

## **Personal Independence Payment (PIP)**

### **Feedback from Preston Learning Disabilities forum:**

This district-based group comprises concerned service user/self-advocates; advocacy supporters, volunteer, professionals, carers and care reps, City council engagement and housing reps, a county councillor, charity providers and development and person-centred planning workers.

The group meets regularly and discusses policy issues. The broad concerns are to be represented but the detail was delegated to feedback.

Overall there is a major concern about the relevance for people with learning disabilities of some of the criteria in that their needs and issues are a very broad range and the impact is very individual but often masked – particularly to those not experienced with the group.

The biggest concern is that those perceived to have lower level needs (on low DLA) now have little if any support from anywhere else and so the impact if this was removed would be to put this group into serious jeopardy it is believed as this income and disability premium is vital to their survival including other passported resources such as the bus pass – without these they will be effectively excluded and at risk.

Those people with the most severe needs usually will have service supports and/family supports – and hence more access than those without these.

(I have attached a copy of a recent article from Community Living magazine – vol 25 no 2) which we feel illustrates the frailty of how the most coping in this group are managing – let alone more commonly similar others with no links or support systems.

Our comments below reflect these concerns in the main. My apologies for them not being in the best format for you but you'll appreciate that you have provided a lot of material and it is hard for an individual to be able to present the groups' concerns in the most coherent way

Rosemary Trustam – volunteer supporter to the group – on their behalf.

### **Public consultation Nov 11 criteria/Jan 12 and March 2012 documents:**

#### **Nov 2011**

*4 d) in assessing the claimant's ability to carry out an activity, the claimant is to be assessed as if wearing or using any aid or appliance which –*

*(i) is normally worn or used; or*

*(ii) the claimant could reasonably be expected to wear or use.*

**This creates a problem if accessing the aid or appliance depends on this DLA/PIP income or associated benefits/concessions.**

**“reasonably” needs to take account of the person’s specific difficulties**

**eg** someone whose behavioural difficulties means they won’t (ie resist) wear an aid; someone whose mental ill health means their obsessions/ (mis)beliefs for example preclude them using a specific aid or equipment.

**6. Failure to provide information in relation to ability to carry out activities**

*Where a claimant fails without good reason to comply with the request referred to in regulation [5](1)(a) or (b), a negative determination shall be made.*

**7. Claimant may be called for a consultation to determine whether the claimant has limited or severely limited ability to carry out activities**

*(1) Where it falls to be determined whether a claimant has limited or severely limited ability to carry out activities, that claimant may be called by or on behalf of a person approved by the Secretary of State to-*

- (a) attend for and participate in a consultation in person;*
- (b) participate in a consultation by telephone; or*
- (c) both (a) and (b).*

*(2) Subject to paragraph (3), where the claimant fails without good reason to attend for or participate in a consultation referred to in paragraph (1), a negative determination shall be made.*

*(3) Paragraph (2) does not apply unless written notice of the date, time and place for, and manner of, the consultation, as the case may be, was sent to the claimant at least 7 days in advance, or unless that claimant agreed to accept a shorter period of notice, whether given in writing or otherwise.*

*(4) In paragraph (3), reference to written notice includes notice sent electronically where the claimant has agreed to accept correspondence in that way.*

**Assessment:**

What support will be given to supporting communication needs – eg support of photos/DVD to show what’s being asked and ensure people understand about prompts as well as being physically able to do things – and to the problem of people not liking to say they can’t do things or not recognising help if it’s prompts/reminders? What specialist experience and training will assessors have?

Also they may need the income to pay for the support they need or supplement that given by LA

**Views on the definitions of ‘safely’, ‘timely’, ‘repeatedly’ and ‘in a timely’ manner?**

*These seem very helpful as this can be a significant issue with people with learning disabilities*

## March 2012 document

### Says:

*“The Government is committed to supporting disabled people to exercise choice and control and lead independent lives, and recognises that disabled people face extra costs in doing so. Disability Living Allowance (DLA) is being reformed to create a new benefit called Personal Independence Payment which will ensure that support towards meeting such extra costs is focussed on those individuals who experience the greatest barriers to living full, active and independent lives.”*

### Eligibility:

1. *“Individuals must have a long-term disability or health condition in order to be eligible for the benefit.”*

However it makes conditions of a “12 month required period condition” and a three-month qualifying period and nine-month prospective test.”

