Personal Independence Payment: assessment thresholds and consultation

Response from NAT (National AIDS Trust)

NAT welcomes the opportunity to comment on the second draft of the assessment criteria for Personal Independence Payment (PIP). NAT is the UK's HIV policy and campaigning charity.

We previously commented on the first draft of the PIP assessment criteria and also separately submitted, in partnership with the Terrence Higgins Trust (THT), additional evidence from our own testing of the draft criteria with current Disability Living Allowance (DLA) claimants living with HIV. We were pleased to see that some of the recommendations we made on the first draft have been reflected in this second version.

For this second consultation we have again partnered with THT as well as the London-based HIV organisation, Positive East, to test the criteria with service users. We have provided at the end of our submission some case studies drawn from this research. We would like to thank all the advisors and their clients for sharing their experiences and trialling the draft PIP assessment, which we know has been a cause of anxiety for some.

The face-to-face assessment process for PIP will be very stressful for many applicants, and particularly so for people living with HIV who often experience fear and anxiety around discussing their condition, owing to previous experiences of stigma and prejudice. We strongly recommend that claimants are not asked to attend a face-to-face assessment until all relevant medical evidence has been considered, and only then if there are real outstanding questions about their level of impairment. Claimants with severe illness or disability should not be required to attend a face-to-face assessment.

NAT considers the thresholds which have been set for each component of PIP to be unreasonably high. We are concerned that these have been informed chiefly by the need to maintain current levels of DLA spending into 2013-14: the equivalent of a 20% cut to the budget. We hope that after consideration of the evidence provided in this consultation, DWP will revise the thresholds so that PIP is available to those who need it to live an active, dignified life.

Contact:

Sarah Radcliffe
Senior Policy & Campaigns Officer, NAT
sarah.radcliffe@nat.org.uk ; 020 7814 6722

Q1 – What are your views on the latest draft Daily Living activities?

Positive changes

There have been some positive changes made to the daily living activities between the first and second drafts. NAT welcomes the following changes:

- The inclusion of 'supervision' as a concept, though we are concerned about how it will be defined (see response to question 8)
- The removal of the concepts of 'intermittent' and 'continuous' assistance and prompting.

We particularly welcome the recognition in the new descriptors that some claimants will need prompting to carry out a task, not because of mental impairment per se but because they lack motivation as a result of poor mental health. However, it must be made clear that this consideration is relevant to the full list of descriptor activities. As it stands, it is explicitly mentioned within some descriptors, but not others.

It needs to be made clear that motivation should be considered for all relevant descriptors. These include: Preparing food and drink; taking nutrition; managing therapy or monitoring a health condition; bathing or grooming; and dressing or undressing.[1]

New activities

Whilst we agree in that it is useful to separate out the previous *Communicating with others* activity into two distinct activities, we are not sure that the current descriptors for *communicating* and *social engagement* are yet reflective of the full range of communication-related needs of people living with HIV.

HIV-specialist welfare advisors who have used the draft assessment with their clients have observed that Activity 7 does not seem to cover situations where clients have difficulty understanding, following or remembering instructions and information, where the communication difficulty is not related to sensory impairment. Although Activity 8 does capture some elements of communication difficulty related to mental or cognitive impairment, the focus is on social appropriateness and relationships, not basic communication abilities.

Activity 7 should be amended to incorporate communication difficulties linked with mental and cognitive impairment.

Gaps in the assessment

There are still some key disability-related needs and costs associated with daily living which are not covered by any descriptor. These are:

- participation in social and leisure activities including peer support, community and faith-based activities

[1] NB- motivation is already noted under preparing food and drink and bathing and grooming

- maintaining a safe and clean home environment, including the costs of utilities bills and household help, where needed
- moving around the home safely, including getting in and out of bed.

The explanatory document to the new assessment criteria notes that in the initial consultation there was a strong call for additional daily living activities to capture "leisure and community activities, social relationships and housework." We are disappointed that this has not been addressed anywhere in the new criteria, which continue to take a very narrow view of participation and do not reflect the social determinants of disability-related barriers and extra costs.

Q2 – What are your views on the weightings and entitlement thresholds for the Daily Living activities?

As we noted in our previous submission, NAT considers the range of activities covered by the assessment to be extremely narrow. These are not representative of an independent life of full participation; rather, they reflect only a very basic existence. Given this, we were disappointed to see the extremely high threshold for eligibility for each component of PIP.

As the scores and thresholds stand, it is very possible that someone who needs 'assistance' or 'supervision' to carry out an essential daily living activity would not be found eligible for PIP. This is clearly contrary to the stated aim of PIP, to help disabled people meet the extra costs associated with participation. Unless this applicant scored sufficient points on another descriptor, they would be left entirely unable to carry out the activity, and without any additional financial assistance to access the help they need to do it.

