



Proposal to replace Disability Living Allowance with Personal Independence Payment

Evidence from NAT (National AIDS Trust)

Summary

NAT is the UK's HIV policy charity. We provide fresh thinking, expertise and practical resources. We champion the rights of people living with HIV and campaign for change.

In our submission, we provide evidence and make recommendations on the following areas of the Committee's terms of reference:

The implications of a reduction in expenditure

Lower rates of DLA currently have a preventive benefit, helping people with HIV stay well and manage a challenging treatment regime. NAT is concerned by proposals to exclusively focus PIP on those with 'greatest needs', as this suggests people with HIV with lower level needs will no longer have the resources to maintain their health. This will make them more likely to develop greater health-related needs in future.

The implications of a six month qualifying period

More than half of people with an HIV diagnosis are diagnosed late, when they will already experience health problems and need to start treatment. Extending the qualifying period will leave them without support when they need it most.

The design of the PIP assessment

NAT does not consider the proposed functional assessment a more accurate method for identifying disability-related needs than the existing DLA assessment. The draft PIP assessment encourages a focus on severity of physical and mental impairment, rather than individual needs and disability-related costs. We are also concerned by the loss of the well-understood concept of 'supervision' needs, considered in the DLA assessment.

NAT welcomes the Committee's interest in the specific issues PIP may raise for people with fluctuating conditions like HIV. We are concerned that the assessment is following the same approach to fluctuation as the WCA, which was strongly criticised by the Harrington review.

The delivery of the PIP assessment

The Harrington Review highlighted a range of problems with the implementation of the WCA, and the most intractable of these were those areas under the responsibility of the private firm contracted to carry out the assessments. The use of a private firm in the delivery of the PIP assessment will likewise lead to less flexibility and transparency in implementation.

NAT recommends the Committee seek a Government commitment that there will be regular independent reviews of the implementation of the PIP assessment, as there has been for the WCA.

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The implications of a reduction in expenditure

1. NAT is extremely concerned that the reform process is being driven by a pre-determined 20% budget cut. This undermines the principle that is fundamental to Disability Living Allowance (DLA) - it should be paid whenever a disabled person faces a significant barrier to participation which could be overcome with some help with extra costs. Whereas DLA was developed following a full analysis of the drivers of exclusion among disabled people, there is widespread concern Personal Independence Payment (PIP) development is driven a desire to cut the current caseload and expenditure.
2. The decision to focus PIP on those with 'greatest needs' is also a move away from the principles of DLA. The May 2011 technical note to the draft PIP criteria claims that DLA gives "priority to individuals with the greatest needs [in relation to care and mobility]". This is not the case. DLA recognises that there is a wide range of need amongst disabled people and provides levels of support which reflect this, something that PIP will fail to do.
3. Figure 1 (below) illustrates how DLA currently assists claimants with needs that are quantitatively and qualitatively different. A, B and C all have disability-related support needs around social participation (which can be defined as doing the things they want to do, including work, social activities, civic participation, etc). B is the furthest away from participation, indicating the greatest level of need. A has comparatively much less need than B. However, A is still below the line and needs help to reach it. Under DLA, A might be claiming the lowest rate of the care component, whereas B might be claiming high rates of both care and mobility.

