

<http://www.dwp.gov.uk/docs/pip-assessment-thresholds-and-consultation.pdf>

St Joseph's Hospice exists to help people live life to the full, to the very last. It has been enhancing lives, easing pain and bringing comfort and understanding for over a hundred years.

St Joseph's broad range of services enriches the lives of patients and their families from the diverse communities of east and north-east London. St Joseph's end of life care is available to all those who can benefit from it: we work to meet all the needs of our patients, including those which reflect their ethnic, cultural or religious heritage.

This is our response to the proposals to change Disability Living Allowance and by so doing, remove a very important acknowledgement of a claimant's disability and financial assistance to deal with the costs of those disabilities.

Disability Living Allowance was introduced in 1992 under a Conservative government to meet the additional costs of disability. Research even from the DWP demonstrates that having a disability is a financial disadvantage¹. We should state that in the first instance that we do not believe that continuing with the current system of Disability Living Allowance for adults with 'tweaks' allowed under current legislation is a bad thing. A decision can currently be re-visited at any stage and even indefinite awards are subject to review. One of the government's stated difficulties is that many people feel that Disability Living Allowance is not a benefit for people who work. A much more cost-effective way of resolving this issue would be to publicise the entitlement conditions to DLA. This would have the added advantages of saving to the public purse, not needing to employ more healthcare professionals through Atos, no new branding and less fear for disabled people.

One of the arguments used to justify Personal Independence Payment is that it will be less subjective and easier for people to understand. It is not clear how this can be said to be so, as whoever is tasked with assessing the points system will face a subjective judgement call and possibly come to a decision that another healthcare professional might query. We are already seeing that many claimants of Employment and Support Allowance are succeeding at first tier tribunal where legally and medically qualified panel members revisit the decisions of the same health care professionals who would be commissioned with the subjective decision of deciding whether someone could perform a given activity with reasonable regularity. In a significant proportion of these decisions, the tribunals find errors, inconsistencies, inaccuracies or insufficient understanding of claimants' issues from the examining practitioner. There must be a lack of

¹ Mike Tibble in <http://research.dwp.gov.uk/asd/asd5/WP21.pdf>

confidence in Atos's competence to effectively produce reports that are "fit for purpose", at least on the part of the claimant. It is not clear how paying the same company more from taxpayers' revenue when it is already, as an agent of the state, failing many claimants would be an acceptable use of public funds.

Many of the people who will be affected adversely by PIP will also be hit hard by other elements within the Welfare Reform Act, for example through the use of their DLA to meet shortfall in rent due to the cuts in housing benefit budgets. In failing to acknowledge that claimants have disabilities, they will also be affected by the benefit cap. The effect of the government's policy will be to create large areas where people who need to rely on benefits will no longer be able to live despite the fact that their support networks, jobs, children's schools, and perhaps their whole lives have been set up to ensure that they do not need additional assistance. This can only succeed in making life unnecessarily more difficult for people who have disabilities, isolating them further.

The latest draft daily living activities are cause for some concern. The first would be that the descriptors generally do not allow for how much help in terms of time is needed to perform an activity. Potentially, if someone needed prompting once to perform the various activities s/he could be entitled to the standard rate of Personal Independence Payment but if the government wants to target this benefit to those who need the most support we would say that the benefit should reflect the frequency of help needed and include more of the activities currently covered in legislation.

Secondly, the idea behind Disability Living Allowance was that people who have disabilities have an equal right to a functional as well as social life.²³ Much was made of the social model of disability rather than the medical one. This gave rise to an acknowledgement that having a disability cost more than not having one⁴. In addition, there is little in the draft daily living activities for people with mental health problems, or learning difficulties, for example. Many people have problems with concentration, memory and logic or motivation. Currently they could receive the lowest rate care component of Disability Living Allowance, however, under the proposed system they will not be entitled to payment of Personal Independence Payment unless they can demonstrate other difficulties, and perhaps not even then. Someone who needs someone to help to motivate them to cook would presumably need to eat pre-prepared or takeaway food thus incurring additional cost to them. Where someone has both physical and mental health difficulties, it appears that only the higher point attracting activity applies. That would appear to

² *Mallinson v Secretary of State for Social Security* (reported as [R\(A\) 3/94](#)),