It also seems unreasonable that someone may be unable to carry out an essential daily living activity 'at all', but still not be eligible for enhanced rate PIP. The activities covered by the descriptors are the absolute basics needed for life. To be unable to carry out even one of these is a significant barrier to participation, and this should be recognised.

For this reason we propose the following:

- **If an applicant needs 'assistance' or 'supervision' to carry out an activity, this should be sufficient to qualify for standard rate PIP (i.e. it should be worth 8 points)**
- **If an applicant cannot carry out an activity 'at all', this should be sufficient to qualify for enhanced rate PIP (i.e. the descriptor should be worth 12 points**).

We have provided below specific comments on the relevance of the descriptors to people living with HIV. The availability of highly effective HIV treatment means that it no longer has to be a progressive disease. People with HIV will not inevitably develop serious illness or opportunistic infection. However, even people who are responding well to treatment experience HIV-related symptoms and side-effects of treatment, which can limit their ability to participate fully. Many of these symptoms are fluctuating.[2]

[2] NAT. 2011. 'Fluctuating symptoms of HIV.' http://www.nat.org.uk/media/Files/Policy/2011/September-2011-Report_Fluctuating_symptoms_of_HIV.pdf

HIV can be effectively treated, but if someone is not able to adhere perfectly to that treatment (including taking treatment at the right time, eating well and managing mental health needs), their health will deteriorate. The role of PIP should be to prevent this deterioration by helping people with HIV access the help they need. The current scores and thresholds will not meet these needs.

Activity 1- Preparing food and drink

People with HIV have greater nutritional needs than the general population. Studies suggest that HIV positive people need around 10% more energy, as their body is constantly fighting infection and illness. Sufficient nutrition is crucial to the success of HIV treatment. People with HIV may also experience serious side-effects of treatment which require a special diet or supplement. [3] Diet is always a determinant of health, but for people with HIV the preventive benefit of access to adequate nutrition is especially pronounced.

PIP should support these needs, by helping people with HIV buy enough food of the right kind, and prepare it in their home. They should not have to rely on microwaved food or ready meals, which can contain a high level of fat and salt and may not meet their specific nutritional needs. For this reason we are very concerned with the descriptors for this activity, where someone who is able to use a microwave is considered able to cook. To buy microwaveable food that meets their nutritional needs, people with HIV will need to spend more than they would if they were able to cook food from scratch. PIP should be available to help pay for these extra costs.

As the current descriptor scores stand, even those who could not use a microwave or safely prepare food would not be eligible for standard rate daily living. Those who rely on a microwave will only receive 2 points. These scores do not reflect the importance of food on the ability of people living with HIV to stay well and participate fully.

In addition, while we welcome the inclusion of 'supervision' in the descriptors, the scores need to better reflect the safety risks which some disabled people face when attempting to prepare food alone. For example, one person living with HIV who participated in a mock assessment is particularly vulnerable to internal bleeding following a cut or fall. This means that even a minor accident in the kitchen could be fatal. This should be reflected in higher scores for descriptors E and F.

[3] Terrence Higgins Trust. 2011. 'Nutrition'. www.myhiv.org.uk

Activity 1 – Preparing food and drink			
		Current score	**Recommended score**
A	Can prepare and cook a simple meal unaided.	0	**0**
B	Needs to use an aid or appliance to either prepare or cook a simple meal.	2	**4**
C	Cannot cook a simple meal using a conventional cooker but can do so using a microwave.	2	**4**
D	Needs prompting to either prepare or cook a simple meal.	2	**4**
E	Needs supervision to either prepare or cook a simple meal.	4	**8**
F	Needs assistance to either prepare or cook a simple meal.	4	**8**

Activity 2 - Taking nutrition

It needs to be made clear to assessors that where someone who needs prompting to take nutrition this may be because they lack motivation, owing to an underlying mental health need. People with HIV are given advice about the importance of eating regularly and well, but the side effects of treatment and HIV-related symptoms can make eating difficult. For example, a HIV specialist advisor also told us about one client who lacks motivation to eat because of the nausea she experiences. Many people with HIV are affected by depression, anxiety and low self-esteem, which can seriously affect their motivation to eat. The impact this lack of motivation has on their health and effectiveness of treatment (see above) must be reflected in the scores.

Activity 2 – Taking nutrition			
		Current score	**Recommended score**
A	Can take nutrition unaided.	0	**0**
B	Needs either – i. to use an aid or appliance to take nutrition; or ii. assistance to cut up food.	2	**4**
C	Needs a therapeutic source to take nutrition.	2	**4**
D	Needs prompting to take nutrition.	4	**6**
E	Needs assistance to manage a therapeutic source to take nutrition.	6	**8**
F	Needs another person to convey food and drink to their mouth.	10	**12**

Activity 3 - Managing therapy or monitoring a health condition

This set of descriptors is the most problematic for people living with HIV. Managing treatment effectively is the key to short and long-term health outcomes for people living with HIV. Those who manage their treatment well can have a long and active life. Poor adherence can lead to serious illness in the short terms and poor long-term health outcomes. It can also lead to the development of drug resistance, limiting future treatment options.