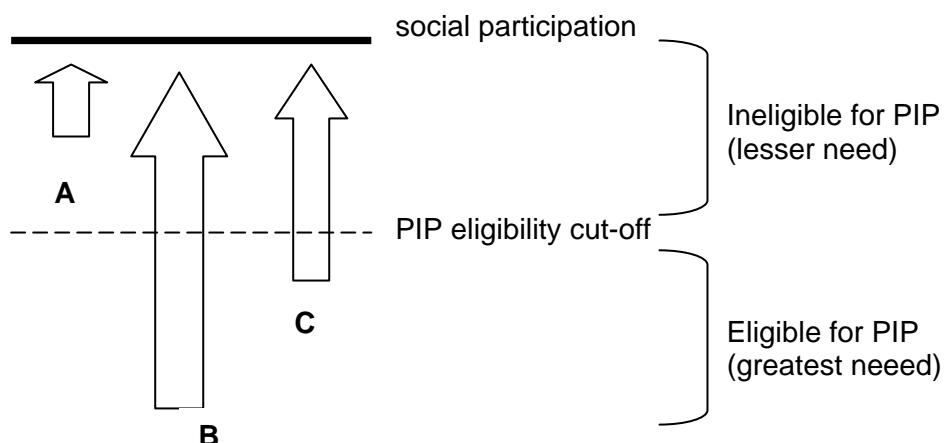


Figure 1

4. If, under PIP, only those with the 'greatest needs' are eligible (represented by the dotted line), A would no longer receive this support. A is still disabled, and still is unable to participate as a result of this disability, but will not be able to access the comparatively small amount of support which would make this possible.
5. For people living with HIV, low rate DLA can have an important preventive and health-promoting effect, which could be lost if the current three rates of DLA care component are replaced with only two rates of the daily living component of PIP.

6. For example, DLA can help someone with HIV manage a treatment regime which is both physically and mentally demanding, especially if they experience common HIV-related symptoms such as depression, fatigue and gastro-intestinal problems.¹ DLA may help them access formal counselling, pay for travel to an informal peer-to-peer support group, or simply keep them in touch with an individual support network. Without such preventive support an individual may fail to manage their condition, deteriorate physically and/or mentally, meaning they will require much more costly assistance in future. Spending £19.55 a week to support these preventive measures is a cost effective use of limited funds.

Recommendations

The same range of disabled individuals currently assisted by DLA should also be supported by PIP.

The committee should ask the Government:

- **What evidence it is gathering about the needs of disabled people.**
- **How many current DLA recipients will not qualify for PIP.**
- **How the participation-related costs of disabled people who will not qualify for PIP will be met.**

The implications of a six month qualifying period

7. More than half of new HIV diagnoses in 2009 were people diagnosed late – that is, after the point at which they needed to have started treatment.² Even though they may be newly diagnosed when they apply for DLA, their health may be already seriously compromised. They may also be experiencing side-effects of their medication or need support to adjust to a strict treatment regime. At present, this group will have to wait for three months before they can get the help they need to manage their condition and stay well. To extend this to six months will leave people living with HIV without support at the time when they are most vulnerable.
8. NAT does not consider the reasons provided by the Government for this increase are sufficient to justify it. The first reason given for the increase is that it will bring the qualifying period and prospective test in line with the Equality Act definition of disability, which notes that to be considered long term, a condition:
 - has lasted at least 12 months; or
 - where the total period for which it lasts, from the time of the first onset, is likely to be at least 12 months; or
 - which is likely to last for the for the rest of the life of the person affected.

(Clearly the Equality Act definition is more complex than this, as certain conditions including HIV are always considered disabilities from the point of diagnosis, so this test does not apply).

9. Aligning with this definition does not necessarily mean that the PIP qualifying period must be six months, followed by a six month prospective test. It would be equally valid to have a three month qualifying period, followed by a nine month

¹ NAT. *Fluctuating symptoms of HIV*. www.nat.org.uk

² Health Protection Agency. *HIV in the United Kingdom – 2010 report*.

prospective test. The advantage of this arrangement would be those who are diagnosed with HIV late, at a point when they are already in urgent need of support, will not have to wait as long to access PIP. Accessing support at this vital time is likely to be more cost effective in the long run by helping people manage their treatment and avoid deterioration of their health.

10. The second reason given for increasing the qualifying period is to align it with Attendance Allowance (AA). It would be equally valid to align AA with the current DLA qualifying period, and the Government has provided no evidence on why the six month period is preferable for either or both benefits.

Recommendation

The committee should recommend retaining the 3 month qualification period. If the Government wishes to align with the Equality Act definition of a disability which considers a 12 month period, the prospective test should be extended to 9 months to make up the difference. This is particularly relevant for those disabilities (including HIV) recognised by the Equality Act as conditions where the 'long term' test is not appropriate.

