

Personal Independence Payments (PIP) As Experienced By Those Affected By Mental Health

Introduction

This is the third published report as part of our Micro Volunteering Project. In December 2017 we published the report on Mental Health and Welfare Benefits [link](#). The second report focused on the experiences of those affected by mental health with regard to Employment and Support Allowance [link](#).

This report focuses on how those affected by mental health, and those who support them, experience Personal Independence Payments (PIP). The report highlights experiences of individuals with a mental health diagnosis, individuals concerned about their mental wellbeing, family members & carers, CA Merton and Lambeth volunteers and advisers/support professionals. We describe PIP and then focus on individual experiences from first awareness of the benefit to challenging decision and sanctions.

The experiences of our micro volunteers reflected practice prior to the December 2017 court ruling that recent restrictions to Personal Independence Payment (PIP) discriminated against people with mental health problems.

***Micro Volunteering – With the support of the Martin Lewis Foundation, Citizens Advice Merton and Lambeth have researched some of the issues affecting our clients and campaigned around these issues through short, bite-sized volunteering opportunities called micro-volunteering. Our micro-volunteers – including clients, existing service volunteers, staff and professionals from other organisations - have shared their experiences through surveys and interviews.**

What is PIP?

Personal Independence Payment (PIP) is designed to help with the extra cost of living for those with a disability or long-term illness. There are two components of PIP – daily living and mobility - and both can be paid at either standard or enhanced rate. It is possible to receive one or both of these components (but only one rate can be paid). In order to receive PIP individuals need to have had the mobility/care needs for at least three months and expect them to last for nine months or longer unless special rules in the event of a terminal illness apply.

PIP replaced Disability Living Allowance (DLA) for all people of working age. It was initially introduced in April 2013 for all new claimants and has slowly been rolled out to existing claimants on DLA. This includes claimants who were awarded life-long DLA awards. DLA continues to be in place for children and young people under 16 and Attendance Allowance for those 65 and over. As with DLA, people 65 and over can continue to receive PIP, providing they claimed before they reached 65.

Unlike DLA, most people who claim PIP will need to undergo a medical assessment to determine whether they qualify. PIP is not designed to be an earnings replacement and other benefits can be claimed as well, for example Universal Credit (UC) or Employment and Support Allowance (ESA). An award of PIP can also 'passport' claimants or other members of their household to additional premiums within UC/income-related ESA and/or Carer's Allowance. In addition, if an award of PIP or DLA is made to either the claimant or a member of their household it will exempt the client from the benefit cap for non-working households.

As with other benefits, to challenge a PIP decision the claimant needs to ask for the decision to be looked at again (a Mandatory Reconsideration). If this is refused the client submits an appeal outlining the reasons why they disagree with this decision. The case will then be heard at a tribunal hearing.

In December 2017m the courts ruled ruling that recent restrictions to Personal Independence Payment (PIP) discriminated against people with mental health problems.

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Merton & Lambeth

If you're claiming PIP for a mental health problem, one part will look at how your mental health affects your daily life, and the other will look at how your mental health affects your ability to travel and make journeys. In March 2017 the Government changed the law so that people who find it hard to make journeys because they experience overwhelming distress are entitled to less support from PIP than other people.

In December the courts said these changes were unlawful because:

- They unjustifiably discriminate against people with mental health problems
- The Government didn't consult on them
- The Government didn't have the right powers to make them

The Government have now said they won't challenge this decision and will make sure that people who experience psychological distress can be eligible for support from PIP in the same way as other disabled people.

Citizens Advice Merton and Lambeth Experience

In 2017, Citizens Advice Merton and Lambeth advised on 1,716 queries relating to PIP.

Requests for our advice and support ranged from assistance completing application forms through to advice/support with appeals. The priority support areas are queries/support re eligibility and appeals (over 20% of requests for support focused on appeals).

60% of clients approaching us with PIP queries were female and 40% male with an age range from under 19 to 70-74 years of age. The majority of clients were aged between 50 and 59 (over 20%) with over 50% affected by a long term health condition. 18% of clients disclosed they have a mental health diagnosis, but many more were reluctant to share or admitted to being concerned about their mental wellbeing or carers/family members.

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CA Merton and Lambeth also provide a Merton Disability Benefits service. Within this service we have seen many clients lose out on PIP, particularly in relation to their mobility or mental health issues, when they are invited to transfer from DLA. We hear from clients that assessors do not have an understanding of the impact of their health condition and therefore do not appreciate the immense challenges clients are facing on a day-to-day basis. This certainly appears to be the case with mental health conditions but also some physical health conditions.