'Good adherence' to HIV treatment means better than 95% adherence, taking medication at a precise time every day as prescribed. This is much more demanding than many treatment regimes.[4] Even though it is effective and generally well-tolerated, people with HIV can experience serious side-effects related to their treatment. It can be very difficult to manage adherence, when medication is leading to severe diarrhoea, nausea, mood swings or insomnia. Mental health problems, especially depression, can be exacerbated by certain medications and are associated with poor adherence.[5]

There is therefore clearly a large psychological burden associated with effectively managing HIV treatment, as well as a physical burden of side-effects. The best way to manage this is through HIV specialist support, such as peer support and other services. DLA currently helps people with HIV access these services, by paying for accessible transport or the cost of a lunch out with peers. Some people with HIV who suffer from moderate or severe depression may need a support worker to regularly prompt them to take their medication, and their DLA helps pay for this. PIP should continue to meet these needs, but the descriptor scores for this activity do not reflect the importance of this support.

Where descriptors in this activity do attract significant points, it is because someone needs supervision, prompting or assistance for a specific number of hours a week. Our reading of the notes is that this will not apply to people with HIV, as the assistance needed is not physical, and may not be directly related to administering the treatment. There needs to be further consideration of this descriptor, in particular how it relates to treatment burdens which are not directly the result of physically administering the treatment.

The HIV specialist advisors reported several cases of clients who needed reminding to take their treatment on a daily basis. This might not be very labour intensive for the person providing the reminder, but it relies on the client having someone else who remembers to do this for them. If they don't have anyone in their social network who can do this (for example, because they have not disclosed to family members), they will rely on a carer or support organisation. There are extra costs associated with accessing this help, even if it is from a voluntary sector body.

It should also be clarified whether assistance with attending essential appointments would be considered under this activity. Our specialist advisors noted that some of

[4] NAM. *Adherence*. HIV treatments directory. http://www.aidsmap.com/Adherence/page/1729978/

[5] Carter, M. 2011. *Consistent relationship between depression and poor adherence to HIV therapy*. NAM, 1 September 2011. http://aidsmap.com/Consistent-relationship-between-depression-and-poor-adherence-to-HIV-therapy/page/2056859/

their clients would not attend their clinic without assistance, chiefly because of mental illness and cognitive impairment.

Scores for this activity should reflect the full range of barriers to managing treatment, physical, psychological and social, and the seriousness of the impact of failing to manage treatment.

Activity 3 – Managing therapy or monitoring a health condition			
		Current score	**Recommended score**
A	Either – i. Does not receive medication, therapy or need to monitor a health condition; or ii. Can manage medication, therapy and monitor a health condition unaided, or with the use of an aid or appliance.	0	**0**
B	Needs supervision, prompting or assistance to manage medication or monitor a health condition.	1	**4**
C	Needs supervision, prompting or assistance to manage therapy that takes up to 3.5 hours a week.	2	**see comments**
D	Needs supervision, prompting or assistance to manage therapy that takes between 3.5 and 7 hours a week.	4	**see comments**
E	Needs supervision, prompting or assistance to manage therapy that takes between 7 and 14 hours a week.	6	**see comments**
F	Needs supervision, prompting or assistance to manage therapy that takes at least 14 hours a week.	8	**see comments**

Activity 4 - Bathing and grooming

The scores for this descriptor must reflect the real barrier to participation caused by inability to bathe and groom. If someone cannot bathe or groom without assistance, or cannot bathe and groom at all, they will not be able to participate in society and should certainly receive PIP. For example, due to his fatigue, Jim (see case study) would not be able to safely bathe without supervision. This is another activity where it must be clear to assessors that someone may need prompting to bathe or groom due to a mental health condition.

Activity 4 – Bathing and grooming			
		Current score	**Recommended score**
A	Can bathe and groom unaided.	0	**0**
B	Needs to use an aid or appliance to groom.	1	**2**
C	Needs prompting to groom.	1	**2**
D	Needs assistance to groom.	2	**4**
E	Needs supervision or prompting to bathe.	2	**4**
F	Needs to use an aid or appliance to bathe.	2	**4**
G	Needs assistance to bathe	4	**8**
H	Cannot bathe and groom at all	8	**12**

Activity 5 - Managing toilet needs or incontinence

Incontinence can be a symptom of HIV, or a side-effect of common treatments. Difficulty managing toilet needs and incontinence can be a barrier to participation for people living with HIV and can also effectively keep someone housebound (see comments on the mobility descriptors, below). One client who spoke to an HIV specialist advisor described how he could not go outside without a change of underwear and a trusted friend who could help him get to a toilet and clean up if he did experience incontinence while out of the house.