The design of the PIP assessment

11. The Government has explained that the PIP assessment will use “proxies for an individual’s ability to participate in everyday life” as an indication of the additional costs that may be faced. NAT agrees with this approach in principle. The existing DLA assessment also takes this approach, asking claimants who attend medical assessments questions such as:

*Do you have any problems with using the toilet?
Can you prepare a meal for yourself using the cooker?
Do you need anyone with you when you are out?
Do you go out socialising?*

However, the approach to the proxies in the proposed PIP assessment is much more focused on specific functions. These necessarily make the focus of the assessment the severity of impairment.

12. Instead of capturing relevant evidence about difficulties the claimant may have with, for example, using a toilet, and the likely impact of this on their independence and participation, the assessment considers five specific physical functions:
 - A. Can manage toilet needs or incontinence unaided.
 - B. Can manage toilet needs or incontinence only with the use of an aid or appliance.
 - C. Can manage toilet needs only with continual assistance.
 - D. Can manage incontinence of either bladder **or** bowel only with continual assistance.
 - E. Can manage incontinence of both bladder **and** bowel only with continual assistance.

As such, the descriptors end up being a proxy for level of impairment, rather than a meaningful measure of barriers to participation or an indication of how assistance in the form of PIP could facilitate greater independence and

inclusion. This is not in line with the social model of disability which DWP stated would inform the PIP assessment.

Scoring of the assessment

13. Similarly, NAT questions the appropriateness of scoring descriptors differently based on how severely impairment limits the claimant's ability to carry out an activity. Under the draft assessment a claimant will be given one of four or five possible scores for each descriptor. As such, claimants will essentially be ranked according to their level of impairment. This adds a significant layer of complexity, as compared to the DLA assessment.
14. DWP has not provided any explanation of how this will help identify the support needs of disabled people who have barriers to participation. For example, on the 'moving around' descriptor, the claimant who is scored on the level 'B' descriptor and the claimant scored on the level 'F' descriptor both have barriers to participation and would clearly incur extra costs in addressing these. However, B is ranked such that it would attract potentially significantly fewer points than F.

B: Can move at least 50 metres but not more than 200 metres either unaided or with the use of a manual aid

F: Can move up to 50 metres only with the use of an assisted aid.

15. While it is clearly necessary to have a means of distinguishing between standard and enhanced rates of PIP, based on two levels of likely costs, the current scoring proposal goes beyond this. It seems likely to exclude disabled people with support needs who are not considered to have severe enough challenges. This does not fulfil the DWP's stated aspiration to "treat people as individuals" in the assessment - rather, claimants are assessed as the sum of their impairments and denied support if they do not meet the threshold of 'greatest needs'.
16. In addition, consideration of the need for various levels of either 'assistance' or 'prompting' in each descriptor means that the new 'daily living' descriptors are in fact making demonstrated care needs core to eligibility. This is contrary to DWP's claim that PIP will take a more holistic approach than the current DLA focus on whether someone requires care.

Activities considered by the assessment

17. NAT has provided DWP with specific comments on each proposed descriptor. This is reproduced at Appendix A.
18. DWP has stated that PIP should support participation among people with disabilities and long-term conditions. However, there is no consideration of social or leisure activities in the assessment. By contrast, DLA eligibility takes into account whether the claimant faced barriers to social activities, participating in their hobbies and attending places of worship, as a result of their health, and if extra support would increase their participation.
19. The other key omission from the assessment is a consideration of utilities costs. The most-cited use of DLA among people living with HIV is 'paying bills, e.g.

electricity, water.³ Utilities are one of the most noticeable additional disability-related costs faced by people living with HIV, who need to ensure they keep their home well-heated, and may also face increased gas and water bills associated with needing to wash clothing and linen more often due to night sweats. However, it is currently not considered in any of the draft descriptors.

Assessing fluctuating conditions

20. NAT is part of the working group invited to provide recommendations on how the WCA could be refined to more accurately assess people with fluctuating conditions, including HIV. As the draft PIP assessment takes a very similar format to the WCA, these recommendations⁴ should be taken into account in the development stages.

