

# ***Personal Independence Payment – What's the problem?***

A SAMH report on Personal  
Independence Payment  
and mental health

SAMH is Scotland’s largest mental health charity operating over 60 services in communities across Scotland providing a range of support including mental health support, homelessness, addictions and employment services. These services, together with our national programme work in See Me, respectme, suicide prevention, sport and physical activity; inform our policy and campaign work to influence positive social change.

# SUMMARY OF FINDINGS

SAMH service users have found the introduction of Personal Independence Payment (PIP) challenging, with the experience of applying and being assessed for the benefit negatively impacting their mental wellbeing. Through focus groups and a survey of both SAMH staff and service users, we heard:

- ⊗ The application form (PIP2) and face to face medical assessment did not adequately assess the impact of mental health, with a focus on physical functionality
- ⊗ Claimants felt disbelieved and at times stigmatised by assessors
- ⊗ There was an overwhelming breakdown of trust in the application and assessment process
- ⊗ Claimants’ rights were not communicated adequately
- ⊗ The experience of assessment had a negative and often long term impact on claimants’ mental health

# INTRODUCTION

Social security in Scotland is changing. Following the 2014 independence referendum and subsequent Smith Commission agreement between Scotland’s political parties, additional powers are being devolved to the Scottish Parliament.

These include Disability Living Allowance (DLA) and its replacement Personal Independence Payment (PIP).

SAMH is determined to help positively shape the development of Scotland’s Security System, to create a system that is fair, grounded in human rights and works to facilitate active participation of all people in society. To shape our views we surveyed both SAMH service users and service managers on their experiences of the transition from DLA to PIP. We also held focus groups with SAMH service users and trainees in Dunfermline, Perth and Edinburgh.

This report is informed by the 60 people who attended the focus groups and answered the survey. It broadly follows the PIP claimant’s journey from application to decision. It supplements previous research SAMH has undertaken on welfare reform including: ‘Fit for Purpose’<sup>1</sup>, ‘Worried Sick’<sup>2</sup> and ‘Ticking All The Wrong Boxes’ (as part of the Scottish Mental Health Partnership)<sup>3</sup>.

# CONTEXT

Personal Independence Payment (PIP) was introduced by the UK Government in 2013 and will eventually replace Disability Living Allowance (DLA) for people aged 16-64.

Both benefits are designed to provide for the additional costs of disability and are not income related. PIP, as its name suggests, is also intended to facilitate greater independence for claimants. Beyond these formal roles both benefits act as a lever to compensate, in part, the cumulative financial impact of long term disability including underemployment and loss of earnings. One of the key changes that PIP introduced was a face to face medical assessment for the vast majority of claimants. PIP is awarded at either the Standard or Enhanced rate for specific time periods after which claimants are reassessed. Unlike DLA there are no indefinite (i.e. lifetime) awards. Similarly to DLA, PIP has two components: a Daily Living component and a Mobility component. Claimants can receive both or one of the components depending on their needs.

PIP's roll out in Scotland began in June 2013 for new claimants, with the first DLA recipients invited to make a PIP application in January 2014. The Department of Work and Pensions (DWP) anticipates all existing DLA claimants will have been asked to apply for PIP by October 2017. As of April 2016 85,350 people in Scotland receive PIP<sup>4</sup>. Of these 32,421 (37.9%) receive PIP due to their mental ill-health, higher than any other group of conditions.

# PIP APPLICATION

When first making a claim for PIP applicants must fill out a PIP1 claim form, then a longer PIP2<sup>5</sup> form describing how their disability impacts them. The forms can be completed in writing or with telephone assistance from a DWP advisor.

SAMH service users reported that the forms were confusing and focused upon physical impairments, lacking relevance to their mental health. The majority of questions cover factors such as ability to dress, mobility, preparation of food and toileting with only a limited number asking directly about cognitive functions<sup>6</sup>. The form also does not make it clear where a person’s mental illness may impact on activities such as dressing or eating due to a lack of self-care.