NAT considers needing help to manage toilet needs as much as a reason to qualify for PIP as needing assistance to manage incontinence of either bladder or bowel. Complete inability to manage incontinence is a severe barrier to participation and this should be reflected in higher rate PIP.

Activity 5 – Managing toilet needs or incontinence			
		Current score	**Recommended score**
A	Can manage toilet needs or incontinence unaided.	0	**0**
B	Needs to use an aid or appliance to manage toilet needs or incontinence.	2	**2**
C	Needs prompting to manage toilet needs.	2	**4**
D	Needs assistance to manage toilet needs.	4	**8**
E	Needs assistance to manage incontinence of either bladder or bowel.	6	**8**
F	Needs assistance to manage incontinence of both bladder and bowel.	8	**10**
G	Cannot manage incontinence at all.	8	**12**

Activity 6- Dressing and undressing

When someone needs prompting to dress, undress, remain dressed or select clothing they are in a potentially vulnerable position and clearly unable to participate socially without support. This descriptor should be worth at least 4 points. NAT considers that whether it is for dressing the lower or upper body, the need for assistance to dress is clearly indicative of the need for support with daily living and should lead to an award of standard rate PIP.

Activity 6 – Dressing and undressing			
		Current score	**Recommended score**
A	Can dress and undress unaided.	0	**0**
B	Needs to use an aid or appliance to dress or undress.	2	**2**
C	Needs either – i. prompting to dress, undress or determine appropriate circumstances for remaining clothed; or ii. assistance or prompting to select appropriate clothing.	2	**4**
D	Needs assistance to dress or undress lower body.	3	**8**
E	Needs assistance to dress or undress upper body.	4	**8**
F	Cannot dress or undress at all.	8	**12**

Activity 7- Communicating

As noted in our response to question 1, this activity does not yet reflect the full range of communication barriers experienced by people living with HIV, who may have mental or cognitive impairment. Even as the activity stands, however, if someone needs assistance or dedicated communication support to access either written or verbal information, they will not be able to participate in daily life without support. They should qualify for PIP on these grounds.

Activity 7 – Communicating			
		Current score	**Recommended score**
A	Can communicate unaided and access written information unaided, or using spectacles or contact lenses.	0	**0**
B	Needs to use an aid or appliance other than spectacles or contact lenses to access written information.	2	**4**
C	Needs to use an aid or appliance to express or understand verbal communication.	2	**4**
D	Needs assistance to access written information.	4	**8**
E	Needs communication support to express or understand complex verbal information.	4	**8**

F	Needs communication support to express or understand basic verbal information.	8	**10**
G	Cannot communicate at all.	12	**12**

Activity 8- Engaging socially

NAT welcomes the decision to take account of non-physical support required to enable someone to engage socially, and the consideration of any 'prompting' needed. However, it should be made explicit that prompting can also mean the need for encouragement due to motivational issues.

NAT welcomes the removal of the previous requirement that the distress must have an effect of several hours. However, the notes say there must be "evidence that the overwhelming distress had/would occur, not just that it might" and there must also be "evidence of an enduring mental health condition, intellectual impairment or cognitive impairment."

NAT is extremely concerned about what level of 'evidence' will need to be provided to show that this distress would occur, and is linked to a specific impairment. We also question that overwhelming distress must be linked to an underlying health condition. For someone living with HIV, anxiety around a physical condition such as incontinence may equally form a barrier to social engagement. For two of our case studies, Jim and Saul (see below), the risk of unpredictable incontinence while engaging socially is a cause of overwhelming psychological distress, but would not be recognised under this activity as it stands. The requirement to demonstrate an underlying mental health condition should be removed from this activity.

In addition, as noted earlier, there may be difficulties with engaging socially which do not manifest in psychological distress – for example, some cognitive impairment. Even in the absence of distress, or uncontrollable behaviour, the individual may have significant support needs. For example, one advisor talked about a client who had difficulty concentrating and engaging due to cognitive impairment, and who in support appointments "will just sit across from me and look like she's day-dreaming". Without support, this client would not be able to engage and may even be in danger without supervision. The current descriptors do not seem to address this situation.

Activity 8 – Engaging socially			
		Current score	**Recommended score**
A	Can engage socially unaided.	0	**0**
B	Needs prompting to engage socially.	2	**2**
C	Needs social support to engage socially.	4	**8**
D	Cannot engage socially due to such engagement causing either – i. overwhelming psychological distress to the individual; or ii. the individual to exhibit uncontrollable episodes of	8	**12**

	behaviour which would result in a substantial risk of harm to the individual or another person.		