21. The draft PIP assessment is not yet fit for “accurately capturing the impact of variable and fluctuating conditions and ensuring that an individual’s safety is paramount in all cases”.⁵ The proposal is that the assessor will:

- consider whether the descriptor applies for at least 6 out of 12 months in the assessment period; and
- score the descriptor based on the need that applies the majority of the time.

To only focus on difficulties which are faced half the time or more is an imprecise and misleading approach to fluctuation, which will lead to inaccurate assessments of need. This is the same approach taken in the Work Capability Assessment (WCA), which Professor Harrington noted was an inadequate approach to fluctuation.⁶

22. Even if a barrier to participation is experienced only a minority of the time, it can incur significant costs to overcome – indeed, the unpredictability of some symptoms may itself create additional costs. For example, if a claimant is using their DLA to help pay for a carer, it is unlikely that they will have the flexibility to not pay for the carer on the days that they feel well enough to manage alone. For complex conditions like HIV, fluctuating symptoms which are not experienced the majority of the time may still be severe enough to impact on participation as much as more predictable or constant health problems.

23. The technical note indicates that all activities considered by the assessment must be able to be carried out ‘reliably, in a timely fashion, repeatedly, and safely’. However, this wording does not appear on the face of the descriptors that will be used. The experience of the WCA has shown that if this wording is not included directly in the descriptor, it will not be consistently considered in assessment. Implementation of the WCA has also shown the importance of

³ DBC survey

⁴ *Employment and Support Allowance Work Capability Assessment Review – Making it work for fluctuating conditions*. April 2011.
http://www.nat.org.uk/Media%20library/Files/Policy/2011/Fluctuating_conditions_report_FINAL%20%282%29.pdf

⁵ DWP. Personal Independence Payment: initial draft of assessment criteria (technical note). May 2011.

⁶ *Independent Review of the Work Capability Assessment* <http://www.dwp.gov.uk/docs/wca-review-2010.pdf>

providing guidance to assessors on what this means – e.g. the ability to safely prepare three meals a day, every day, without assistance.

24. Some descriptors differentiate between whether someone needs ‘continual’ or ‘intermittent’ assistance or prompting in order to carry out the activity. In others, points are only allocated where ‘continual’ assistance or prompting is needed (planning and buying food and drink; preparing food and drink; managing medication and monitoring health conditions; washing, bathing and grooming; managing toilet needs or incontinence). This automatically excludes claimants with needs in these areas which are severe but not constant.
25. This new terminology has replaced the concept of ‘supervision’ needs currently used in assessing DLA eligibility for both the mobility and care components. Supervision is well understood by advisers and easy to understand for claimants, and can apply to those with fluctuating conditions as well as those with more constant needs. Separating out this concept to make distinctions between the need for ‘assistance’ versus ‘prompting’ on a continual or intermittent basis adds complexity and the possibility for confusion, which may lead to claimants’ needs being overlooked. For example, the assessment now distinguishes between the following needs, which attract different points:

C: Can prepare and cook a simple meal only with continual prompting

D: Can prepare and cook a simple meal only with continual assistance

Under DLA, both activities are examples of where someone else needs to be present “to avoid substantial danger to yourself or others” and therefore illustrate a need for supervision, which will incur costs to provide.

26. DWP have provided no explanation as to why it is helpful to add this layer of complexity. NAT is concerned that the main outcome will be fewer disabled people attracting sufficient points to be found eligible for the benefit.

Recommendations

The Committee should seek further information from the Government on why a functional assessment is considered a more accurate means of identifying disability-related needs than the existing proxies used to assess DLA eligibility.

The PIP assessment should not take a ‘majority of the time’ approach to fluctuation. Instead, the approach to fluctuation should reflect the recommendations of the independent review of the WCA and the working group on fluctuating conditions.

The Committee should recommend retaining the DLA concept of ‘supervision’.