This would seem a nonsense for many people affected who have a clear long-term permanent condition and hence appears to be just in order to save money. (There is obviously an unnecessary cost to seeing and re/assessing people who are clearly eligible and have substantial needs) If it is supposed to eliminate people whose disabilities are in process and short-term, then ***the impact appears to be disproportionate*** on those people it is supposed to help – ie the long-term disabled such as those with severe learning disabilities or other disabilities from birth where the impact is known to be long-term and likely to be unchanging.

The suggestion would be that there should be the ability of an application to be made immediately in such cases supported by a letter/form from the doctor or relevant professional confirming a long-term condition. This should be vital on the way to making available resources necessary to met the “extra costs of enabling “disabled people to exercise choice and control and lead independent lives”. Delaying this just weakens the avowed government intention and leads one to suppose this is just a way of government saving money.

2. The target of *“those individuals who experience the greatest barriers to living full, active and independent lives”* makes a lot of sense but the definition of how that is assessed is not felt adequate:

Currently those with the greatest needs are targeted by all statutory support Agencies – national income benefits, social care through local authorities and health agencies, and concessionary support to reducing barriers to engagement in society by district authorities.

With the cuts the people suffering the greatest impact are those perceived to have the more moderate or lower needs. Local authorities have in the main moved to only meeting the social care needs on FACS bandings of those in substantial or critical needs. This has disqualified those in moderate or low

needs. Currently those people whose lives are affected and limited by the impact of their disability currently have to rely on their low level DLA to support their extra costs to manage which also entitles them to the disability premium in their income support which helps people also who struggle to manage and with the extra costs, and in turn the DLA also passports them into other concessions such as a free bus pass, leisure passports etc – which help prevent an escalation in needs and reduce some barriers to engagement.

It would be hoped that the PIP assessment will understand the need for these people in particular to have the support of a PIP payment but the abolition of a lower rate does seem to risk their exclusion. There would also be an accelerated impact if someone loses their eligibility to the DLA replacement through the loss of other supportive disability benefits payable when someone has DLA – thus likely to increase their exclusion and needs. The current assessment criteria seem designed to disqualify these groups and the consequent escalation of need is also likely to increase costs on other budgets such as social care, health and have knock-on effects on housing, police and local communities.

People for example with a more moderate learning disability have cognitive impairments and without any support are likely to fail to manage, pushing them from a currently more independent position (due to the current support of benefits and community engagement) into a position of failure and exposure to more exploitation – which they are currently more exposed to as they are now without social care watching briefs. (We have seen the concerning levels of “hate” and (so-called) “mate” (exploitation by people purporting to befriend) crimes – which will worsen at a time when other budgets are cut and under strain).

Apart from the social (and health) consequences of most probably isolating people and removing them from any community engagement (without their current concessions to support them into the community), people with cognitive disabilities are less able to manage in the most cost-effective way their living expenses and money. They may now get no support in developing these skills due to both their disqualification from social care (FACS moderate or low needs) and the impact of the steady erosion of the Supporting People grants now no longer protected and reduced. Unless people already have any SP support and it has been maintained, then housing support is no longer there in reduced budgets – and certainly is unlikely to be there for new people with long-term ongoing needs, if they are identified as in need at all.

NB If people are on low DLA (£20.55) and hence also get the disability premium (23.95/week) this means they stand to lose potentially £44.50/week, and I'm not sure if any of us could afford to manage a low budget with such a loss of income; if people have additional cognitive difficulties this means they are less equipped to manage than the rest of us. There may also for some be additional impacts on housing costs – particularly if they are in higher cost rented accommodation in a safe area; if they get any council tax exemptions due to disability or housing benefits reductions. If they have some work, the latter two may be critical to managing.

This group also work hard to “pass” ie they have a life-time struggle with the effects of being negatively labelled and are often skilled in managing at times to “give the right answer” to protect their independence from what they may previously have experienced as limiting support services who have exercised control in attempts to protect. Hence in assessment because they have speech and can answer, without skilled interrogation they will often give the answers they think are required (ie that they can do things) whereas if probed to explain how they manage would start to show the gaps in their abilities and the way that the current benefits help them to manage. A concern also about people who may appear physically able and not show their disability but who may not be able to do things emotionally – eg Asperges/autism.

