Personal Independence Payment and the re-assessment of Disability Living Allowance claimants

April 2017

Executive Summary

1. Personal Independence Payment (PIP) was introduced by the Coalition Government as a major element of the Welfare Reform Act 2012, to be the new benefit for disabled people of working age. It was to be simpler to administer and easier to understand than the working age disability benefit it would eventually replace, Disability Living Allowance (DLA). In this report we assess the extent to which is has achieved its objectives, with evidence drawn from the experiences of people seeking help with the transition from DLA to PIP from us at Citizens Advice Sheffield.

2. We find that there are winners who receive more benefit and losers whose benefit is reduced – often substantially. Our evidence indicates that:

   - More restrictive PIP criteria have adversely affected many disabled people with severe walking problems, with older people particularly badly affected.
   - A growing cohort of older people has no opportunity for a review of their benefit if their condition worsens.
   - The assessment process presents specific access problems for Deaf clients and places particular strain on people with mental health issues.
   - There is a question over the quality of DWP decision-making, given the high proportion of decisions reversed by the independent appeals Tribunal, and many clients spend months without benefit while going through the appeal process.
   - DWP decisions can be confusing and even contradictory when award letters notify clients of a review date earlier than the end of their award period.
   - Reduced awards under PIP can have a serious knock-on impact on other 'passported' benefits, with sudden and substantial losses and deterioration in overall quality of life.
   - The PIP process, and subsequent decisions, are far from easy to understand for many clients accustomed to DLA arrangements.

3. The full report below explores these issues in more detail, explaining the impact of PIP decisions on people's lives, and sets out the rationale for our recommendations, to:

   - Reinstate the benchmark distance of 50m originally proposed by DWP in its public consultation as a gateway to the enhanced rate for

Mobility, to avoid people with substantial walking difficulties due to unchanging chronic long-term disability suddenly losing financial support for getting around.

- Allow people undergoing DLA-to-PIP reassessment at age 65 and over the same opportunity for subsequent review and reassessment of the Mobility component that is available to people reassessed before age 65.
- Give qualifying claimants over 65 an indefinite award, unless their health condition/disability is one which is clearly likely to improve.
- Remove the unnecessary, counter-productive ”planned intervention” measure, since other provision exists for limited short-term awards which are reconsidered on renewal.
- Ensure that interpretation or other communication aids for face-to-face assessments are provided when requested on the PIP2 claim form, without further covert barriers.

The introduction of Personal Independence Payment

4. With the overt aim that 500,000 fewer people would receive the new benefit by 2015-16 than would have received DLA under the existing rules, PIP also promised to deliver savings of over £1 billion a year by 2014-15, rising to £1.5 billion a year by 2016-17.[1] The criteria for PIP would be more restrictive and there would be an increase in the numbers of claimants having to undergo a face-to-face assessment by health care professionals in order to assess entitlement to the benefit.

5. However the envisaged savings have yet to materialise. In early 2016 proposals to restrict PIP criteria further were rejected and led (in part) to the resignation of Iain Duncan Smith as the Secretary of State for Work and Pensions. In his resignation letter to the Prime Minister he wrote "I have for some time and rather reluctantly come to believe that the latest changes to benefits to the disabled and in the context in which they've been made are a compromise too far..."[2]

6. In its Welfare Trends report of October 2016 the Office for Budget Responsibility reported that "the introduction of PIP is estimated to have reduced spending by just £0.1 billion in 2015-16, well short of the initial goal of cutting working-age spending by 20 per cent relative to DLA..."[3]

PIP in Sheffield

7. In Sheffield, PIP was launched for new claimants in June 2013 and the roll-out to existing DLA claimants began at the end of February 2015. There were understood to be 18,000 DLA claimants in Sheffield at the start of the process. The roll-out is not expected to be completed until late 2017.

8. The introduction of PIP was rushed. The Department for Work and Pensions (DWP) did not pilot the new process and received widespread criticism of the resulting delays and administrative inefficiencies. The impact on disabled people of the introduction of PIP in Sheffield was

[1] *Disability Living Allowance reform - Commons Library briefing* (UK Parliament, February 2011)

[2] *In full: Iain Duncan Smith resignation letter* (BBC News website, March 2016)

[3] *Welfare Trends Report* (OBR, October 2016)

detailed in an earlier report by Sheffield Citizens Advice in May 2015[4]. That report described the introduction of PIP, drawing upon the experiences of some of the 1,260 people who contacted us for help with the benefit between October 2013 and October 2014, and mainly focused on the problems caused by delays in the claim and assessment process and the consequent broader difficulties experienced by our clients in Sheffield.