The delivery of the PIP assessment

27. It is also essential that the problems with the implementation of the WCA, highlighted by the Harrington Review, are not repeated with PIP.⁷ The most intractable implementation issues highlighted in the review relate to the interaction between DWP and the private company contracted to carry out medical assessments.
28. The experience of the WCA and the Harrington review indicates that when introducing a new assessment, refinements will be necessary. With the WCA, many of these changes were made relatively quickly– for example, better communication between JobCentre Plus staff and claimants and the development of new training to ‘empower’ DWP decision makers. However, there has been less rapid change where action from the contracted provider, Atos, was required. NAT is concerned that if responsibility for PIP assessments is also contracted out to a private firm there will be less flexibility and room for responsiveness if there are issues with implementation.
29. The use of a private firm means there is less transparency in the delivery of the assessments. For example, stakeholders participating in the Harrington Review have had to rely on second-hand reports from claimants in order to understand the role of the LiMA computer system used by Atos in the WCA, as this may only be viewed in an assessment room on Atos premises. In addition, as certain aspects of the contract are considered commercial in-confidence, it is difficult for stakeholders to analyse and provide comments on how the contracted relationship shapes delivery of the assessments.

Recommendations

The Committee should consider the outcomes of the first Harrington review and ask the Government

- **What steps have been taken to avoid the problems experienced with implementing the WCA.**
- **How they will ensure flexibility and transparency in delivery of the PIP assessment, if a private firm is used.**

The Committee should seek a commitment from the Government that there will be regular independent reviews of the implementation of the PIP assessment, as there has been for the WCA.

NAT

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2,935 words

⁷ *Independent Review of the Work Capability Assessment* <http://www.dwp.gov.uk/docs/wca-review-2010.pdf>

Appendix: comments on individual descriptors

(Reproduction of submission to DWP call for evidence on draft PIP assessment)

Daily Living component

4.1. Planning and buying food and drink

- 1.1.1. More than half of DLA claimants with HIV surveyed said that buying food was one of the top three uses of their benefit.⁸ Maintaining a good diet is crucial for people living with HIV. Fighting off infections with a compromised immune system increases the need for energy and therefore food, at the same time that essential medication may trigger nausea and gastro-intestinal problems. As such, both the quality and quantity of fresh food available is important, and dietary supplements may also be necessary. Both add significant additional costs, especially for people on low incomes or reliant on out of work benefits.
- 1.1.2. Using DLA to pay for these special health-related food needs is a cost-effective intervention against subsequent ill-health (which could lead to the need for higher rates of support in future), as well as helping people with HIV stay well enough to participate fully.
- 1.1.3. The draft descriptor on 'planning and buying food and drink' does not consider these special needs and additional costs. Points may only be scored for difficulties with planning the purchase of food and drink. Cognitive issues with planning will not be an issue for the majority of people living with HIV, but many will still face barriers to buying the food they need for their health related needs.
- 1.1.4. As well as direct financial barriers to purchasing sufficient food and drink, people living with HIV may not be able to go to a supermarket due to mobility problems and/or lack of public transport routes. With online shopping, supermarket orders can be delivered, but this also comes at a cost of around £4, which is a significant proportion of a shopping budget for someone on a low income. Convenience stores, which are more likely to be within short walking distance, are more expensive and less likely to have the sort of fresh foods needed.

If I do the supermarket shopping (which entails an hour's bus ride just to get there) I know that by the time I get home (I use the home delivery service) I will be finished for the day. I don't eat ready meals, but instead cook from scratch in large batches to freeze for later.

-Person living with HIV

- 1.1.5. We are also concerned about how this descriptor will interact with the second descriptor, preparing and cooking food. If someone living with HIV who can use a microwave (but not a cooker) is not found to have severe enough needs to be eligible for PIP assistance, they will be forced to rely on less

⁸ Analysis of anonymous online survey data collected for the DBC report *Benefiting Disabled People?* (March 2011) <http://www.disabilityalliance.org/dbcreport.pdf>

healthy food options such as ready meals. As well as being insufficient to meet all of their health-related nutritional needs, these meals are more expensive.

Recommendation

The descriptor on buying food and drink needs to consider barriers to access which are not limited to the ability to plan a meal. For people living with HIV, nutrition is an important aspect of maintaining good health, and the additional costs associated with this should be recognised in assessing eligibility for PIP.