³ *Halliday v Secretary of State for Social Security*

⁴ Mathematica Policy Research Inc. <http://research.dwp.gov.uk/asd/asd5/rports2009-2010/rrep542.pdf>

suggest that only one difficulty is to be acknowledged. We know however that often the barrier to carrying out an activity is greater than the sum of the parts and that over-arching conditions can mean that a claimant may be able to deal with one part or another of the process. When someone does not have motivation to eat or cook, and on top of that has problems with their hands, we are concerned that the claimant will not be deemed to be unable to prepare a simple main meal or take nutrition. The difficulties in cutting up food are already reflected in current legislation, so the government's argument that having specifically separated them for the purposes of PIP is sophistic.

The previous two paragraphs support the premise that current legislation could properly address the government's aims.

Thirdly, many people who currently have an entitlement to a car under the Motability scheme would lose. For many people, this is the only means of independence that they have. This is likely to cause difficulty for people who do not otherwise have access to transport and will either further isolate disabled people or create more demand for transport to hospitals, or requests for funding from local authorities' social services departments. Locally, the public transport system cannot accommodate the needs of people with mobility difficulties, so people who depend on Motability cars are unlikely to have alternatives.

Looking more closely at the individual matter of each activity and the descriptors within them, we are disturbed that many disabled people will have no recognition of the amount of difficulty they face. The "taking nutrition" activity focuses on the difficulty involving therapeutic sources. No acknowledgement is made that the need for help with motivation to eat or take nutrition effectively means that without it the claimant is effectively unable to eat or drink. The descriptor attracts only 4 points. There must be concern that without recognition of this as a need for what would be deemed a basic 'bodily function' under current legislation, the claimant will be at risk of neglect which will put more pressure on social services or the NHS at a time when their budgets are also being cut. When a claimant cannot eat, surely this is the ultimate demonstration of vulnerability. As a result, we consider that either more points are appropriate for this activity, or the threshold needs to be lowered so as to award a rate of benefit with fewer points.

Managing medication and monitoring health conditions does not account for people who for whatever reason cannot tolerate a medication, aid or appliance which might be expected for someone who has their health condition. The only medication that appears to be considered is that prescribed, although the claimant or family may have already discovered that there is an alternative therapy that works. Many claimants who have mental health difficulties are unaware of the change in their conditions

and rely on someone else to be aware of changes and significances of them. It is not clear how people who live alone would be assessed; whether as now the help that is needed is considered or whether if there is no-one to monitor the condition/treatment the claimant will be deemed not to need the supervision, prompting or assistance. People who have diabetes are not always aware of their changing condition and without intervention from others the consequences can be significant. It could be suggested that someone who was at risk of overdose either by accident or design could be said to require more than 14 hours per week to minimise the risk of taking too much medication, whereas someone who self harms would need less supervision for an act with similarly undesirable outcome because of the syntax of the regulations.

We feel that bathing and grooming should be broken down into individual activities and a higher points award to reflect the importance of the lack of motivation on each of the actions. If someone has no or low motivation to bathe or groom themselves, it is unclear why that should not be deemed to be an activity worth points. The ultimate alternative would be that the local authority social services would have to provide care to meet that need. Poor motivation is more than someone saying "I don't feel like doing ...", and if someone has no impetus to carry out the activity, especially on a task as basic as bathing or grooming, we feel that this should continue to attract points if PIP is introduced.

We agree that claimants should have acknowledgement of the difficulties they face in dressing, however it seems incongruent that someone who has problems with dressing their upper body scores 4 points whilst someone who has difficulties with their lower body scores 3 under these proposals. There seems to be no acknowledgement that if someone needs help, they may need help for both, as the only descriptor that applies is that which attracts the higher points value. This could be the difference between a claimant being awarded the benefit and not, or the difference between the standard and enhanced rates. The only way to ensure that the correct points were awarded would be to say that the claimant could not dress themselves and that is not accurate.

The idea that someone can preclude the need for assistance to dress themselves by using slip on shoes cannot be said to address the issue. To many people, the way they present themselves to the world is important and takes precedence over the difficulties they may face in the process of dressing. That is not to say that the difficulties or the need for help do not exist. If someone has always worn lace up shoes and has a wardrobe full of them, their ability to wear slip on is irrelevant. Under DLA/AA regulations prompting and assistance have always been considered, so it appears that the government recognises the need to carry this over to PIP; or as stated above a better solution would be to retain DLA with amendments.