With regard to claiming for care needs, our experience has been more positive although there remains misunderstanding about the impact of mental health conditions. With the lowest rate of DLA care component being removed from PIP, we had expected many clients to lose out on being able to claim for their care needs. This, however, has not necessarily been the case and we have clients, who previously would have only been awarded lowest rate care under DLA (£22 per week), now receiving the daily living component of PIP at standard rate (£55.65 per week). This would also enable someone caring for the disabled person to claim Carer's Allowance if they were not working, or severe disablement premium if they were claiming ESA.

With regard to medical evidence, our experience is that most GPs/specialists are unwilling to provide medical evidence to us even when a form of authority has been enclosed. We therefore ask clients to request their own medical evidence, which sometimes places additional stress for the client, particularly with regard to mental health conditions.

Although some GPs produce reports of a high standard clearly stating clients care and other needs as result of their mental health diagnosis, others simply list medical diagnosis (which for psychiatric illnesses can often be confusing in name) and often insufficient to support a PIP application or an appeal. We therefore support the client in explaining the impact of their mental health condition, which, understandably, at times can be difficult for the client.

We find that in contrast to the DLA claim form, the initial PIP application (PIP1) relies more on completing 'yes/no' answers rather than having free text boxes that allow for the claimant to clearly explain the mobility and care needs they have. This puts some clients who are affected by mental health at a significant disadvantage due to their care and mobility needs not fitting the 'boxes'. Our Merton Disability Adviser works closely with clients in this regard. Of the PIP1 forms the Adviser supports, around 80% of clients receive the award we believe to be correct for their care and mobility needs.

Due to cases very rarely being overturned at Mandatory Reconsideration stage, we normally only provide a short summary of why we feel the decision is incorrect when asking for a Mandatory Reconsideration Notice. Again we normally only list the points we disagree with briefly on the appeal form (SSCS1) as nearly all cases will be heard at tribunal.

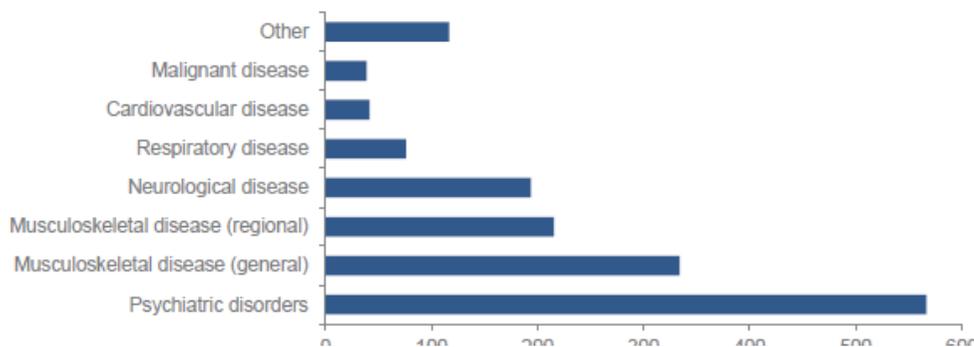
Of the cases that we support to tribunal, around 90% are overturned in our clients favour.

UK-Wide Evidence

According to the latest Quarterly Benefit Summary (published in November 2017), as of end-May 2017 1.4 million people were in receipt of PIP and a further 2.3 million people received DLA.

The report: Personal Independence Payment: Official Statistics (published December 2017) [link](#) shows the following breakdown of the type of condition, claimants are most commonly claiming PIP for, known as disabling conditions. The most common disabling condition, accounting for 36% of total claims, was 'Psychiatric Disorders' which includes 'mixed anxiety and 'depressive disorders' and 'mood disorders'.

Claims (normal rules) by main disabling condition, thousands, as at October 2017



Main disabling condition for people in receipt of PIP (normal rules):

- 567,000 (36%) were recorded with 'Psychiatric disorders' (which includes 'Mixed anxiety and depressive disorders' and 'Mood disorders').
- 334,000 (21%) were recorded with 'Musculoskeletal disease (general)' (which includes 'Osteoarthritis').

The main disabling condition of the claimant is reported by disability category and subcategory level. Further breakdowns are available from [StatXplore](#).

The remainder of the report focuses on individuals' experiences using the following colour coding: **Clients**, **Volunteers**, **Charity staff members/other organisations professionals**.

When and how did you first hear about PIP?

“Approx. 60% of our clients have been on DLA for years and are now having to transfer from DLA. The other 40% hear about the benefits mainly from friends and, to a lesser extent, GPs, hospitals and Social Services. There is a misunderstanding around PIP as it is not linked to your health or disability. This is a common misconception and is particularly a problem for clients who have mental health issues.”

“When discharged from hospital my support carer mentioned PIP and suggested I look to get advice.”