9. DWP and its subcontractors carrying out the medical assessments (ATOS Healthcare in Sheffield) have largely succeeded in reducing these delays and this is welcomed; our recent experience confirms DWP's statistics which show that the time taken for assessments has been greatly reduced. In order to achieve this, however, the subcontractors had to take on additional staff and open more assessment centres, and DWP also introduced new guidance for assessment providers "to support them to increase the proportion of cases …… assessed from paper evidence…", an apparent departure from the original intention to increase the numbers of claimants undergoing a face to face assessment under PIP.[5]

10. Having introduced PIP as the new disability benefit for people of working age, the next, and final, phase of the PIP programme is the reassessment of all DLA claimants under PIP criteria, to make a new decision on continued entitlement to benefit. This reassessment applies to all DLA claimants who were aged under 65 on 8 April 2013, even in cases where their existing DLA award is for an indefinite period. Many of these 'DLA reassessment' claimants have come to us for help.

11. In this report, which follows up our 2015 research, we set out the key issues currently facing PIP claimants and describe the impact on their lives, incorporating individual anonymised case studies which illustrate this in depth. This time we focus mainly on the impact on DLA claimants going through reassessment for PIP. As before, our evidence comes direct from our work with clients, drawing on the experiences of the 2,235 people who contacted us for help with PIP between 1 October 2015 and 31 December 2016.

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[4] *Personal Independence Payment: a report into the impact on the people of Sheffield who approached Citizens Advice for help* (Citizens Advice Sheffield, May 2015)

[5] *Touchbase: DWP news for advisers and intermediaries* (October 2014)

Differences between DLA and PIP

12. The key differences are:

- PIP has different qualifying rules to DLA, and the two benefits view disability from different perspectives in that, unlike DLA, PIP is a points-based system, meaning that if a claimant cannot show that he or she meets the narrow points-based criteria then they cannot get the benefit.

- The DLA Care component was assessed on the reasonable requirement a claimant may have for either help or supervision from another person (even if that help or supervision wasn't actually provided). Decisions on the rate of DLA awarded were clearly related to whether the need for help arose either during the day and/or at night. PIP Daily Living component, while not in any way discounting the need for a carer, places greater emphasis on a claimant's ability to carry out certain narrowly-specified daily living activities and scores claimants against these.

- There is consequently less flexibility within the PIP criteria for decision makers to explore the evidence holistically and then make an appropriate award.

- PIP requires an assessment from DWP's contracted-out services before a decision on entitlement can be made. Many DLA claims were decided solely on the information given by the claimant and/or their GP.

- PIP claimants are more likely to have an assessment involving a face-to-face consultation, notwithstanding the changes to guidance referred to above.

- The PIP Daily Living component has two rates of payment whereas the DLA Care component has three.

- Most PIP awards will be reviewed on a more frequent basis than DLA, even for permanently-disabled claimants.

However in practical terms the main difference for claimants between DLA and PIP is how entitlement is assessed.

PIP roll-out in numbers

13. In November 2015 the Office for Budget Responsibility predicted that 74% of transferred claims would result in an award of PIP.[6] DWP statistics revealed that, by the end of October 2016, 526,500 DLA reassessments to PIP had been "cleared" in Great Britain. [7] Of these claimants, 75% had received an award, specifically:

   - 209,600 (40%) had their benefit increased;
   - 62,900 (12%) had their benefit left unchanged; and
   - 120,700 (23%) had their benefit decreased, but not stopped altogether.

14. Of the claims which did not receive an award:

   - 110,000 (21%) were disallowed after the assessment;
   - 19,500 (4%) were disallowed before the assessment; and
   - 3,700 (1%) withdrew their claim (mainly where people failed to take up the 'invitation' to claim PIP).

15. In comparison with original forecasts[8]:

   - 40% of DLA claimants who registered to claim PIP received an increase in the level of benefit, a significantly higher proportion than the 29% forecast in December 2012;
   - 48% of those who registered received a lower level of award or no award, below the 55% forecast in December 2012; and
   - 25% of the cases registered were awarded PIP at the highest rate (enhanced Daily Living with enhanced Mobility components). This compares with 15% under DLA.

16. These figures also confirm that more people with mental heath problems are receiving PIP than under DLA and this is to be welcomed as a positive step towards the Government's stated aim of creating a 'parity of esteem' between physical and mental health problems. However, at the time of writing, this issue is the ongoing subject of debate and parliamentary

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[6] *Economic and Fiscal Outlook* (OBR, November 2015)

[7] *Personal Independence Payment: Official Statistics* (DWP, October 2016)

[8] *Timetable for introducing Personal Independence Payment and estimates of projected caseloads policy briefing note* (DWP, December 2012)

scrutiny as the Government has introduced amendment regulations to restrict PIP criteria to exclude the impact of "overwhelming psychological distress" which we consider is a backward step in achieving 'parity of esteem'.

