PIP application process must reduce the burden of proof upon the applicant, not increase it.

How could we make the claim form easier to fill in?

The form must be shorter – it is currently 60 pages. If face-to-face meetings are going to become the norm for most cases, this may be an opportunity to make the form less detailed. At the very least, the meetings should not duplicate questions already covered on the form.

The form should also include a space towards the beginning for the claimant to explain in their own words why they think they will benefit from DLA/PIP, and how it will help them exercise choice and independence in their lives.

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?

At present it is not very clear to many what DLA is for. The key message of DLA/PIP, that it is to help with the extra costs associated with having a disability, needs to be made more clearly with the reformed benefit. There is also a need to emphasise that it is available to all who meet the eligibility criteria, whether or not they are in work, as there is often a misconception that it is an out of work benefit. At present, the information

provided about DLA on the direct.gov website does not make either of these points clearly or prominently enough.

On the direct.gov website and at Jobcentre Plus offices there should be easily accessed copies of the assessment criteria, as well as information about how the assessment will be carried out, to allow claimants to make an informed decision about whether the benefit is suitable for them.

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

The final decision about who evidence should be sought from should be the claimant's. DLA/PIP claimants should be given a list of possible professionals who may provide evidence.

For someone living with HIV this is likely to include their HIV consultant and/or nurse. Some may wish to also include evidence from their GP, but it should be clear that this is not compulsory if it is not going to add to their claim.

The assessment should also consider in addition evidence from relevant professionals who are not healthcare workers. For example, claimants may wish to include supporting statements from their HIV advice worker, counsellor or social worker alongside their medical evidence.

11. An important part of the new process is likely to be a face-to-face discussion with a healthcare professional.

NAT strongly urges DWP to consider the lessons learnt from the Work Capability Assessment to date, and not to repeat the same mistakes with this new benefits assessment.

What benefits or difficulties might this bring?

As in the present system, arranging for DLA/PIP claimants to meet with a healthcare professional in particular cases may be beneficial.

However, NAT is concerned that introducing meetings with healthcare professionals in almost all claims will create many of the same difficulties already experienced with the Work Capability Assessment (WCA) for Employment and Support Allowance (ESA). Some of the key difficulties with the WCA are:

- The assessment does not consider key HIV clinical markers, such as CD4 count, or the impact of fluctuating symptoms, pain, fatigue, side-effects of HIV treatment, and depression and anxiety for people living with HIV.

- The healthcare professionals carrying out the assessment display a lack of knowledge about HIV, both the basics of the condition and what are the common barriers it creates to participation.

- The interview is often a stressful or frustrating process. Claimants do not always have the opportunity to discuss important issues around their physical and mental health.

- When deciding claims, DWP decision-makers often give greater weight to the opinion of the healthcare professional making the assessment than to HIV clinicians and other specialists who have provided medical evidence.

- The assessment, including the interview, impacts negatively on the health of claimants living with HIV. The stress and pressure experienced affects the ability of claimants to effectively manage their HIV treatment.

NAT opposes any proposal to introduce a new assessment for DLA/PIP that shares any of these features of the WCA. Although the language used in the consultation document is different, and DWP have stressed that this will be an 'objective' (not 'medical') assessment, there appear to be significant similarities between the proposed new DLA/PIP assessment and the WCA.

Chiefly, although the consultation document promises that a social model to disability will be used in assessing DLA/PIP, the description of the application process on p16 contradicts this. The proposed assessment relies entirely on a range of tests of function, administered using rigid criteria. NAT supports the goal to make the assessment objective. However if, like the WCA, the assessment relies on consistency of process as the guarantee of objectivity, it is unlikely to accurately assess the barriers experienced by people living with HIV. The failure to take a context-sensitive approach to disability will lead to inconsistent and unfair outcomes, as has been observed with ESA.

If the DWP does go ahead with the proposed test, NAT suggests involving occupational health professionals in the assessment process, where possible. As has been learned through the WCA, their expertise is likely to be more suited to this form of assessment than that of GPs and nurses.

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?

There will be some cases where people living with HIV should be excluded from a face-to-face meeting. This would be appropriate when the medical evidence indicates a low CD4 count and/or the presence of opportunistic infections (including but not limited to serious co-infections like TB). This is because a claimant meeting any of these criteria is very unwell and also extremely susceptible to further illness. We are aware of individuals in this situation being required to attend a meeting with a healthcare professional as part of the WCA process, with serious consequences for their health.

12. How should the reviews be carried out?

As with the proposed new assessment, reviews must take into account the fluctuating nature of conditions such as HIV.

What evidence and/or criteria should be used to set the frequency of reviews?

As noted in our response for question 7, many people with HIV experience fluctuating symptoms, which are often unpredictable.

If review dates are set for people living with HIV, these should be based on clinical judgement, e.g. someone recently diagnosed or who has just commenced treatment may be seen again 6 months or a year later, depending on their clinician's opinion on how they are likely to respond to treatment.