*“Absolutely no account of mental health problems ... Asking you if you can lift a cardboard box and how many stairs you can walk up”*

***“It was the worst form I’ve filled in”***

Service users were clear that they required professional support from welfare rights organisations and other care providers (including SAMH staff) when completing the form. Several said that the form would be “impossible” without support. Reasons given included the distress caused by the overall application process and lack of accessibility in the form. Many were unaware they could access telephone support for completing the form

*“You’re looking at all the negativity in your life on a piece of paper – then they’re asking you how this affects your life? Its stripping you of your dignity.”*

These difficulties were compounded for people with additional learning needs or multiple disabilities. SAMH managers confirmed this finding, with 66% in our survey stating the application process was difficult for service users to understand and required significant support.

## ADDITIONAL WRITTEN INFORMATION

To support an application for PIP, claimants can submit additional written information from health and other professionals who are supporting them. The onus is upon the claimant to gather and submit this information, which can be stressful and costly with some GP practices charging for the information.

Service users were asked how this process could be improved and if they would be happy for public bodies, such as their GP, the NHS or social services to be able to share information directly with the DWP, or prospective Scottish Social Security Agency, to support their PIP claim:

*“If they could go directly to your doctor - yeah with your permission- it would take a lot of the pressure and stress off”*

There was consensus that relevant data sharing would be an improvement but it must uphold a claimant’s right to privacy and should operate within the current data protection legislative framework. Data should only be shared with informed consent from the claimant and where it is relevant to determining eligibility for the benefit.



# FACE TO FACE MEDICAL ASSESSMENT

Unlike DLA, PIP claimants must undergo a face to face medical assessment to determine their eligibility. Assessments are inherently stressful for claimants, particularly for people living with mental health problems, as experience with Employment Support Allowance (ESA) Work capability Assessments (WCA) has shown<sup>7</sup>.

SAMH service users overwhelmingly reported that the face to face assessment had a negative, and at times, a long lasting impact on their wellbeing:

*“I’ve not quite recovered from all this. Without the help of my Dr and support I’d have been demolished. It still upsets me talking it through.”*

*“It was really worse than anything else than I could imagine.”*

*“I wouldn’t go through it again. I’ve got PIP till 2020 – that’s it, I’m not going through it again, I’m finished.”*

This was echoed by SAMH service staff who saw the negative impact of the PIP process on those they support:

***“Seeing people who are working really hard to get on top of things then they get hit with these PIP forms and assessments and we see it all back pedalling – really dreadful for us. We feel powerless”***

The main criticisms of the medical assessment raised by SAMH service users were:

- A lack of understanding of mental health and other fluctuating conditions by assessors
- An overwhelming focus on questions relating to physical functionality rather than mental health
- The attitude and demeanour of assessors
- Lack of clarity of the claimant’s rights including the right to ask for a home assessment
- Lengthy distances to the assessment centre

Many of these criticisms mirror findings from previous SAMH research into the ESA WCA<sup>8</sup>. Claimants were clear that the medical assessment did not allow them to fully demonstrate the debilitating impact of their mental ill-health, particularly where it fluctuates.

Very worryingly a number of service users reported facing negative and stigmatising attitudes from some assessors:

*“I got told because I was clearly fit to look after my animals that I was clearly fit to look after myself. The fact that I choose not to look after myself doesn’t mean I’m entitled to benefits. But I wouldn’t be alive if it wasn’t for my animals”*

*“I got told that my conditions don’t impact on my life. I go to bed at night crying praying that I don’t wake up. I’ve lost my house, and this has no impact on my life?”*

This was not the universal experience of those we spoke to. A small number of focus group participants reported that they were treated with dignity and respect at assessment:

*“Everyone was very nice, person who interviewed me was exceptionally nice, but I still wasn’t confident when I came out”*

# DISTRUST OF THE PROCESS

A theme that ran through the responses from SAMH service users was substantial distrust in the PIP application process, particularly the face to face assessment.

There is a belief that assessors are “trying to catch them out” or trick claimants with their questions.