Impact on our clients

Moving the 'walking' goalpost

17. Prior to the introduction of PIP, a physically disabled person could show entitlement to the higher rate of the DLA Mobility component if they were assessed as being "virtually unable to walk" under Regulation 12 of the relevant secondary legislation. This assessment took into account four factors: distance, speed, time and manner.[9]

18. While the DLA legislation did not require a specific distance to be used when determining inability to walk, commonly, when assessing against the other factors, disabled applicants were found to satisfy this test if they struggled to walk up to 50 metres. This approach was generally supported by Upper Tribunals and Courts and became a benchmark for entitlement to the higher rate of the Mobility component.

19. For many disabled people with severe walking difficulties an award of the Mobility component at the higher rate gave access to schemes and concessions designed to improve mobility and independence, including Blue (parking) Badges, travel passes and concessions and reductions in Vehicle Excise Duty.

20. One of the most important of these is the Motability scheme which offers cars, including adapted cars, powered wheelchairs and mobility scooters. Cars supplied through Motability come inclusive of insurance, MOT and breakdown cover thereby reducing stress and worry for users and their families.

21. The benefits of the Motability car scheme to disabled users, their families and the wider economy have been highlighted in independent national research[10]. This confirms that the scheme greatly increases its customers'

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[9] *The Social Security (Disability Living Allowance) Regulations 1991* (HMG, December 1991)

[10] *Economic and social impact of the Motability Car Scheme* (Oxford Economics and Plus Four Marker Research, September 2010)

independence, enabling them to make spontaneous and independent decisions to travel, and undertake activities of their own choosing. Over 70% of car users surveyed said that they were more independent with a Motability car, with 49% saying “a lot more”. Disabled people’s own ranking of the choice and control they had over their lives increased, on receipt of a car, from an average of 3.8 to 7.9 (out of a maximum 10). Some 77% of car users surveyed also reported a positive difference to their physical and mental health.

22. Research participants’ own ratings of their ability to travel independently outside their home increased from an average 3.5 to 8.3 (out of a maximum 10) after getting a car, with increases also in the likelihood of their driving themselves and the frequency with which they did so. There is evidence too that this improved mobility enhances many other aspects of the lives of disabled people and their carers, including their access to health services, education, employment and social activities. For example, of Motability users able to work, 39% said that their car had enabled them to gain or keep employment or get a better job, and the car enabled 7% of carers to improve their employment prospects, in total worth an estimated £1.2 billion in gross wages per year.

23. The research also attempts to quantify the benefits of the Motability scheme to the wider economy, in income and public sector savings. For example, reduced usage of ambulance/dial-a-ride services by Motability customers was estimated to save the public sector £30m, with a decline in missed medical appointments saving an estimated £32-£79 per appointment. Overall, it calculated that in 2009 the Motability scheme contributed an estimated £2,015m to UK GDP (0.1% of the total) and £468m to the Exchequer in tax receipts; also that it supported 21,080 jobs (nearly one in every thousand jobs in the UK).

24. The equivalent PIP criterion is the enhanced rate of the Mobility component which is established if the claimant is awarded 12 points in the ‘moving around’ assessment. Repeatedly during DWP’s public consultation on the introduction of PIP, their proposal set the qualifying threshold at 50 metres, which would have mirrored the equivalent DLA higher rate Mobility criterion. However, when the final Regulations were published the relevant distance had been reduced to 20 metres, thus raising the bar for many claimants with the inevitable consequence for some, including those who condition was unchanged, that they would see

a reduced award. For many, this would mean losing access to the Motability scheme.

25. This change in qualifying distance therefore deprives some disabled people and their families of all the benefits highlighted above, causing a sudden, major deterioration in their quality of life. Although there is limited compensation available for some people losing their cars – one-off payments of either £1,000 or £2,000 depending on when they joined the scheme - the amounts involved for individuals are an inadequate substitute, and this funding will sooner or later run out. (The charity Motability received a one off £150 million payment from the Government in 2014[11] to "deliver the one-off transitional package of support for disabled people … no longer eligible for the Motability scheme".)

26. At the beginning of 2016 it was reported that nearly 14,000 disabled people had had their cars taken away as a consequence of moving from DLA to PIP. [12]

Mary is 34 and has Multiple Sclerosis. She has been in receipt of DLA since January 2013. At her last DLA claim renewal in 2015 she was awarded highest rate Care and higher rate Mobility in recognition of the severity of her condition and its effect on her daily living and walking ability, being assessed as being "virtually unable to walk". On her claim form she declared that she couldn't walk further than 40-50 metres without severe discomfort, and this was verified in writing by a specialist MS nurse.