Should there be different types of review depending on the needs of the individual and their impairment/condition?

As with the initial assessment, any review of a DLA/PIP claim must take a longer-term view of health and support needs, including fluctuations of symptoms prior to the interview and anticipated fluctuation in the future – not just the present health of the claimant.

13. The system for Personal Independence Payment will be easier for individuals to understand, so we expect people to be able to identify and report changes in their needs. However, we know that some people do not currently keep the Department informed. How can we encourage people to report changes in circumstances?

The fluctuating symptoms experienced by many living with HIV make it difficult to predict how changed circumstances will translate to changes in need. Strengthening obligations to report will put individual claimants and their advisers in a vulnerable position.

HIV-specialist benefits advisers have expressed to NAT their concern about the strengthened obligation to report circumstances and penalties for failure to report. For people with HIV, a key change in circumstances would be commencing or switching antiretroviral (ARV) treatment. The availability of highly effective ARV treatment has meant that people living with HIV can live healthy, active lives. However, for each individual there is no certainty about how their will respond initially to the ARVs prescribed, and many experience side effects, as discussed in response to Question 1. A benefits adviser who understands this would recommend that a client wait some weeks or even a couple of months to see how they respond to their medication, prior to reporting how their circumstances have changed.

However, the new emphasis on self-reporting proposed by the consultation document would make it very difficult to 'wait and see'. This may lead to claimants losing benefit when they most need it, or risking penalties if they wait to see if they experience significant side-effects. It will also add to the workload of decision-makers, who may receive multiple reports from a single individual over a short period of time, as they adjust to their treatment and find their support needs are greater or different to those they anticipated.

As already discussed, the most important thing is responsiveness. People with HIV, and other fluctuating conditions, should be able to advise when they are in need of the support, and quickly receive it. Likewise, if they advise that their circumstances have changed, and lose some or all of their benefit as a result, the system should allow for a quick re-start if it turns out that they will still need support.

A more general point to make here is that many existing DLA claimants have not been in the habit of notifying changes of this sort. DWP needs to ensure there is special outreach to long-term claimants, in particular, communicating the rules of the new system without causing undue anxiety.

The new improved system of regular review of DLA/PIP claims should be sufficient to identify changes in needs, without the additional burden on 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?

It would be helpful if DLA/PIP claimants with HIV are provided with information about HIV support and advice services, if they are not already accessing these.

There may also be cases where claimants would benefit from referrals to social care or health services, including psychological support services. However, these services should not be considered as 'alternatives' in supporting people living with HIV who need extra support through DLA/PIP (see also response to question 15).

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?

NAT opposes any plan to make it compulsory for any DLA/PIP claimant to access other advice and support services.

DWP should offer information and referrals to provide additional support to DLA/PIP claimants. However, NAT is concerned that the emphasis on "other forms of support in the health and social care systems" in the consultation document reflects a belief that

some of the functions of DLA/PIP can be replaced or substituted with better access of these services. While this may prove to be true in some cases, it cannot be assumed for most. Moreover, with the reduction across all social care funding and the loss of the ring-fenced AIDS Support Grant, it is even less likely that social care can fulfil all of the support needs of people living with HIV. NAT is also aware that many HIV services will be affected by the loss of local authority funding, so will be less able to provide extra support in many cases.

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?

It may be appropriate to use DLA/PIP to pay for a one-off aid or adaptation if that is the best use for the claimant's needs. NAT does not have any specific comments on this proposal.

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

The concerns that we have already expressed around the assessment also apply to children. As with adults, the needs of children with HIV need to be understood in a social context, not just through measuring functional ability. There are also some specific sensitivities around assessing children with HIV.

In particular, it should be kept in mind that not all children living with HIV have had their condition disclosed to them by their parents or guardians – they may be receiving treatment without having yet had a discussion about what it means to be HIV positive. It is very important that those involved in the assessment do not make any assumptions about how much the child knows. Healthcare and other professionals involved should ensure that children are not disclosed to unintentionally as part of any assessment process, as this would be distressing for them and their family.

It should also be kept in mind that within some families affected by HIV, children can take on caring roles for parents who are unwell, even when they are also living with HIV themselves. These children will have particular needs for extra support. Where children take on caring roles, it is also crucial that their parents are properly assessed, and receive appropriate rates of DLA/PIP, as this can help alleviate the pressure on children care by providing a means of accessing outside support.

Finally, in respect of the claims made in the consultation document about the role that schools play in supporting disabled children, it is worth noting that this is not an always option for many children living with HIV. HIV is still a highly stigmatised condition, and for children with HIV school can unfortunately be a site of harassment and discrimination.[5]

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[5] "HIV Children turned away from schools". *The Observer,* 13 January 2008; NAT and THT.