*“they try to catch you out on everything... if you say you have a dog they just assume you can walk. But I can’t walk very far. That’s why I’ve got the car”*

Distrust was exacerbated by claimants not having a clear understanding of when the assessment actually began or on what criteria they were being assessed.

*“It’s a bit like smoke and mirrors- they’re asking questions but they don’t tell you what they mean by that”*

A number of focus group participants reported that their physical appearance was scrutinised by assessors, with cleanliness and punctuality used as evidence against their claim. One service user, who was unsuccessful in their PIP claim, was informed in the decision report that:

*“It said I was well-kempt, I was an average build, although I said both hands shook she noticed only one shook, [the report said] she volunteers so it shows I can do familiar journeys”*

Another service user whose application was also unsuccessful stated:

*“They put on my form when I was refused it, that I maintained good eye contact; as though I should be looking at the ground- I got refused about 3 months ago- I didn’t appeal it because it was just too stressful.”*

To combat this, service users reported purposely altering their demeanour and appearance at assessments to better correspond with stigmatising stereotypes of mental illness and disability, undermining their dignity. Indeed this was advised by a number of professionals supporting the service users:

***“People advise you don’t shave, turn up dishevelled – to show that mentally they are unwell. Just because you’re articulate doesn’t mean you don’t have a mental health problem”***

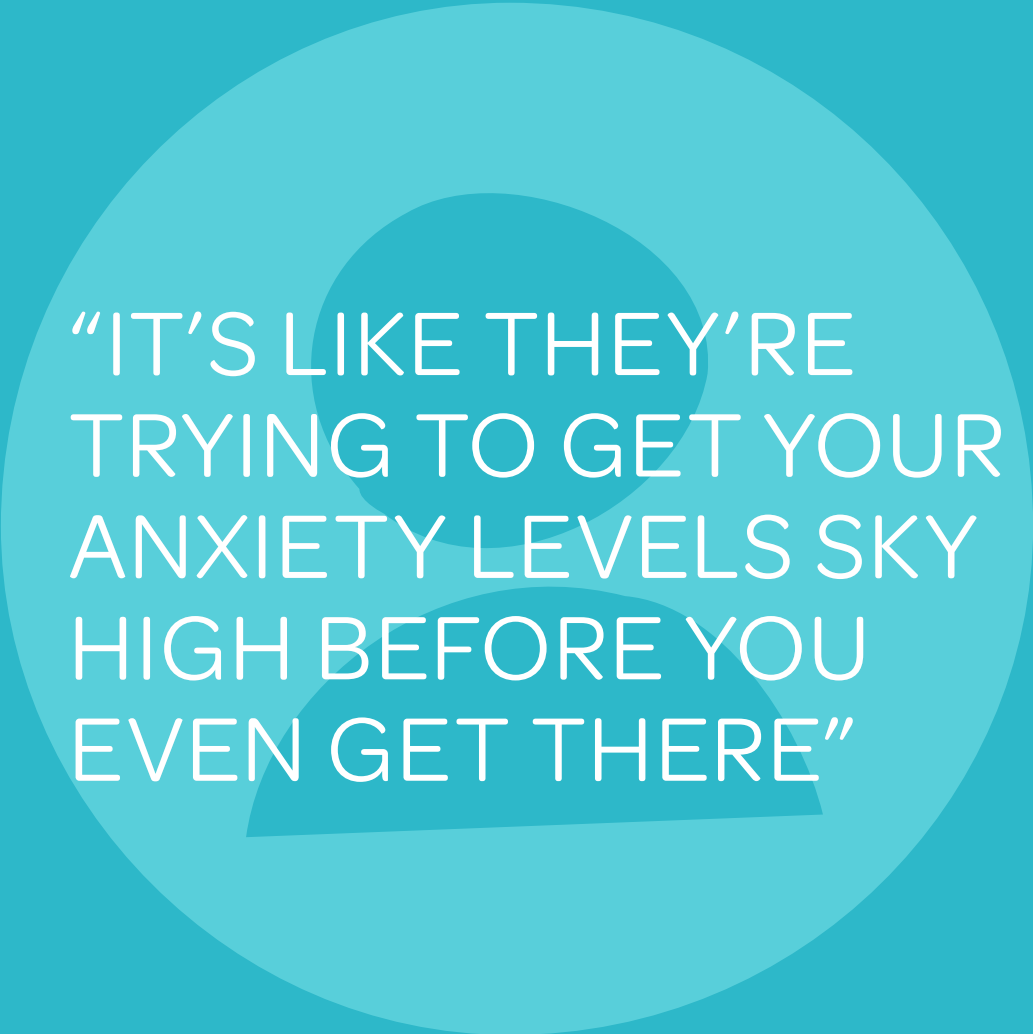
*“My CPN said don’t look at them in the eye, but that’s just not me- how good am I going to be at acting on the day?”*