In October 2016 she was invited to claim PIP, by which time her overall condition had deteriorated further so that her walking was limited to 30-40 metres. After assessment she was awarded the standard rate of both Daily Living and Mobility components, scoring 10 points for each. Her mobility score in the 'moving around' activity was based on an assessment that she could walk more than "20 metres but no more than 50 metres."

Although Mary is considering challenging her award the decision is unlikely to change as it is an accurate reflection of her walking ability, assessed under the

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[11] *Charity Income Spotlight report highlights continued growth in sector* (UKFundraising website, May 2016)

[12] *Nearly 14,000 disabled people have mobility cars taken away* (BBC News website, February 2016)

more stringent PIP criteria. Mary will lose £62.85 per week. She is struggling to understand why she has been penalised in this way when it is accepted that she suffers from an incurable and very disabling health condition which severely limits her mobility.

Impact on older people

27. Some older people who have contacted Citizens Advice Sheffield after PIP reassessment have reported a reduction in their Mobility award (which for some has led to the subsequent loss of their Motability car). Many of these people have seen no identifiable improvement in their walking ability since they were awarded the DLA Mobility higher rate after being assessed as being "virtually unable to walk." The award of standard rate under PIP can often be identified as being solely due to the change in the criterion which reduced the qualifying walking distance from 50m to 20m. As the assessment often accurately reflects a client's walking capacity this decision would be unlikely to change on review or appeal.

Joan, aged 68, had been in receipt of DLA since 1994 due to a number of health problems including osteoarthritis, fibromyalgia, lupus and an anxiety disorder. In 2002 her walking problems had deteriorated to the point where she asked for her DLA to be looked at again and, following a medical examination at home by a doctor sent by the then-Department for Social Security, she was awarded the highest rate of both the Mobility and Care components. The mobility award was made on the basis that she was, in effect, virtually unable to walk, and she used her award to get cars through the Motability scheme. When her DLA was last assessed she was awarded it for life (indefinitely).

On reassessment for PIP she was awarded the standard rate of both components scoring 11 points for Daily Living and eight for Mobility, her walking ability having been assessed as limited to 20-50 metres. As a consequence her benefit has been reduced from £82.30 to £55.10 and she has had to give up her Motability car as she no longer qualifies for the scheme. This has had a dramatic effect on her quality of life: previously she was able to go out as she chose, for leisure and to visit friends and family, whereas now she restricts herself to leaving her house just twice a week by taxi. This costs her well over £20 per week, meaning that the one-off compensatory payment for loss of her Motability car will be exhausted within two years. Joan is still struggling to understand why this has happened. As she told us, she "went to the [PIP] assessment in her car having been assessed as needing it and came out having been assessed as not. Even though I'm a lot older now and my health hasn't got any better."

28. With short-term finite awards preferred to indefinite “ongoing” arrangements, more and more people over 65 will face uncertainty over their Mobility award under PIP due to the likelihood of repeated reassessment, despite getting older. Many of these claimants will have previously been informed that their DLA mobility award was indefinite.

No opportunity for review for some over 65s

29. The effect of the change in the Mobility qualifying criterion is all the more stark for older people because their options for redress are much more limited.

30. As with DLA, first-time claimants for PIP must be aged between 16 and 65. New claimants with disabilities aged over 65 must claim Attendance Allowance which has no Mobility component. Claimants awarded PIP before they were 65 will continue to receive it after they are 65 (subject to reassessment rules at the end of finite award periods) rather than transfer to Attendance Allowance.

31. Anyone in receipt of DLA who was over 65 on 8 April 2013 (the date PIP was introduced) will not be transferred to PIP. However, all DLA recipients who were under 65 on that date will be reassessed for PIP when roll-out of the new benefit catches up with them. As that timetable has slipped, some people have turned 65, and older, while waiting for this reassessment, so that, with PIP roll-out not expected to conclude until late 2017 at the earliest, the upper age at which that first reassessment may take place is increasing, standing at 68 and rising at the time of writing.

32. This matters because although people first assessed for PIP before turning 65 have the opportunity to get the Mobility component reassessed at a later date if their walking ability deteriorates, those whose first PIP assessment comes at age 65 or over must remain permanently on the Mobility rate they are awarded at that time, or with no Mobility award at all, with no subsequent opportunity for review or re-assessment, no matter how much worse their mobility becomes. There is a cohort of over-65s caught in this unfair position, and their numbers will have increased due to the delays in PIP roll-out.