The activity of communicating has been narrowed to cover support from a trained person or someone directly experienced in communicating with the claimant. If one assumes that for the majority of the time the claimant is unlikely to have access to a trained person, for example when out of doors, shopping or on public transport, it appears unjust to only consider the help given by a trained person. Do we mean that people who do not have access to a person trained in their particular difficulty with communication should not communicate? The second draft assessment criteria states "The initial proposals included an explicit assessment of communication ability, a significant departure from the current Disability Living Allowance assessment." We are unclear as to the validity of this statement because Disability Living Allowance approved help needed by a claimant with the bodily function of communication. Furthermore, no consideration appears to have been given to people who have mental health issues. All of the proposed descriptors relate to either cognitive or physical difficulties in understanding. Someone who has difficulties in understanding what s/he is being told or who has difficulties in retaining information, concentration or focussing on that information has as much of a barrier to social intercourse as does someone who has a sensory impairment.

The consultation document states "The descriptors now reflect the impact of impairments on an individual's ability to access written information – whether using an aid or appliance or requiring 'assistance'. Disability Living Allowance already considers the difficulties of accessing and understanding written information. It could be argued that someone who needs help to complete the application form for DLA/PIP would reasonably require help to communicate. If the government states that the reason for proposing a change to PIP is that it is a simple to understand benefit, then the claimant must have her/his needs recognised as difficulties in understanding simple/basic information.

If we accept that someone who has a disability should expect to enjoy a social life, then we feel that the descriptors addressing the need for help with that should be as broad as possible. Simply to say "needs (social) support to engage socially" attracts points cannot even begin to address the impact of the lack of a social activity. Disability Living Allowance recognises the sophisticated lives that we lead as a society. If the help that the claimant needs is physical, that may include helping to change clothes, psychological support to go out, cut up food at a restaurant, swim, deal with fatigue, help to sit, stand or rest to carry out the activity, no allowance is made in the current proposed descriptors to explain the difficulties that a claimant may face and therefore no recognition of those barriers to socialising. Whilst people who exhibit disruptive behaviour should be entitled to the benefit and currently are, the needs of people that we see who have physical problems should not be discounted.

Another concern would be the definitions of the financial decisions. We have clients who have standing orders or direct debits to pay bills because they would not be able to remember which bill to pay or when. It is a safety net that allows people to almost delegate the decision to the bank so that they do not face additional charges due to unpaid bills. Those clients may say that they do not understand how to make a complex financial decision and that they have had to open a bank account as a vehicle for the receipt of benefit, so they use the bank as a means of reminding them to pay. Does a claimant have to face debt before s/he can validate this so that s/he is entitled to a disability benefit?

In respect of the mobility activities, the major worries relate to the lack of recognition of pain or fatigue as an inhibitor to walking for those who have physical problems walking, or the need for someone else to have planned every journey for someone who has mental health or cognitive difficulties.

In summary, then, we have many worries about the government's aims in removing Disability Living Allowance for people of working age. This is particularly unjust as we understand that there is to be no change to the benefit for children, nor is there to be any change to Attendance Allowance. This will mean that for the first 16 years of someone's life they will be assessed and have benefit awarded on the basis of the activities they cannot perform and the amount of time they need help from another person, as is currently the starting point for both Disability Living Allowance and Attendance Allowance. When a claimant reaches 16, their entitlement to benefit is likely to be adversely affected by an altered test based on different criteria. Their care needs may not have changed, in fact they may even have increased, but because of the proposed changes and the very narrow criteria to be considered under these descriptors, they are much less likely to be entitled to benefit. When they reach the end of their working lives, the criteria reverts to the current system. We are not clear why the government would wish to complicate the benefit system in this way. It is difficult to imagine that the purported savings from these changes would come close to the huge expense of changing a benefit's name, publicising that, printing new claim forms and paying an organisation to undertake assessments, which by their very nature must be subjective. This would be especially so, when considering the history of these assessments and how many of the decisions based on these assessments are overturned at first tier or upper tier tribunal, thus adding to the costs.

As previously stated, unless the government's aim is to victimise people with disabilities, the power to re-examine claims already exists within the legislation and could effectively achieve savings without complicating the benefit system further.