1.2. Preparing and cooking food

- 1.2.1. We are concerned by how the new descriptor on preparing and cooking food takes the simple and easy to apply DLA test of 'preparing and cooking a main meal (not a ready-made meal or convenience snack)', with a list of activities describing different levels of ability including making a sandwich, using a microwave, and using a conventional cooker.
- 1.2.2. Each of these activities will attract a different number of points. We are concerned that this will mean that someone who is able to make a sandwich or use a microwave without assistance or prompting, but would need help to cook a main meal from scratch safely, will not attract enough points to receive PIP.

When I cook I do need someone with me, or the place gets flooded, gas gets left on etc. Suffice to say I am not really cooking the meal, I am being humoured while I pretend I am - but that's fine by me, I am safe.

-Person living with HIV

Recommendation

Ranking descriptor points based on the complexity of the food preparation task involved and whether 'prompting' or 'assistance' is required means that people with real difficulties may not be found eligible for PIP. A claimant who can show they are unable to safely prepare and cook a meal on a conventional cooker, even if they can prepare a snack or ready meal, should be able to access PIP.

- 1.3. **Taking nutrition** - NAT has no specific comments on this descriptor

1.4. Managing medication and monitoring health conditions

- 1.4.1. NAT welcomes the consideration of managing medication in the PIP assessment. Adherence to medication is central to living well with HIV. If antiretroviral treatment (ART) is not taken consistently as directed, the individual will become unwell. They are also more likely to pass on HIV when

they are not adhering to ART. In addition, poor adherence to ART can lead to the development of drug resistance and the need for more expensive retreatment options in the future.

- 1.4.2. However, the proposed descriptor on managing medication does not identify all of the relevant factors and costs involved in ensuring that someone living with HIV is supported to adhere to their medication.
- 1.4.3. One of the main omissions is the lack of consideration that while all essential medications are life-preserving and/or health-promoting, not all medications have the impact of making the patient 'feel better' all of the time. ART, while highly effective, is associated with a range of common side-effects. A survey of over 250 people living with HIV showed that HIV treatment was a main factor in the experience of symptoms such as fatigue, gastro-intestinal problems, neuropathy (nerve damage) and depression and anxiety. For example, 73% of those experiencing gastro-intestinal problems such as nausea, vomiting and diarrhoea and two-thirds of those experiencing neuropathy said that their treatment was a cause of their symptoms.⁹
- 1.4.4. Experiencing severe side-effects, either on a regular or unpredictable basis, has a psychological as well as physical impact. In addition, people with HIV are disproportionately affected by mental health issues such as depression and anxiety.¹⁰

My medication causes very vivid dreaming and sometimes hallucinations/night terrors which can be very distressing. It also can cause feelings of vertigo and being 'spaced out' and I find that if I make changes in my routine this becomes more prominent and can lead to confusion, anxiety attacks, and unsteadiness on my feet. Occasionally in the past I have needed assistance at night as I have got up whilst asleep and have fallen over or walked into things and I often need convincing by someone that the 'visions' I have seen (which can be very real and often scary and confusing) are not real and that I am safe.

-Person living with HIV

- 1.4.5. The technical note to the draft PIP assessment notes that mental and cognitive problems will be given greater consideration, as compared to the DLA test. However, in this descriptor the impact of mental health factors in managing medication is limited to the need for 'continual prompting'. This is an extremely narrow and impairment-focused conception of how people with mental health problems may need to be supported to manage their treatment needs.

I am not sure what 'continual promoting' means...sounds close to harassment.

-Person living with HIV

- 1.4.6. For people living with HIV who need some psychological support in order to manage their treatment needs, this help will rarely take the form of 'prompting', which implies either cognitive difficulties with understanding and managing a treatment regime, or resistance to engage with an essential treatment regime. Instead, DLA may at present help support someone with

⁹ Forthcoming NAT report on Fluctuating Symptoms and HIV.

¹⁰ NAT. 2010. Psychological support for people living with HIV'. www.nat.org.uk

HIV to connect with a full range of psycho-social support, including but not limited to peer support programmes and support groups, counselling services, and informal social networks. Simply by meeting the extra costs associated with participating in social activities such as these, DLA can help support the mental and emotional wellbeing of someone living with HIV who is having difficulties adhering to a challenging treatment regime.