33. The use of 65 as a cut-off point is harder to justify given that this is, in effect, no longer the upper end of ‘working age’, and, as we note above, the right Mobility award can support people’s capacity to continue working.

The PIP assessment process

24. The claim process for PIP differs markedly from that for DLA. DWP decision makers could, and did, make DLA award decisions based solely on the claim form completed by the claimant, in conjunction with the medical or other evidence that they provided. Decision makers could also arrange a medical examination if they felt it necessary or request factual reports from the claimant's GP or other health professionals in order to decide a claim.

35. In contrast, the majority of PIP claimants are expected to have a face-to-face assessment, which in Sheffield is carried by ATOS Healthcare. According to ATOS, examinations are carried out by "Healthcare professionals (physiotherapists, nurses, occupational therapists and paramedics) … trained to accurately assess the impact of your health conditions or disabilities on your daily life using DWP criteria"[13]

Problems reported to us by Deaf clients - no access to interpreters

36. At the time of writing most of the 56 Deaf clients who have contacted us for help, either with new PIP claims or DLA to PIP reassessment, were reporting that their requests for communication support, such as by BSL signers or lip speakers, were not being acted on. This includes all cases where our advisers had helped to complete the PIP2 questionnaire and made specific requests for help with communication at the face-to-face assessment. The evidence of our clients, confirmed by ATOS healthcare when we spoke to them, was that any such request would not be acted on without a further telephone call to them to confirm this help was needed. For many Deaf people, who cannot use the telephone without help, this additional step presents a further hurdle for them in the assessment process and shows a concerning disregard for the basic needs of Deaf people.

37. The Original PIP2 claim form (pre-October 2016) stated: *"You are likely to be contacted soon to arrange a face to face consultation……Tell us about any help you (or someone who may accompany you) would need if you have to go for a face to face consultation. This will help us ensure your needs are*

[13] *Who performs your PIP Assessment* (ATOS Healthcare website)

met.....For example tell us if: .....you/they have communication needs and what support you/they will need...Please be specific about the needs you/'they have...". Assisting a deaf man with the PIP2 form, the adviser wrote *"Mr K requires a British Sign Language Interpreter to be provided....He is unable to contact you regarding this matter. Please accept this as a formal request."*

38. The current PIP2 form (from October 2016) asks: *"Tell us about any help you (or someone you bring with you) would need if you have to go for a face-to-face consultation"*. When assisting another deaf man, the adviser wrote *"British Sign Language interpreter needed for a face to face assessment. C cannot telephone and arrange this himself so please accept this as a formal request."*

39. In both of these examples, when the adviser called ATOS Healthcare they were told that an interpreter was not arranged for the face-to-face assessment and would not have been arranged had the follow-up call not been made. Despite reassurances from ATOS Healthcare to our Deaf Advice Team that their systems would be amended to ensure that a BSL interpreter would be available at the face-to-face assessment if requested on the claim form, evidence at the time of writing points to this not being the case.

Problems reported to us by people with mental health problems

40. The face-to-face assessments are almost universally disliked by our clients, and those with mental health problems find them especially stressful. Many complain of lack of sleep in the days and weeks leading up to the assessment. Joseph's experience is illustrative:

    Joseph is 49 and has chronic mental health problems, suffering from Obsessive Compulsive Disorder. Consequently, he finds daily life very difficult, and was receiving DLA (middle rate Care, lower rate Mobility). He found the transition to PIP extremely stressful, worrying constantly that there might be insufficient information on the PIP2 form and then being so traumatised by the face-to-face assessment in February 2016 that he was unable to leave the venue for an hour after the process was completed. He couldn't understand the point of some of the questions and reported afterwards – as do many of our clients - that he had the impression that they were trying to catch him out.

41. Other clients with specific mental health diagnoses have reported poor experiences with the face-to-face assessments in which they were

disadvantaged by the healthcare professional's lack of understanding of their condition, resulting in a negative decision.

Gina is 17 and has a long history of involvement from Child and Adolescent Mental Health Services. She has been diagnosed with Post-Traumatic Stress Disorder, severe anxiety and an eating disorder, and has attempted suicide several times.

The ATOS health care professional in Gina's PIP assessment was a paramedic. His report - which led to her DLA stopping and no further award of PIP being made – included his assessment that "the fact she does not eat is more in line with her feelings that she cannot be bothered, than out of any medical reason". He also maintained that Gina had "no cognitive impairment" despite having available to him a recent extensive report from a consultant psychologist which reported "low verbal comprehension, extremely low processing speed and problems with working memory".