*“I was told to dress down as my middle class accent and all that means they think I can’t be unwell– it’s the stigma attached to whole of mental health”*

Service users’ suggestions to address this overwhelming mistrust included:

- Sight and sign off of the assessor’s report at the time of assessment;
- Mental health professionals assessing those with a mental health problem;
- Much greater clarity over the terms of assessment;
- An automatic right to independent advocacy and welfare advice;
- Greater emphasis on written evidence at initial and reassessments





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# TRAVEL TO ASSESSMENTS

A common problem with the assessments, reported in the survey and focus groups was the significant distances people had to travel to assessment centres, often at substantial cost.

For many this added to their anxiety due to the impact of their mental health on their ability to travel confidently:

*“I wouldn’t be able to make it to Edinburgh – to me it’s a very daunting place.” (Fife Service User)*

*“it’s like they’re trying to get your anxiety levels sky high before you even get there”*

SAMH service managers also reported the impact of travel for assessment had on service users and their staff:

*“Assessors do not appear to understand how hard it is for a service user to travel to an out of town appointment. The support that is required from my staff to get service users to feel ok about travelling can take weeks” (Fife Service Manager)*

SAMH service staff reported that one service user from the Isle of Cumbrae had to attend a PIP assessment centre in Kilmarnock, requiring a ferry and 2 buses, costing over £15 in total. PIP weekly instalments can range from £21.80 to £139.75. This means that the abovementioned travel costs would amount to 10% of the highest award, and 68% for the lowest. Some assessment centres were also not signposted with a number of service users stating they were given incorrect directions, adding to their distress.

***“Service users from this area are given the option to either go to Dundee or Dunfermline. This can be very inconvenient due to travel time. For instance the assessment centre for Dundee is near Ninewells Hospital. The times of the buses do not coincide with times of assessment. There is nothing in the surrounding area” (Perth Service Manager)”***

# RIGHTS AND SUPPORT

Claimants have a number of rights and protections when making a PIP claim<sup>9</sup>. These include:

- The right to be accompanied by someone, including a carer, friend or independent advocate, at the medical assessment. This person has the right to take part in the discussions and make notes.
- The right to ask for adjustments. Examples include: the size of room if this impacts the claimant’s anxiety; an interpreter or signer; the person carrying out the assessment to be the same gender as the claimant.
- The right to ask for a home assessment
- The right to ask for an audio recording of the assessment

Both our survey of SAMH service users and the focus groups highlighted that claimants are too often unaware of their rights or are prevented from realising them. Only 16% of service users who completed our survey knew they had a right to ask for a home assessment, with just 40% aware that they could be accompanied to the medical assessment.

*“They said if I used my own recording device they said it could be tampered with- but they couldn’t accommodate my asking for it to be recorded because theirs was broken.” (SAMH service user)*

Professional welfare advice and advocacy support has been shown to be highly effective at supporting claimants to achieve a correct result to their PIP claim as well as help reduce the impact of the process on their wellbeing. This was demonstrated by a recent, Scottish Government funded, welfare advocacy pilot which supported clients with mental health problems or learning disabilities during their ESA or PIP assessments<sup>10</sup>. The evaluation of the pilot found that the provision of advocacy decreased the stress felt by claimants during assessment, empowered claimants to remain engaged with the process and more fully communicate to assessors the issues they face. The evaluation also found that the presence of advocacy positively impacted the behaviour of assessors.