- 1.4.7. In addition to the very limited understanding of support outlined in the descriptor, we are disappointed that this descriptor and the one following it, managing prescribed therapies other than medication, are the only two activities to be classed as 'low scoring' in the draft weighting of descriptor points. This undervalues the importance of managing essential treatment to avoid deterioration of health (and the creation of greater support needs), and to promote independence and participation.

Recommendations

The descriptor on managing medication and monitoring health conditions needs to incorporate an appreciation of the impact of challenging treatment regimes, including those which cause severe side-effects, on the ability to manage medication.

The descriptor on managing medication and monitoring health conditions should consider a broader range of types of psychological support when considering whether a claimant will need support from PIP to manage their medication.

The descriptor on managing medication and monitoring health conditions should be medium scoring.

1.5. Managing prescribed therapies other than medication

- 1.5.1. We have the same concerns about the scoring given to this descriptor as raised above, especially as it may impact those who are accessing prescribed mental health therapies.

Recommendation

The descriptor on managing prescribed therapies other than medication should be medium scoring.

1.6. Washing, bathing and grooming

- 1.6.1. The descriptor on washing, bathing and grooming takes an extremely narrow view of the hygiene needs of disabled people, with no reference to the social context of these needs beyond the 'social acceptability' of 'self neglect'. These extremely high thresholds do not promote participation and inclusion - in order to be involved with employment, volunteering or any form of social activity, it is important to dress and groom to an appropriate standard, as well as feel confident. Someone who needs support to dress and groom so that they look smart enough to participate in work or other social activities should be able to access this, without having to be at a level of 'self neglect' to do so.

- 1.6.2. Moreover, the descriptor only assesses how mental or physical impairment affects the claimant's ability to wash, bath and groom their own body. It does not take into account the ability to maintain hygiene beyond the body. This would include washing clothes and keeping a clean living environment.
- 1.6.3. For people living with HIV, washing clothes and bedclothes can be a frequent and demanding chore, as night sweats are a common side-effect of medication. For someone who experiences fatigue, pain or problems with lifting or manual dexterity, changing and washing linen and clothes several times a week is extremely difficult without help. Nor will everyone have access to their own washing machine, let alone clothes dryer. Accessing a laundrette is not an option for those with mobility problems and can be very expensive (at least £3 per load at shops in London). One of the common reasons that people living with HIV approach charity hardship funds is to help with purchasing a washing machine or dryer.¹¹

I get night sweats. I am too tired to do anything, wishing I had the support of family or someone close to help me around the house or for a bit of company even. Being alone with this diagnosis is not easy. I struggle to find the time to keep changing bed linen, having hot baths, getting time for cooking, looking after my child- it's quite demanding...

- Person living with HIV

- 1.6.4. People with HIV who experience problems with mobility, dexterity, upper and lower limb movements and bending, pain and fatigue will also find it challenging to keep their home clean without assistance. In the case of fatigue, it may be that someone living with HIV is able to work, but is then too exhausted to do anything else. Having support with household cleaning would help them stay in work. Without any help, they may not be able to maintain both their employment and their health.

Recommendation

The costs associated with household cleaning, including washing clothes and bed linen are key aspects of hygiene and should be considered in the descriptor on washing, bathing and grooming.

1.7. Managing toilet needs and incontinence

- 1.7.1. Gastro-intestinal problems, including diarrhoea, are a common symptom for many people living with HIV, often a side-effect of medication. This means that immediate access to a toilet is a key concern.
- 1.7.2. NAT is concerned that the descriptor on managing toilet needs and incontinence does not take into account any difficulties experienced in getting to a toilet while in the home. This is often more difficult at night time, and some people may need assistance with this. If not specifically dealt with in this descriptor, ability to move around the home should be considered elsewhere in the assessment.

¹¹ See NAT and THT. 2010. Poverty and HIV: 2006 to 2009. www.nat.org.uk

Why is night time no longer considered to be a more difficult time than day time? It's not. Getting to the toilet when one is up is easier than doing so when in bed, which is where people usually are at night and without access to the help and support they may be able to access in the day time.