42. Similarly:

Martin, diagnosed with Autism Spectrum Disorder and selective mutism, lost his DLA and wasn't awarded PIP following a face-to-face assessment, attended by both Martin and his mother, in which the healthcare professional advised that he did not have a medically-recognised anxiety disorder but simply chose not to communicate.

A Tribunal later decided that Martin was entitled to the Enhanced rate of both components of PIP. No new medical evidence was presented, but the Tribunal – unlike the ATOS assessor - took into account their observations of Martin and the verbal evidence of his mother.

Winners and losers

43. It is clear from what our clients tell us, and confirmed by DWP statistics, that there are winners and losers in the transition from DLA to PIP. Many more claimants are being awarded PIP at the enhanced rate than anticipated. This also applies to new PIP claimants. We welcome this. However it is also clear that there are losers who either lose benefit totally or see a reduction in the amount paid.

Cynthia is 37, and lives alone. She suffers from depression and phobic anxiety which prevents her leaving the house; she has been diagnosed with Tourette's disorder, experiences panic attacks brought on by paranoia and has a history of self harm. Cynthia has one friend who helps her but she sees nobody else

socially apart from her mother and sister. Her mother always accompanies her when she goes out.

Cynthia claims Income-related ESA, and is in the Support Group. Until recently she was also receiving DLA highest rate Care and lower rate Mobility. After DLA reassessment in June 2016, she was refused PIP, scoring no points for Daily Living and four for Mobility. Because of this decision she has also lost the Severe Disability Premium on her ESA and is left with £165.95 per week less in benefit, receiving only her basic ESA of £125.05 per week. So as a consequence of the PIP decision she has lost over half her income.

44. The question arises as to how so many people with unchanging long-term disabilities like Cynthia can lose out so heavily when they go through the reassessment from DLA to PIP. It might be logical to assume that one or other of the awards, DLA or PIP, must be the result of an incorrect decision, but this is not always the case. Cynthia was entitled to the DLA award that she received. It is hard to see the justification for the (frequently large) differences in payment between a previous DLA award and a subsequent PIP decision for the same person with the same chronic medical condition.

45. The validity of the DLA and PIP criteria as tools for assessing disability can be debated. But in our view it cannot be right that such a large number of vulnerable people experience such sudden and substantial losses of income because they met the criteria for DLA but not those for PIP.

Concerns about the quality of decision-making

46. Many of our clients who have come to us for advice and help with appeals against PIP decisions find that DWP's conclusion on their entitlement can be radically different from that reached on appeal by the First-tier Tribunal, even though both are based on exactly the same evidence. The case history of Martin, above, is a good example, of this as is that of Sabina:

Sabina suffers from Post-Traumatic Stress Disorder (PTSD), depression and epilepsy. She lives with her 21 year-old daughter Laila who, as well as being a student at University of Sheffield, is Sabina's main carer, coming home between lectures to check on her.

Sabina's PTSD originates from seeing relatives and friends die in bombing in Afghanistan. Her condition deteriorated in 2008 and 2009 and she received support from social services between 2010 and 2014. Sabina's epilepsy

seizures are unpredictable, varying between three-four attacks a day and four-five a month; she sometimes goes as many as 10 days without a seizure but has not been seizure-free for two months or more for many years. Laila tells us that her mother is either angry when she isn't on medication for depression, or completely indifferent to everything when she is.

Sabina was receiving DLA highest rate Care component and lower rate Mobility. After assessment for PIP, she was awarded two points for Daily Living and four for Mobility, meaning that her PIP claim was turned down and she lost her DLA. On appeal, however, the Tribunal awarded her 36 points for Daily Living and 20 points for Mobility so she now receives PIP enhanced rate for both Daily Living and Mobility.

47. Many of our clients have had similar experiences. It is hard to see why the considered conclusions of DWP and the First-tier Tribunal differ so radically, such that 65% of PIP appeals are successful, overturning DWP's original decision.[14]

48. For disabled people, and for their carers, there are many aspects to a disability. They live with their problems every day. By contrast, DWP sees a disabled person claiming PIP solely through a set of 'descriptors' which can be scored. To be successful, a claimant must demonstrate, in the evidence they provide on the PIP2 claim form and at the medical assessment, how their ability measures up to the relevant descriptors and thus score sufficient points for a PIP award. Many struggle to complete the long and complex form without help. As is often the case, Martin and Sabina only sought advice from us once their PIP claims were refused. Sabina's daughter told us that Sabina found it difficult to articulate her problems in the way required by the PIP criteria, but she also felt that the face-to-face assessment did not identify the severity of her illness.