9. Making financial decisions

The inability to make any financial decisions is a sure indication that someone needs support, and without it will not be able to live an independent life (and may be left vulnerable). They should qualify for PIP on these grounds.

It is not clear what evidence will be required for these descriptors. Our advisors noted that several of their clients currently need assistance to manage a budget, or they will not have enough to live on. Our concern is that the assessment will seek additional evidence that the person is objectively 'incapable' in order for this to be awarded. We stress that this should not be the case.

Activity 9 – Making financial decisions			
		Current threshold	**Recommended threshold**
A	Can manage complex financial decisions unaided.	0	**0**
B	Needs prompting to make complex financial decisions.	2	**4**
C	Needs prompting to make simple financial decisions.	4	**6**
D	Cannot make any financial decisions at all.	6	**8**

Q3 – What are your views on the latest draft Mobility activities?

The approach to mobility taken in the draft assessment is too narrow. NAT is concerned that some people living with HIV face barriers to getting out and about which are not reflected in the two activities.

Chief among these are the extra costs associated with accessing appropriate transport. Transport costs including taxi fares are a key use of DLA for disabled people generally, including people living with HIV.[6] This is sometimes because of difficulty walking, but may also be because of difficulty managing incontinence. For example, someone living with HIV may live on a bus route to their clinic, but as the journey takes 30 minutes or more they may avoid the bus in case of incontinence. A taxi ride may take only 10 minutes, which is much more manageable.

Transport is also of course relevant to accessing food and drink. If someone is unable to carry their groceries home they may have to use a taxi. The alternative, which is home delivery, is also associated with an addition fee of around £4 per delivery.

These extra costs are not reflected in the current activities. DWP should consider adding an additional activity around getting out and about, including accessing appropriate transport.

[6] DBC survey of disabled people's use of DLA – available on request.

Q4. What are your views on the weightings and entitlement thresholds for the Mobility activities?

As with the daily living descriptors, the current alignment of scores and thresholds will leave people with real mobility support needs ineligible for PIP mobility component. As there are only two activities for mobility, it is crucial that the scores reflect the barriers that exist and facilitate access to PIP for those with mobility-related costs - there is no risk of people 'over scoring' on this activity.

Activity 10 - Planning and following a journey

As noted in question 2, NAT has concerns about how 'overwhelming psychological distress' will be defined and operationalised in the assessment. We are concerned about the impact on the claimant of having to provide 'evidence' that a) they have an underlying mental health condition and b) that if they did not have assistance the overwhelming distress would occur.

Also as with Activity 8, we do not think it is helpful that this distress will only be considered if it is linked to an underlying mental health condition. Someone with HIV may be effectively housebound because they experience unpredictable incontinence. They would still need support from someone else to make journeys, and should not be penalised because their anxiety is related to a physical problem, and not necessarily an underlying mental health condition.

The descriptor choice B may be misleading. If someone is essentially unable to independently undertake any journey without experiencing overwhelming psychological distress, they clearly have a real support need. Describing this as 'prompting' only minimises the importance of this role. In addition, the notes indicate that this would in fact apply when the applicant needs to be accompanied in order to leave the house. For this reason we recommend that the wording is amended to include 'or supervision'.

As, in the absence of prompting or supervision, someone meeting this descriptor would be effectively housebound, this should qualify them for PIP. To leave the home without assistance and experience 'overwhelming psychological distress' is not a genuine alternative for this person and they should receive support.

Activity 10 – Planning and following a journey			
		Current score	**Recommended score**
A	Can plan and follow a journey unaided.	0	**0**
B	Needs prompting **[or supervision]** for all journeys to avoid overwhelming psychological distress to the individual.	4	**8**
C	Needs either – i. supervision, prompting or a support dog to follow a journey to an unfamiliar destination; or ii. a journey to an unfamiliar destination to have been entirely planned by another person.	8	**10**

D	Cannot follow any journey because it would cause overwhelming psychological distress to the individual.	10	**12**
E	Needs either – i. supervision, prompting or a support dog to follow a journey to a familiar destination; or ii. a journey to a familiar destination to have been planned entirely by another person.	15	**15**

Activity 11 - Moving around

As this activity stands, the measure of whether someone has serious difficulty with moving around is if they use a wheelchair. This is a very narrow interpretation. Someone whose mobility is restricted to 200m faces significant barriers to independence and participation and should receive standard rate PIP on this basis.

HIV-specialist advisors have raised concerns with us about the similarity of this assessment criteria, to that used for ESA. They note that in the application of the Work Capability Assessment, there is not the same recognition of the impact of pain, breathlessness and discomfort which is usually given in the DLA assessment. Notwithstanding the proposals around fluctuation (below), it does seem possible that when the below criteria are applied, only those who must use a wheelchair will be found unable to move the specified distances. This apparent bias should be carefully considered and addressed in the descriptor wording and the guidance on this activity.