Those taking part in our focus groups echoed the positive impact of welfare advice and independent advocacy, but highlighted the lack of availability:

***“We sign post to CAB – we don’t have the expertise – but the flipside is that folk have to wait in massive queues” (SAMH staff member)***

***“Someone sat for 4 hours and still didn’t get seen”***

# MANDATORY RECONSIDERATION AND APPEAL

When challenging a PIP award decision, claimants must initially ask for a ‘mandatory reconsideration’ and only after this can they appeal to a tribunal. A mandatory reconsideration involves the DWP looking again at the decision and any newly submitted evidence from the claimant.

UK Government figures show that as of April 2016, in 40% of reconsiderations, the award is changed<sup>11</sup>, with 63% of PIP appeals successful between January and March 2016<sup>12</sup>.

A small number of service users we spoke to had challenged their initial PIP award decision, both in terms of being found ineligible for any award or on the level of award. The experience was reported as onerous, and stressful even where the final result was positive.

*“I never got enough points so I had to go to a tribunal. Sitting with the head doctors and all those scary folk. I had a CAB woman there but she couldn’t say anything – I had to say it all myself. It was terrible”*

*“Had to wait 20 mins before speaking to someone for my mandatory reassessment – not a free phone call – £2.39 – my mum tracks this – it’s the worst point when you’re waiting – hearing the same music over and over “*

A number of service users who were found ineligible for PIP did not ask for a mandatory reconsideration or appeal due to the perceived impact this would have on their mental health:

***“I didn’t go [for a MR / appeal] I just wanted to forget about it, such a horrible experience”***

***“The lawyer said ‘you missed out on 10 points, I think you should appeal, I would do it’ – I said I can’t go through this again.”***

# CONCLUSION

The experiences of SAMH service users and staff make clear that the introduction and transition to PIP is fundamentally flawed, detrimentally impacting the mental wellbeing of those engaging with the process.

The application and assessment process does not allow the impact of mental health to be adequately assessed, is highly stressful and assessors do not have expertise in mental health. The process, as described by those we spoke to, does not support claimants’ dignity or right, contributing to a lack of trust in the system.

The Scottish parliament will soon have the opportunity to radically reform disability benefits. SAMH believes reforms must include designing an assessment process which minimises the need for stressful face to face assessments and reduces the need for unnecessary reassessment. These assessments must take place in a facility local and familiar to the claimant, or indeed in their own homes, to avoid the risk of further deterioration of claimants’ mental health. The greater use of written evidence and safe information sharing between public bodies should be explored. Claimants also need better access to adequately resourced independent welfare advice and advocacy. Fundamentally the Scottish Social Security system must uphold claimants rights at all points in the claimants journey and fully recognise the impact that poor mental health has on a person’s life, including their ability to engage with the social security system.

# NOTES

- 1 SAMH [Fit For Purpose](#) 2015
- 2 SAMH [Worried Sick](#) 2014
- 3 Scottish Mental Health Partnership [Ticking All The Wrong Boxes](#) 2015
- 4 DWP Stat-xplore accessed August 2016
- 5 DWP [Sample PIP2 form](#)
- 6 See sample PIP2 form
- 7 Scottish Mental Health Partnership [Ticking All The Wrong Boxes](#) 2015
- 8 SAMH [Fit For Purpose](#) 2015
- 9 Citizens Advice: [Preparing for your PIP assessment](#)
- 10 ALLIANCE [Evaluation of Welfare Advocacy Support Project Evaluation Report](#) 2016
- 11 DWP [Personal Independence Payment: Official Statistics Data to April 2016](#) June 2016
- 12 Ministry of Justice [Tribunals and gender recognition certificate statistics quarterly: January to March 2016](#) June 2016







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