49. Even given the above factors, the disparity in the number of points awarded to Martin and to Sabina by the Tribunal and by DWP, using exactly the same evidence and criteria, cannot be easily explained.

50. The PIP First-tier Tribunal is made up of a judge and two other people, one of whom is always a doctor. It is independent and impartial but bound by the same rules and Regulations as DWP. It is inquisitorial by nature, using

[14] *Tribunals and gender recognition certificate statistics quarterly: July to September 2016* (Ministry of Justice, December 2016)

questions in a forensic manner to test evidence and establish facts. In the cases of Martin and Sabina it is hard not to conclude that if the face–to-face medical assessment had been carried out effectively and in a similar manner, their eligibility for PIP should have been identified in the first instance.

Impact of incorrect DLA reassessment decisions

51. The first reaction of many of our clients who are refused PIP after receiving DLA for many years is often disbelief. *"When am I going to get my money back?"* Cynthia, whose appeal is underway at the time of writing, keeps asking us.

52. Many of our clients also find it difficult to grasp that the new PIP assessment is **not** linked to their DLA award or any previous DLA assessment. *"They already know all this"* is a common reaction. Although DLA reassessment claimants can request that account is taken of previous medical information held on them, this is not done automatically and DWP is effectively starting with a blank sheet of paper, requiring fresh evidence that supports the PIP criteria rather than those for DLA.

53. Unsurprisingly, claimants do not always see it like this: from their point of view, the PIP award is a continuation of the support they received through DLA. Their DLA award pays for the extra costs of their disability and goes some way towards enabling them to lead more rewarding, inclusive and productive lives. The name "Personal Independence Payment" suggests that it is paid broadly for the same purposes. For many this can mean being able to leave the house and take part in activity that non-disabled people routinely take for granted, for others it can help with paying for support and care in the home. For some it may be the extra financial help needed to find or keep work.

54. The abrupt ending of support when a PIP claim is refused after a DLA reassessment is having a serious effect on the lives of claimants and their carers. It also has potential to place extra strain on NHS and social care services. In cases like Cynthia's it is not an exaggeration to say that her ability to live independently is threatened by the loss of her disability benefit.

“Planned intervention”/review

55. Medical conditions do change and it makes sense for there to be mechanisms in place to review decisions as necessary, for example by limiting the term of the initial award and considering a claimant’s circumstances again at the time of renewal. However, the PIP Regulation on ‘redetermination of ability to carry out activities’ [15] allows for an award of PIP to be reviewed (and revised) at any time and for any reason without the need to establish that any change in a claimant’s condition has taken place.

56. One of the ways that this manifests itself has become known as a “planned intervention”, an entirely new mechanism for review. In cases selected for “planned intervention”, DWP awards benefit for a fixed period but at the same time notifies the client that they will look at the claim again at a date (usually a year) before the expiry date of the award. In effect this makes the period after the review date a provisional award only. Clients are understandably confused by such contradictory messages from DWP (in essence saying “we agree you should have PIP for X years but actually we might change our minds earlier”) and in some cases this causes great anxiety and distress. Our clients with mental health difficulties are particularly badly affected.

57. Concerns are exacerbated by the fact that no rationale is ever given for why someone has been chosen for this type of review. Our own evidence does not reveal any pattern based on the type or severity of condition which might explain this. From DWP’s guidance, we now understand that a decision to review is made because the case manager thinks, on the basis of the PIP questionnaire and the health professional’s recommendations, that there is a possibility that a client’s condition may change, for the better or the worse, in a certain timescale. The relevant Regulations also appear to allow one DWP decision maker to overturn another’s decision without having to show grounds for doing so.

58. This is best illustrated by Joseph’s experience:

Joseph’s decision letter tells him he has been awarded PIP until August 2018 but also states that DWP will review his claim in August 2017. This “planned

[15] *The Social Security (Personal Independence Payment) Regulations 2013* (HMG, 2013)

intervention" will require him to complete another PIP claim form a year before his award ends, and if he does not do this, his claim will be stopped. As far as he is concerned, he hasn't been awarded PIP until August 2018 but only as far as August 2017. As the decision on his original claim was made in February 2016 he will be repeating the claim process just 18 months after being notified of his current award. Joseph has severe and enduring mental health problems, typified by paranoia, severe anxiety and Obsessive Compulsive Disorder. Instead of reassuring him that his benefit is secure for a further two years, the award letter, notifying him of the intended review, had the reverse effect of increasing his anxiety levels, compounding the difficulties he faces every day due to his overall mental health problems.