*What support will be given to supporting communication needs – eg support of photos/DVD to show what’s being asked and ensure people understand about prompts as well as being physically able to do things – and to the problem of people not liking to say they can’t do things or not recognising help if it’s prompts/reminders?*

There does appear to be a potential flaw in the move from a system of DLA which is very much an income to support the additional costs of a disability – to one which appears to be testing out how people manage with their current support and aids, which may only be possible because of the use of their benefits and without which they would not be able to manage. The system needs to assess people without their “paid for” supports and anticipating how they would be without all the other passported benefits.

In many ways those in greatest needs now are many of those on the margins and for whom the small support of the current low level DLA and its associated benefits makes the difference between them coping and not coping. (This also where I’d suggest SP grants should have been targeted and where any housing support money (if it has survived not being ring-fenced) should be targeted)

The government needs not to look only at the impact of change between DLA and PIP but needs to contextualise this both with the knock-on impact on other benefits support as well as taking account of the changes in support due to the cuts in local authorities and the likely costs on other higher costs health, criminal justice and social care systems if the low level is removed.

(Please see scan of article written by a group of people with learning disabilities which shows an example of the critical importance to them of the DLA as they struggle to maintain their independence)

Please look more widely across different support streams to assess the impact and to understand what a disproportionate impact this is likely to have on those we’d argue may well be some of the people ***most in need*** of this small amount of support to survive. Your definitions will not so identify them we feel on your current eligibility criteria and our fear about the limited skills of your assessors if they do not understand this group.

Certainly for this group, the reassessment and likely loss of this benefit will throw many people into critical need after for some a relatively short period – and some like those with learning disabilities may well not have the resources (due to cognitive difficulties and/or the associated emotional difficulties) to seek help, as they fail tend to translate this as a route to “getting into trouble” with the authorities due to failing and to either avoid reaching out to an authority or put themselves in danger through being vulnerable to people who will exploit their vulnerability – which we know happens now.

The risks for the government of saving 20% on this review of benefits is likely we feel to cost far more on other budgets – let alone the cost on society of undoing the frail independence this group has managed due to the current system.

### **Mobility:**

There seems a real risk that these criteria are not sufficiently allowing for the fact that moving around/planning trips are likely to depend on resources to assist. Without the resources for example someone with learning disability can't pay the fare of the person accompanying them which is essential to their mobility. Someone else may depend on the mobility allowance for an expensive individually designed wheelchair which has meant they can now get out and about for longer periods; is significantly reducing the escalation of skeletal problems and improving their posture but doesn't come within the NHS provision – however means they can get out and about more without pain, for longer periods and so reduces the barriers to their independence/an electric wheelchair dispensing with the need for someone to push them – and increasing their ability to get out and about; a mobility scooter which has enabled them to get out where buses don't give access. If they are assessed using these resources, this doesn't take account of the costs to maintaining this.

With people with Id, there are also major problems with people who may be physically able but who wouldn't be safe to go out – they couldn't plan a trip but also their behavioural difficulties are such that they may for example refuse to move/may not be able to use public transport due to the impact of their behaviours on others and may need to rely on taxis or a mobility car.

Because there is no scoring system, it is not clear that people with these issues will attract sufficient benefit when the second Q seems to retain the higher scores for people needing wheelchairs.... When behavioural issues affecting mobility may be far more costly due to the same problems of not being able to access or use ordinary public transport but often not be able to even use taxis because of the extent of support that may be needed eg time required for support staff to appropriately help someone to go out and be calm enough to travel.

Many people with more moderate learning disabilities can't plan a trip unless they have already been helped to learn the trip and will need assistance to

learn a new trip; there are also issues such as being able to use a timetable and understand the needed to be somewhere at the right time. This can also mean that they get over-anxious and may well be at a train or bus stop a long time before the time – again increasing their risk. Many have to have taxis at night due to the risks after dark for them from people who will exploit or even assault. It can be a very frightening and dangerous experience. For most people who currently have the low level DLA, this is critical to them being able to get out and about because of the safety issues and the pressures on them without support of being able to plan and negotiate the public transport system – particularly outside any regular planned route. This seriously can otherwise limit their life.

## **Reassessment**

### **Question 15**

There will be limited appeal rights against the decision to terminate DLA and safeguards will ensure that people who genuinely were not able to claim Personal Independence Payment within the time limits will be able to re-engage with the claiming process without penalty. Is this a fair and proportionate approach to ensure people engage with the claiming process?