“We often tell people about PIP. Clients may have a vague idea that there is a disability benefit. Many have heard of Disability living allowance. So there is some familiarity, but most are completely confused about the detail of what it is and what they may be entitled to”.

“For PIP, some people will find out if they are already on DLA and being transferred, or by seeing an organisation like Citizens Advice or Merton CIL, mainly when we are doing a benefits check with them. I don't think the average person would know much about disability benefits. People are unlikely to do their own benefits check very often, most people haven't done this when they come to us. So I think most people get their information through a combination of signposting”.

The Application Process

“For PIP it is difficult for the lay-person to understand the rules, what is being assessed and what their eligibility might be. It also changes often, things keep being tweaked, which does not help. I can’t always keep up!”

“As far as mental health is concerned, it’s more difficult explaining the impact than for physical health. For example, a client might be able to say ‘I can’t raise my arm’... but for mental health explaining a condition is much more difficult. Mental health conditions are also much more variable and the application does not take account of this.”

“It is different for people with mental health conditions. Mental health affects different people in different ways. For most people there are good days and bad days. Some people will say that today they can do a certain thing, but tomorrow they might not be able to, who knows? Sometimes people don’t know themselves. But that doesn’t seem to be an answer that fits the criteria, and the questions are very difficult because of that.”

“With PIP it is a little clearer as questions focus on both physical and mental health.”

“Generally people feel there is a lack of understanding amongst those making decisions. Mental health is a really complex area to understand, so it is not surprising that people feel this way.”

“The forms are extremely difficult for any member of the public, but for someone with mental health problems can be more confusing.”

“Forms are almost impossible for clients to fill in.”

“The forms are better-designed for physical health problems. They’re not at all easy for clients with mental health problems especially.”

“Some questions are difficult for the client to explain all the information. Support from our Disability Benefits Adviser makes a lot of difference as he knows how to best support the client to explain the impact of their mental health condition.”

“It is very difficult to tease out things like depression for example, which covers an enormous range of things. It can be difficult for clients to explain the impact for daily living particularly if they are in a very low mood.”

The Decision

“We have seen housing benefit cut as a result of PIP decision.”

“There are a range of difficulties that affect people who have their income cut very substantially, many ways in which people are affected by a shortage of money. These would be difficult for anyone to cope with, but much more so for people with mental health problems.”

“When she was rejected she felt that DWP were calling her a liar and this really negatively affected her. It went to tribunal, and we did not submit any new evidence, but it was overturned. They awarded 28 points at tribunal. It was awful to put someone through this, when it was obvious from the start. This would have added to her distress.”

“With PIP, you do not get any income when you are appealing. This can mean that you are left without money for PIP for a significant amount of time, perhaps 8 or 9 months. And then when you do get a decision you have to wait several weeks to get the money. The DWP have to sort out the decision and have the right to appeal in 28 days. It can take 8 weeks for the back payments and the money to be sorted out, even when you have won an appeal. The whole experience can make people suicidal. The longer it drags on, it clearly exacerbates existing conditions.”

“Clients mental health conditions are impacted by the decision process. I’ve supported many clients whose condition deteriorates when receiving the decision and we’re supporting them via mandatory reconsideration. They are caught in a vicious cycle.”

“There are also other things that people don’t understand well. For example, if your PIP stops, it could affect your ESA and the amount you get. You need to tell DWP about this, even though they have just informed you about it! If you don’t you will be fined £50 and be liable for the overpayment.”

“The decision has an enormous impact beyond the actual benefit itself. For example, if you lose your PIP you could lose your mobility scooter or motability vehicle and that can mean you lose your independence.”

“We have seen issues where mental health is not taken into account, meaning that people are disadvantaged in booking assessments, and get written off as not cooperating as a result.”

“We had someone awarded one point for a PIP application, and were told they weren’t eligible. The impairments were pretty extreme and obvious. She wouldn’t leave home, or read her post, answer her phone. Her only contact with anyone was with the support worker. We had to pass messages via the support worker, to slowly build up trust so we could communicate directly, and only then could we communicate by text. It was so obvious that she was eligible. She did not always eat, did not wash or change her clothes. She didn’t go out. She had trouble managing her medication and her finances.”

Challenging Decisions

“I don’t think people know about mandatory reconsideration (MR) and part of this is because it’s fairly new. With DLA people knew they could challenge a decision, whereas the MR process applies for PIP but did not apply to DLA. So people may not be aware of this, because it is different to the old system. This means that people may miss the deadlines and miss out on making an appeal. “

“People need a lot of help with the system for mandatory reconsiderations and appeals because this is difficult.”