Activity 11 – Moving around			
		Current score	**Recommended score**
A	Can move at least 200 metres either – i. unaided; or ii. using an aid or appliance, other than a wheelchair or a motorised device.	0	**0**
B	Can move at least 50 metres but not more than 200 metres either – i. unaided; or ii. using an aid or appliance, other than a wheelchair or a motorised device.	4	**8**
C	Can move up to 50 metres unaided but no further.	8	**10**
D	Cannot move up to 50 metres without using an aid or appliance, other than a wheelchair or a motorised device.	10	**12**
E	Cannot move up to 50 metres without using a wheelchair propelled by the individual.	12	**12**
F	Cannot move up to 50 metres without using a wheelchair propelled by another person or a motorised device.	15	**15**
G	Cannot either – i. move around at all; or ii. transfer unaided from one seated position to another adjacent seated position.	15	**15**

Q5 – What are your views on how the regulations work regarding benefit entitlement?

We welcome the decision to alter the qualification period from 3 and 9 months to 6 and 6 months, respectively.

Q6 – What are your views on how we are dealing with fluctuating conditions?

The second draft assessment attempts a more sophisticated approach to identifying the impact of fluctuating conditions, but we are still concerned about how this will work in practice. The move away from a simple majority of the time approach is welcome, but the new test is complex. Clear and simply guidance for implementation is crucial, or the risk will be that assessors will apply it inaccurately or not at all, as it seems too onerous. The precise equation, as outlined in the consultation, should not be the focus of the assessment of a person with fluctuating conditions.

The only workable approach we can see would be to co-produce the decision of which descriptor to choose. Under this approach, the applicant would be asked which descriptors apply and how often, making it clear that multiple descriptors may apply at different times. From this, the assessor should be able to make a judgement about which descriptor applies, without requiring the applicant to break their experience down into percentages. Finally, the assessor should always confirm with the applicant that they have accurately judged which situation applies 'most often' of those which apply, before making their decision.

In addition, we remain concerned that the new test will not capture people who have severe symptoms for a significant minority of the time but not at all at other times. At present DLA has a significant preventive benefit for people with some fluctuating conditions. For example, someone with HIV may receive lower level DLA to help them manage a challenging treatment regime which includes acute periods of side effects on a fluctuating basis. Their DLA helps pay for them to access the support they need, including psychological support, which is proven to help people with HIV adhere to their treatment. It can also help them access appropriate food and to keep their home warm, both of which are crucial to the success of their treatment. Without help to manage their treatment regime, they may become seriously ill and end up with longer term impairment. At this point, they would become eligible for PIP – this is a false economy.

There seems to be an exception to this rule, which applies epilepsy (p47). In cases "where an individual can have no functional imitation one minute and considerable limitation the next. Assessment should be based on the impact of these causes". This approach to acute and unpredictable episodes should apply to all people with fluctuating conditions.

Q7 – What are your views on the definitions of 'safely', 'timely', 'repeatedly' and 'in a timely' manner?

NAT strongly agrees with the proposal to include the terms 'safely', 'timely', 'repeatedly' and 'in a timely manner' in the regulations. It must be made clear that this applies to all activities, both daily living and mobility. This could be as a general provision or within each activity, as long as it is clear to assessors, decision-makers and appeals judges that this is the case.

From our knowledge and experience, the definitions proposed for 'reliably' and 'in a timely manner' seem broadly reasonable. The most important thing is that each of the concepts is considered in combination with the other three for every activity.

We do have some concerns around the way in which the impact of pain and fatigue will be included. The definition for 'repeatedly' says that:

…Consideration needs to be given to the cumulative effects of symptoms such as pain and fatigue – i.e. whether completing the activity adversely affects the individual's ability to subsequently complete other activities.

This is important, but it should also be clear that the activity *per se* may cause pain and fatigue, or that pain and fatigue make the activity effectively impossible. For example, someone may be physically capable of walking 50m but this causes pain. It must be clear that this is the same as someone not being able to do the activity. HIV specialist advisors have noted also that the loss of the concept of 'severe discomfort', which is used in DLA, will make it harder to accurately assess the needs of people living with HIV. For example, one current client would describe severe discomfort while walking due to the physical effects of chronic incontinence. Similarly, while doctors may use concepts such as 'visceral pain', many individuals would be more likely to describe these sorts of pain as 'discomfort.' We also recommend that the impact of breathlessness is considered alongside pain and fatigue.