It's really not clear how this will be judged but in our view afterwards is too late – it's making sure you identify people who may have real difficulties in understanding the letter(s) sent and get help to them before they are disqualified – as they will probably also not be able to easily access an appeals anyway.

Because some people with learning disabilities (with more moderate or low support needs no longer qualify for social care support and so unless they have a relative to help, many such won't have support to help them with their correspondence and many who don't read or whose literacy is very compromised may not understand the letters coming through about reassessment and change. As a long-term benefit which they may have been on for many years they probably have no idea about the change and may thus not understand the risks to their income. The same people are also likely to struggle with making phone calls. (This is also likely to be an issue with some other people with such difficulties)

Any suspension of benefit will for many result in a lack of understanding about this and an inability to know what to do. If the DLA record shows a learning disability, there needs to be some kinds of adjustments made to be able to get some contact before suspending payments or arrangements should be made from the start. Otherwise we will see a disproportionate impact.

Could the Pathfinder period specifically explore this and try out some ways to manage this – it may be a phone call made to some if they have a phone number; it may require paying a grant to local community groups to visit – or maybe even the Post Office could be employed for their post deliverers to be trained to deliver and translate/support the recipient (letters with a specific address line for example) – maybe to refer.

=We are extremely concerned about early casualties to such a review. It may be only a small proportion without any connection to help but... we have no

way of knowing and the numbers will have increased due to many no longer having social care support and becoming increasingly isolated.

We appreciate the difficulties and suggest that the assumptions maybe that anyone with DLA has someone supporting them, but now in the light of cuts there are a growing number of people for whom this benefit may be the only support they are getting.

#### **Question 16**

*Do our plans and timetable to reassess people for Personal Independence Payment appear sensible and reasonable? If not, what changes do you think we should consider introducing?*

A concern really for you to identify the groups most at risk (without other services in touch) and hence to look at what delays this might cause and extra support in communicating needed. IF there is real concern about the changes then risking escalating needs for a significant minority would not be a good outcome

#### **Question 17**

*We intend to build in a process to help us identify claimants who may need additional help to claim, for example those with learning difficulties or mental health problems who do not have an appointee. Although this process will not be subject to regulations, we would be grateful for any views on this proposal and how best to identify those people who need additional support from the Department or from other organisations.*

See our comments above

In addition, whilst you do say people will be offered a face-to-face if they are identified as “requiring additional support”, you do not say how this will happen or where. Again it's the issue of appropriate support being offered. It is likely that the appropriate support will need to be someone with knowledge about the specific problems raised by the nature of the problem eg a local charity with specialist workers who would be properly able to support their understanding, getting to an interview and assist the person to understand the questions being asked and respond appropriately. For those who have someone in touch there is no problem as you identify they can bring someone.

The problem is those without anyone, and how in the scale of current claimants you will be able to identify them and get the right support before you start suspending people's benefits. You or the system may also identify the people most at risk as we see it (ie those on low level DLA who may well not have any other support in touch) as people least in need and hence not respond appropriately.

We feel people with learning disabilities living more marginally in the community without family support and not eligible for social care are most at risk of being excluded in the process and if disqualified from the new PIP through not responding (or if they don't seem to meet the assessment criteria as the currently apply) they are at high risk of moving toward critical/dangerous levels of need



### Question 18

*Our plans include procedures and rules to ensure that everyone invited to claim Personal Independence Payment will be repeatedly reminded before their benefit is first suspended and then terminated. Are there any other matters we should consider to ensure that everyone currently on DLA who may be entitled to claim Personal Independence Payment does so, and within reasonable time limits?*

Our feeling is that you should be checking through the DLA applicants early to identify those with learning disabilities on low DLA and designing a preventive process **now** to prevent them falling through the net once their reassessment starts. (That may mean an initial letter to identify those who can respond first and then for those not responding a direct contact process supported by someone with the right specialist knowledge so that appropriate supports can be put in place)

Alternatively, having identified them, a transitional protection could be put in place which would only be removed once the person has accessed the assessment interview, properly supported. These people are the people most in need of specialist assessors.

*“Our intention for Personal Independence Payment has always been that benefit entitlement will be based on the degree to which individuals are able to participate in society, not on their health condition or impairment. Health conditions and impairments, including degenerative ones, can affect people in a range of different ways.”*

NB Those not being helped by any other agency are likely to be those now most excluded from participation.

Rosemary Trustam – Preston learning disabilities Forum