“There is a big problem with the way back-payments are handled. Because of how long the process can take, this can be several thousand pounds, which is paid to people at once. Some people do not know how to manage this money and it can cause problems when it is paid, on top of the problems of not being paid it in the first place. The DWP seem to think it doesn’t matter, that if they get the money in the end that it is okay. But we think this can lead to all sorts of problems to do with money management, and that this is not really being recognised.”

“When it comes to MR, they expect to fail. They are more positive when it comes to tribunal because they expect to get a fairer hearing. With MR they think the DWP are very reluctant to change their original decision, because it is the DWP being asked to re-examine their original decision, and they are reluctant to admit mistakes. When it comes to tribunal they are more confident as the tribunal is independent.”

“Also people now need to fill in the tribunal forms themselves and this is something that some people find really difficult. Before, with DLA, they did not complete any court forms, just said they wanted to challenge a decision, and the DWP did the court forms. Now they have to do ‘direct lodgement’, and before it would have been automatic by the DWP. Sometimes people miss this and miss the opportunity because they did not lodge it at the tribunal. It is also more difficult for them and they may not have filled in legal forms before. If you are not used to it is very confusing and baffling.”

Other Concerns/Issues

“Is there any point in mandatory reconsideration? It causes the nonsense where people have to go onto JSA and then back onto ESA when their appeal happens.”

“Government needs to think on how to support individuals on an interim basis who are challenging the decision.”

“It is the wait from the benefit being turned down and going to tribunal. People have no money, and it can be months and months to hear anything, and in this time they feel left in limbo, and have it hanging over them. They don’t know what the decision will be. If they have anxiety, for example, this can make that worse.”

“When you have a mental health issue and are quite fragile, to be turned down for something as important as this is terrifying. The benefit pays for everything - food, travel being able to call someone – everything. The £76 per week, I have to stretch it... but it is only just enough. Thank god for the pound shop or I would have starved!”

“Clients suffer due to the hard to read letters, difficult to deal with situations such as appointments and how to get help. Some clients find it hard to make a link to the outside world at all.”

“Reading the letter and trying to understand what it meant was difficult. And obviously them saying no was hard. And the reconsideration form - this is really hard! It’s really impacted my mental health.”

“All have increased anxiety. Clients with mental health issues don’t understand the decisions.”

“Make forms so they have to be countersigned by someone that is in a position to help the client to ensure the best possible outcome.”

“I think to bring in people who understand mental health. People from the NHS should be involved, not private companies who are getting commission. They are on commission not to give you money.”

“From our perspective, if there is any way that someone could be supported, or have access to some income while they are being considered that would help. It seems ridiculous – people are already in a difficult position, they can’t work, and then they need to go through a stressful process of challenging the decision, and they have to do this and live without any income at all for a period of time. I don’t know how it would work, but it would be good to have some sort of subsistence payment that could be made, perhaps something they could pay back later, like you do with a social fund loan.”

“Everything – the whole system is geared towards someone that is clear thinking, not one who is mentally impaired.”

Conclusion

The experiences of our micro volunteers illustrate that people affected by mental health are affected in their eligibility for and access to PIP. It is of some significance that amongst our micro-volunteers, negative experiences are less prevalent than with Employment Support Allowance (ESA) [link](#).

People affected by mental health experience some particular challenges relating to PIP, including:

Difficulties accessing clear information about PIP, unless they are supported by an agency or care worker, which means many do not have a good understanding of the benefit and what it is for. Many people do not understand the difference between PIP and DLA, and why they need to re-apply.

In particular there is a poor understanding of what PIP is for and that it's linked to the costs of the support needed rather than to the disability or illness itself, or the capacity of the client to work. Our micro volunteers indicated this lack of understanding is more prevalent amongst those with mental health conditions. This means PIP is likely to be under-claimed by this group.

An application form which most feel is confusing and does not allow them to fully explain their illness/disability, especially fluctuating conditions.

A process for application which many feel is off-putting, lengthy, difficult and can exacerbate conditions such as anxiety and depression

Decisions which are hard to understand, can lead to significant financial hardship and cause problems in other areas, like debt and housing, and exacerbate conditions like depression and anxiety

A complicated mandatory reconsideration process

Additional difficulties such as understanding conditions and getting back-pay awarded.

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As illustrated within the report, individuals affected by mental health can be supported throughout the PIP process through statutory services, specialist advice and support charities and informed family members and friends. There are many examples of good practice where service/support organisations work together to better support clients needs.

With our immense thanks to all our micro volunteers who participated within this research.

For further information about this report or micro volunteering with CA Merton and Lambeth, please contact peter.bradley@caml.org.uk. For more information about our research and policy work, please contact suzanne.hudson@caml.org.uk.

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