- Person living with HIV

Recommendation

The ability to get to a toilet should be considered in the descriptor, managing toilet needs and continence. Alternatively, moving around in the home more broadly should be considered in the PIP assessment.

1.8. Dressing and undressing

- 1.8.1. It is not clear from the descriptor how severe the impairment to the lower body or upper body would be in order to be considered to have barriers with dressing and undressing.

Recommendation

Further information is needed on how to interpret the severity of lower limb and upper limb impairment when scoring the descriptor on dressing and undressing.

- 1.9. **Communicating with others** - NAT has no specific comments

Mobility Component

1.10. Planning and following a journey

- 1.10.1. As in the descriptor on purchasing food, the descriptor on planning and following a journey considers a very narrow range of barriers, in this case apparently linked to learning disabilities, cognitive or sensory impairment. The descriptor does not act as an effective proxy in measuring the full range of disability-related costs in making a journey.
- 1.10.2. People with HIV who face access barriers to making a journey will often need to spend more in order to make their journey. The obvious example here is paying for taxis. Taxis may be needed because there are not accessible public transport routes. In London, which has a high HIV prevalence, not all public transport routes are accessible to those with mobility difficulties. Those who live in more rural areas may not be able to access public transport because there aren't routes near enough to their house, or frequent enough buses to meet their needs with attending, for example, clinic appointments. For those who experience pain due to neuropathy or lipodystrophy,¹² it may not be possible to ensure a bus trip of a half hour with frequent stops, but a

¹² Characterised by the loss or redistribution of fat deposits, e.g. from the face, buttocks and the soles of the feet. Lipodystrophy is a side-effect of certain HIV medication. It can make it painful to sit down, or walk.

taxi will reduce travel time to 10 minutes. Access to transport is essential to independence and participation and PIP should help cover the costs of this.

Recommendation

The descriptor on planning and following a journey should consider physical barriers to mobility and the costs associated with addressing these barriers, such as additional taxi fares.

1.11. Getting around

Moving around indoors is often difficult for me because of my Peripheral Neuropathy and because of the amount of medication I take. I have ataxia and am otherwise often 'clumsy' and have poor co-ordination. Sometimes it's not noticeable to others because of the effort I am making to 'hold it together'. Other times it's dangerous and I can appear as if I am 'drunk'... The draft assessment looks at your ability to move around outdoors. Well, outdoors is a problem too, and sure I feel safer indoors- but feeling safer is not the same as being safer.

- Person living with HIV

1.11.1. The proposed descriptor on getting around only addresses moving around outdoors. This does not take into account the significant mobility challenges that may be faced inside the home, especially when living alone.

I have difficulties walking around, using stairs, (stairs are a nightmare, I can get down them with difficulty but getting up them without great pain is a no- no), and getting in and out of a chair (often a job and half!)

- Person living with HIV

1.11.2. In addition, when considering moving around outdoors, the descriptor does not take into account factors that may stop the claimant going out, which are not solely related to physical inability to get around. For example, depression and anxiety, either in general or related to specific physical symptoms (such as incontinence), can affect the ability of someone living with HIV to move around outside without support

1.11.3. These barriers can be addressed through PIP, both in direct ways (paying for a taxi to allay fears of incontinence on longer journeys using public transport) and less direct means (helping pay for access to a support group or informal support networks, to improve mental and emotional well-being.)

Trying to do the amount of exercise recommended not just on general health grounds, but in order to lessen the impact of muscle wasting and osteoporosis and as an antidote to depression, is an aspiration seldom achieved in full. The depression and fears about continence issues mean that I often get ready to leave the house and then am unable to do so. Or I get as far as the tube station and then have to return home aborting my journey. This limits and curtails my social life as well as my ability to do my own shopping.

- Person living with HIV

Recommendations

The descriptor on getting around should consider mobility both inside and outside the home.

The descriptor around should consider a broad range of barriers to getting around, including the impact of mental health (including depression and anxiety) and physical impairment not limited to mobility (such as incontinence).