As such, they may need other forms of support, whether or not their HIV positive status is known at their school.

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?

NAT has no specific comments on current DLA passporting arrangements.

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?

NAT are concerned that if DLA/PIP did not provide a passport to other benefits, people living with HIV may not be as well linked to other benefits and services which can have a significant impact on their ability to lead independent lives, including help with transport, housing and emergency financial support. Any review must involve careful evidence-gathering about the current passporting arrangements, and an assessment of how disabled people with a variety of individual circumstances will be affected by any change.

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?

NAT supports DWP's proposal to consider how assessments for, e.g. DLA/PIP and social care services may be combined, or relevant information may be shared, to reduce the burden on the individual claimant and medical professionals to provide evidence. However, it is absolutely essential that if any information sharing system is implemented, it adheres fully and consistently to principles of data protection and confidentiality, including ensuring that the claimant has given full, informed consent for the information to be shared.

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?

DWP has not yet provided sufficient information about how the proposed changes may affect ethnic minorities, in particular migrants.

"Poverty and HIV: 2006 to 2009". www.nat.org.uk

The Equality Impact Assessment notes that people from ethnic minority groups are less likely to claim DLA. This is an issue that should be considered in the reforms, as it suggests that individuals who may be eligible are not aware that they could claim DLA/PIP. In the case of HIV, one of the most affected groups is black African people. DWP should ensure that relevant information about DLA/PIP is available in all communities.

Also, NAT are concerned that impact upon the many people living with HIV who are migrants (especially from Africa and the Caribbean) of the proposal to change residency rules for DLA eligibility. The consultation document notes that eligibility for PIP will require proof of 'habitual residence', as with other benefits, as opposed to the test of 'ordinary residence' currently used for DLA. The difference between these two tests has not been outlined, and is not clear if this test will be more onerous on claimants, in particular migrant claimants. DWP should provide more information on this change.

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

Justification for reducing caseload

While NAT agrees that the assessment process for DLA/PIP must become less complex, we disagree with the logic presented in the consultation document that this complexity, and the "subjectivity of the benefit" (p7), have led to a 30% increase in successful claims in the past 8 years. It could equally be argued that the complexity of the system had resulted in fewer claiming than were entitled to the benefit for the majority of time since its introduction in 1992, and that the recent increase reflected a growing awareness of the benefit among disabled people who were eligible. DWP have not provided any evidence that their explanation for the increase is the correct one.

Relationship between benefits and rights

NAT is also concerned by the references to developments in equalities legislation (pp 7 and 11), which imply that as disabled people have more clearly articulated and judiciable rights, they will have less need for benefits such as DLA/ PIP. This again is flawed logic.

Firstly, as was pointed out by the Disability Benefits Consortium in their response, nearly a quarter of individuals in families with at least one disabled member live in relative income poverty and over 50% of working age disabled adults are not in paid employment.[6] People living with HIV are disproportionately affected by poverty, with one in six having to seek help in the form of cash payments from charity. [7]

While the Equality Act 2010 (and before it, the Disability Discrimination Act 2005, which defined HIV as a disability from the point of diagnosis) undoubtedly strengthened the ability of people living with HIV to demand equal treatment in work and in accessing goods and services, it cannot be assumed that social attitudes change alongside discrimination law. HIV is still a stigmatised condition, and people with HIV still report

[6] http://www.statistics.gov.uk/elmr/06_10/downloads/ELMR-Jun10-Barrett.pdf
[7] NAT and THT. "Poverty and HIV: 2006 to 2009". www.nat.org.uk

discrimination in employment and in their daily life[8], including while accessing healthcare.[9]

In addition, the proposed changes to the scope and access of Legal Aid will further reduce the ability of disabled people to use these rights.[10]

Increase in the qualifying period

Currently, individuals must be able to demonstrate need for at least 3 months before they can make a claim for DLA. Under the proposals, PIP will only be available to people who can demonstrate need for at least six months before they can make a claim. As under the current system, they will also need to show that it is likely that they will satisfy the entitlement conditions for a further 6 months. So the overall qualifying period will be extended from 9 to 12 months. This may affect people living with HIV who are newly diagnosed and could benefit from support while adjusting to treatment. This is one instance were early support can have a positive impact. It will also be problematic in relation to fluctuating symptoms, where future need can be difficult to predict.

8 NAT. 2009. “Working with HIV”. www.nat.org.uk ; The People Living with HIV Stigma Index. 2009. “Give Stigma the Index Finger”.

9 Nearly a third of HIV-positive people in London report discrimination, often from healthcare staff. Elford J et al. 2008. “HIV-related discrimination reported by people living with HIV in London, UK”. *AIDS and Behaviour.*12 (2)255-264

10 Even though discrimination cases remain in scope under the proposals, legal practioners have observed that cuts to other areas such as employment will make hybrid cases at best complicated and in some cases untenable.