59. We believe that there is no justification for "planned intervention" and cannot see any good reason why it is useful to DWP itself, as it appears to generate a greater administrative burden. If an award letter states that an award is for three years it should not, in the next paragraph, then reduce this to two years, as it clearly has in Joseph's case.

Conclusions

60. This evidence from our clients' experiences points to the introduction of PIP having so far failed to realise its main aims.

61. The case for reform was based on the assertion that DLA had remained unchanged since the early 1990s and had "failed to keep pace with the changing approach to disability in society"[16]. PIP would be fairer, simpler to administer and easier to understand, and would support those disabled people facing the "the greatest challenges" in "remaining independent and leading full active lives." At the same time it would save £1 billion a year by 2014-15 (rising to £1.5 billion by 2015-16).[17]

Fairer

62. That PIP is by design a fairer benefit than its predecessor has yet to be borne out by the evidence.

63. DWP statistics show that there are winners under the new benefit, many of whom have been awarded benefit at higher levels than originally envisaged, and losers who similarly have lost benefit under reassessment from DLA.

64. Winners and losers are to be expected under a major benefit reform. However there is nothing obvious in the PIP outcome decisions, on either winners or losers, which can confidently be attributed to a fairer assessment of their disabilities. For disabled people undergoing DLA reassessment, under PIP criteria, the fact that they win or lose is not an indicator of fairness or merit.

65. We welcome the fact that many vulnerable disabled people have been awarded benefit at increased levels. However, we have major concerns that some of the losers in this reassessment, in particular the older disabled people with mobility problems described earlier in this report, have been disproportionately affected and that, as PIP losers, with limited options for redress in the future due to their age, this is blatantly unfair.

[16] *Personal Independence Payment: an introduction - Commons Library briefing* (UK Parliament, November 2012)

[17] *Disability Living Allowance reform - Commons Library briefing* (UK Parliament, February 2011)

Simpler to administer

66. The evidence of certain groups of people who sought help from Citizens Advice Sheffield points to the administration of PIP presenting additional hurdles for them to overcome. The experiences of our Deaf clients being required to telephone to request a BSL interpreter at face-to-face assessments is an obvious example.

67. The catch-all “planned intervention” Regulations, with no requirement to justify such action, also installs an unnecessary complication in the administration process, causing confusion and uncertainty for many of our clients.

Easier to understand

68. The PIP points-based assessment system, scoring against a series of statements describing certain daily living and mobility activities, is ostensibly more transparent than was the case with DLA.

69. However in practice clients often struggle to understand why they are asked about their capacity to perform these specific activities rather than being able to describe their own circumstances. Furthermore, we find that the PIP statements can be narrow and arbitrary in that they do not always capture disabilities, conditions and resulting care needs clearly experienced by our clients, which would have been recognised under DLA.

70. We also see evidence of assessments and/or DWP decisions denying people points on activities which they cannot themselves perform because they happen to have support available – for example, from a family member. This forced reliance on others entirely contradicts the ”independence” aim of PIP.

Savings

71. The Office for Budget Responsibility has found that the actual overall saving of £0.1 billion in 2015/2016 falls far short of what was envisaged. DWP statistics confirm that more claimants are being awarded benefit at higher rates and fewer are seeing their benefit reduce than was originally anticipated. If these trends continue it is hard to see if any further savings will materialise, and increases the likelihood that this major welfare reform will actually end up costing more than the benefit it sought to reform - without having achieved a fairer system.

72. It is also worth noting that loss, reduction or interruption of benefit potentially places an additional strain on other public services including adult social care and the NHS.

Recommendations

73. Our contact with other parts of the Citizens Advice service indicates that the concerns set out above are widely shared, and we know too that PIP has been receiving closer attention from MPs and peers recently. Naturally, we welcome this, and hope this report makes a useful contribution to the debate. We call on Government to prioritise the following improvements, which we believe would help to ensure that PIP is indeed providing a fairer and more consistent mechanism for delivering support for personal independence:

- Reinstate the benchmark distance of 50m originally proposed by DWP in its public consultation as a gateway to the enhanced rate for Mobility, to avoid people with substantial walking difficulties due to unchanging chronic long-term disability suddenly losing financial support for getting around.

- Allow people undergoing DLA-to-PIP reassessment at age 65 and over the same opportunity for subsequent review and reassessment of the Mobility component that is available to people reassessed before age 65.

- Give qualifying claimants over 65 an indefinite award, unless their health condition/disability is one which is clearly likely to improve.

- Remove the unnecessary, counter-productive ”planned intervention” measure, since other provision exists for limited short-term awards which are reconsidered on renewal.

- Ensure that interpretation or other communication aids for face-to-face assessments are provided when requested on the PIP2 claim form, without further covert barriers.

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