The definition of 'safety' should also make it clear that when considering if the activity is likely "to cause harm to the Individual", harm can include worsening of their condition in the future, not only sudden or dramatic physical harm. So for example, if someone is unable to take their HIV medication without assistance, this may not lead to immediate physical harm, but within a period of months of this continuing they are likely to become ill. Or, if their ability to take medication is periodic, they may not experience illness as a result for some time, but will in future find that they have developed drug resistance, limiting their future treatment options (and therefore health outcomes).

Q8 – What are your views on the definitions in the regulations?

Aid or appliance

We do not agree that the definition of aid or appliance is particularly helpful, as it is entirely possible that an aid or appliance which may be ordinarily used by a non-disabled person as a choice, is in fact a necessity for a disabled person. The MS Society has suggested as an example, that an electric toothbrush may be essential to grooming for someone with chronic fatigue, not only a matter of preference.

Bathe

We welcome the decision to change the definition of bathe which no longer include the phrase "above a level of self neglect". However, we still consider the proposed definition too narrow – it should really describe whether someone is able to wash their entire body in a shower or bath. There may be some people who use adapted washrooms without a conventional bath or shower, but the test should still be based on a typical bathroom (as the descriptors already address adaptation).

Communication support
We welcome the acknowledgement that support may come from someone experienced with the person's needs, and need not be someone trained.

Overwhelming psychological distress
This is a circular and therefore meaningless definition. As discussed earlier, someone could experience psychological distress related to the impact of a physical impairment, such as unpredictable incontinence. Short of listing every possible symptom of distress, this is a concept which may need to be developed through case law.

Simple meal
We welcome the inclusion of 'fresh ingredients' in this definition. We also agree with the decision to remove the concept of a 'snack' from the descriptors.

Supervision
Supervision has been defined as "continuous presence". This is not as supervision is defined under DLA, which is a "continual presence." "Continual" is taken to mean "frequently occurring". By contrast, "continuous" is understood to mean "uninterrupted". This is an unreasonably high threshold. The DLA definition should be used here.

Toilet needs
It should be made clear that this includes ability to reach the toilet in a timely manner without assistance. This should also be included in the definition for ***manage incontinence***.

Q9 – Do you have any other comments on the draft regulations?

The one-month time-limit for providing evidence in regulation 5 does not seem realistic. The experience of the Work Capability Assessment shows that the most important thing is for all the relevant evidence to be provided first time.

In relation to regulation 7, we would stress that face-to-face assessment should not be conducted where the initial application makes it clear that there is severe illness or impairment and/or someone has a severe and progressive condition.

More broadly, we are concerned by the consequences of the loss of DLA case law. This was raised with us by several welfare advisors. HIV is a complex condition which can affect the whole body in sometimes unpredictable ways. People with HIV also have specific safety concerns associated with poor immune function. This means it is always difficult to accurately assess the needs of people living with HIV using standard criteria. DLA case law has developed over time which has made it possible to apply these rules appropriately, consistently and fairly to people with HIV, without the need for unnecessary appeals. We urge the DWP to consider how this case law may be incorporated into the rules and guidance for PIP, to avoid the need for costly re-invention of what has taken years to establish.

Additional comments

In order for any assessment of someone living with HIV to be successful, it is essential that the assessor and decision-maker each have a solid basic knowledge of HIV. The evidence from the Work Capability Assessment (WCA) is that this is not the case. The guidance on HIV which has been used by Atos assessors is out of date and not relevant to the UK context. We have provided comments and suggested improvements on this guidance, which we hope will be implemented.

For PIP, it is essential that the right training and guidance is in place prior to the implementation of the assessment. NAT strongly recommends that disability charities and expert organisations are involved in the development of this guidance and training. We would welcome the opportunity to discuss this further with DWP.

NAT, April 2012

Case studies

All case studies were collected by HIV-specialist welfare advisors. They have suggested the score which they think is most accurate for their client's needs (shown in brackets). However, it is not clear to us whether the client would in fact be given this score, because they do not neatly meet the descriptor. These cases raise many questions about how the needs of people living with HIV will be measured by the assessment.

All names are pseudonyms.

A. Jim

Jim is in his thirties. He currently receives low rate mobility and high rate care components of DLA.

He has severe symptoms of HIV including nausea, fatigue and sweating. He has had chronic, persistent diarrhoea for two and half years. This has left him extremely week due to loss of fluids and nutrients.

Activity 1 – preparing food and drink (F-4)

Jim needs prompting to prepare a meal because of excessive fatigue. He also needs assistance for problems with manual dexterity, which is also linked to his fatigue. His advisor was concerned that fatigue-related impairment would not be fully appreciated by the assessor.

Activity 2- taking nutrition (D- 4)

Due to his fatigue, Jim needs his water and food to brought to him or he will not eat. He is also reluctant to eat because it may trigger his diarrhoea. As an HIV positive man, eating enough is essential to the success of Jim's treatment and future health.

Activity 3- Managing therapy (B- 1)

Jim needs his medication brought to him and encouragement to take it.

Activity 4- Bathing and grooming (E- 2)

Jim is so weak that he needs supervision to bathe safely.

Activity 5 – Managing toilet needs and incontinence (E- 6)

Jim is sometimes able to clean up after himself, but most of the time he cannot. He is also exhausted by the physical impact of his diarrhoea, which also causes him a lot of pain and discomfort.

Activity 6 – Dressing and undressing (E- 4)

On around 60% of days, Jim needs physical help to dress due to fatigue. On a good day he may be able to do it himself, but still needs to be prompted. [NAT: we are not sure if Jim would qualify for E based on fatigue, though he clearly has needs here.]

Activity 7 – Communicating (A-0)

Activity 8 – Engaging socially (C-4)

Jim needs support with using the telephone, completing forms and dealing with everyday affairs. Fear of incontinence stops him from engaging with strangers unless he is supported. Due to bad experiences with disclosing his HIV status, he is also fearful about communicating with others and revealing person information about himself.

Activity 9 – Making financial decisions (B-2)

Jim is too tired to plan and calculate his budget and manage or pay bills, but is supported in this by his partner. His advisor was not sure if he would qualify for any points under this descriptor.

Activity 10 – Planning and following a journey (B-4)

Jim can plan a route and follow it, but experiences social anxiety connected to his incontinence.

Activity 11 – Moving around (B-4)

Jim experiences severe discomfort in his rectum when he walks. Fatigue also means he cannot reliably, repeatedly and safely walk more than 200m.

Suggested award

Daily living: Enhanced rate
Mobility: Standard rate

B. Saul

Saul is in his 50s and currently receives low rate care and mobility components of DLA. He is chiefly affected by mental health problems. His advisor struggled to find the relevant descriptors to describe his needs.

Activity 1 – preparing food and drink (D-2)

Due to severe concentration problems, Saul would not be able to prepare a meal without help.

Activity 2- taking nutrition (A- 0)

Activity 3- Managing therapy (B- 1)

Saul often forgets to take his medication or may take a double dose by accident.

Activity 4- Bathing and grooming (E- 2)
Saul is able to bathe and groom unaided, but he may need to be prompted to do so.

Activity 5 – Managing toilet needs and incontinence (A- 0)

Saul's advisor notes that while he is able to manage his incontinence unaided, these episodes cause severe mental distress. The impact of this is not recognised in this activity.

Activity 6 – Dressing and undressing (C-2)

Saul has some difficulty dressing but has developed ways of coping with this. However, due to his mental health problems he sometimes needs prompting about appropriate dress.

Activity 7 – Communicating (A-0)

This was a particularly difficult activity to score against, as Saul's concentration makes communication challenging, but not in any of the ways described.

Activity 8 – Engaging socially (D-8)

The advisor was worried about the sort of evidence that Saul would be required to present for this descriptor.

Activity 9 – Making financial decisions (A-0)

Activity 10 – Planning and following a journey (B-4)

Saul plans his journeys ahead effectively so he can avoid crowded public transport, which would trigger distress. However, he does need support on some journeys. He also experiences panic attacks while outside, but not on all journeys. He also sometimes experiences severe confusion in public places. His advisor did not think this activity accurately described his challenges.

Activity 11 – Moving around (B-4)

Saul can walk up to 200m but would be very breathless by the end.

Suggested award

Daily living: Enhanced rate
Mobility: Standard rate

C. Larry

Larry is in his forties and was initially awarded DLA under the special rules for people living with HIV in 1993. A subsequent re-assessment in 2007 found that he was still eligible for higher rate care and higher rate mobility.

As well as his HIV-related symptoms, Larry has severe lower back pain which affects his mobility.

Larry's advisor was not able to provide as much information about his circumstances than other cases, but did go through the assessment with him.

Activity 1 – preparing food and drink (C-2)
Activity 2- taking nutrition (A-0)
Activity 3- Managing therapy (A-0)
Activity 4- Bathing and grooming (E- 2)
Activity 5 – Managing toilet needs and incontinence (E- 0)
Activity 6 – Dressing and undressing (D-3)

Activity 7 – Communicating (A-0)
Activity 8 – Engaging socially (A-0)
Activity 9 – Making financial decisions (9-0)
Activity 10 – Planning and following a journey (A-0)

Activity 11 – Moving around (8)

Larry's advisor noted that while he can move 200m, this is in severe pain.

Suggested award

Daily living: None
Mobility: Standard rate

Larry seems likely to lose a significant amount of support which he currently receives through DLA. He has for many years been receiving higher rates of both components. Although it has been 5 years since his reassessment, it is unlikely that his condition has improved greatly, as he was diagnosed with HIV almost twenty years ago – long-term survivors are more likely to have life-long impairment.