



A New Future For Social Security: Consultation on Social Security in Scotland

Summary of SAMH event 27th October 2016

SAMH held an event on 27 October 2016 to launch our PIP research: *Personal Independence Payment – What's the problem?*¹ and to hold focus groups with individuals with lived experience of mental health problems who had been through the PIP assessment. The following notes summarise the discussions about their experiences, in terms of what they found challenging in the current DWP system, and their suggestions for a more supportive and rights-based system when the new powers are devolved to Scotland.

- There is an extremely high level of distrust in the DWP system, due to peoples' poor experiences in the application / assessment / appeals process.
- The stressful nature of the current process has had a detrimental impact on peoples' mental health, in some cases leading to suicidal ideation.
- While there must be a process to determine who qualifies for social security support, the nature of mental health problems means that some claimants find the process particularly stressful and detrimental to their health, and as such, should not have to go through assessments unless absolutely necessary.
- The Scottish social security system must be rights-based and fair. Language is important to convince people who have been treated badly by the DWP system.
- People with disabilities must be supported to access their rights through advice, advocacy, as well as support from health, social care and peers. This support should not be at any cost to the claimant.

We welcome the opportunity to submit this summary of discussions at the event, along with our report, to the Scottish Government's consultation on Social Security in Scotland.

SAMH's substantive response to the consultation has been through the Disability Agenda Scotland (DAS)² submission to the consultation. Our input to DAS's response was informed by focus groups of SAMH service users and a SAMH staff and service user survey on experiences of PIP, which contributed to the report. In total over 60 SAMH service users and staff took part in the research. There were 30 participants at the report launch on 27th October, the majority being SAMH service users and others with lived experience of mental health and accessing PIP.

Two round table sessions were undertaken at the event, one exploring peoples past experience of applying and being assessed for PIP with the second exploring ideas to improve the process. Direct quotes from participants are included in the summary below where possible.

Session 1 – Experiences of applying, being assessed, and engaging with PIP

➤ Application Process:

¹ SAMH *Personal Independence Payment – What's the problem?* 2016

² <http://www.disabilityagenda.scot/>

All groups reported that the PIP application form was very lengthy and had little relevance to mental health. Most questions were about physical functionality. Participants felt they were being “set up to fail” with the way questions were framed.

Some taking part in the discussion reported that guidance included in the forms was itself complicated and that they were unaware they could access phone support from the DWP to complete the form. Where people did contact the DWP they had to wait significant lengths of time for an answer, were charged for the call if using a mobile and often signposted to Citizens Advice Bureaux or other support agencies rather than helped directly.

Examples from the discussion groups:

“My friend lost their entitlement to PIP because she said on the form that she was unable to prepare food. She was taking a cooking course at college so DWP said this must be false. They always use your progress against you.”

“I was asked if I could peel a potato!”

➤ **Face to Face Medical Assessment:**

The experience of undergoing a face to face medical assessment was overwhelmingly negative. People taking part in the discussion reported the experience of assessment significantly impacted their mental health, both at the time of assessment and in the longer term. Some participants had previously been assessed for Employment and Support Allowance (ESA). The experience of the ESA Work Capability Test (WCA) compounded participant’s anxiety and distrust of the PIP face to face medical assessment.

Questions at face to face assessments were described as invasive and unclear, lacking sensitivity around mental health and claimant’s history of trauma. People reported that they couldn’t give honest answers, or were not clearly aware of what was expected of them. One participant said during the assessment they were *“made to feel like scum.”*

Participants spoke about the practical problems with assessments such as living in Dundee and being asked to travel to Edinburgh; the assessment centres being uncomfortably warm/dark/small; appointments being changed at last minute; and appointments made at a time which was not possible due to public transport constraints.

The length of time people had to wait between assessments was also mentioned: one participant said it was a month before he heard the result during which time he worried about it constantly. There was a lack of awareness that claimants could ask for reasonable adjustments to their assessment including room size, to help manage their anxiety.

The participants largely felt that assessors are not fit for purpose. Assessors were described as not qualified in mental health, and lacking empathy, and not having an understanding of the impact of their decision making - including in cases where being found ineligible for PIP may lead to the claimant losing their tenancy or facing significant financial hardship.

Some spoke of the assessments inaccurately recording information, leading to a ‘failed’ test resulting in the need for a stressful appeals and mandatory reconsideration process or tribunal. It was strongly felt that assessors and decision makers should be held to account for the accuracy of assessment reports and quality of decision making.

➤ **Supporting Written Evidence**

Multiple people taking part in the event reported that they had submitted supporting written evidence when applying for PIP. This included evidence from their GP’s and other mental health clinicians involved in their care and treatment. Many participants felt this evidence wasn’t being believed or considered in the initial decision by DWP.

Other problems with supporting evidence that were highlighted were varying levels of understanding and ability to communicate effectively about mental health by claimants GPs impacting the quality of evidence; the onus for collection of written evidence being on the claimant; and lack of guidance on who could or should provide evidence. A number of participants reported that they had to pay for evidence from their GPs – this up to £30 for a supporting letter. One participant said that asking for supporting evidence put a strain on her relationship with her GP, as she felt she was “recruiting” her GP and felt guilty about it.

Other people present said that not using medication was used against them when determining their eligibility for PIP. This even if written medical evidence outlined other methods (e.g. talking therapies) that the claimant were using to manage their condition and reduce the pain and other side effects that previous medication caused.

➤ **Support during application and assessment**

The discussion groups were asked about any support they received during the PIP application and assessment process, including independent advocacy and welfare advice.

Many of those who took part in the discussions did not know they could access advocacy or professional welfare advice. Where participants had accessed support (most commonly from Citizens Advice) it positively impacted their experience, although the process remained extremely stressful. This broadly mirrors findings from the ALLIANCE Welfare Advocacy Support Service pilot where SAMH sat on the national steering group³.

Despite the positive impact of advocacy and welfare advice participants spoke of the challenge of getting appointments with welfare rights advisors or Citizens Advice, who were regarded as very stretched. Where people had ‘wraparound’ support including advocacy to enable communication, welfare rights and peer support they reported a better experience of assessment.

➤ **Impact on mental wellbeing**

All groups reported the detrimental effect the process has on their mental health – both in the short and long terms. Participant reported feeling ill before their assessments and very distressed after

³ <http://www.alliance-scotland.org.uk/what-we-do/our-work/policy/welfare-advocacy-support-project/>

assessments. One participant felt that she couldn't speak to her support worker in the waiting room as she felt the assessors would assume she had no problem with social interaction.

In the longer term, the short award periods resulted in prolonged distress as people felt they "don't get a break" from the anxiety it can cause. This was a particular concern where the individual also receives ESA and potentially faces multiple face to face assessments over a short period of time.

Overall participants expressed that their distress and anxiety was compounded by the breakdown in confidence and trust in the PIP system. Participants spoke about the dread they feel when receiving letters, with some people saying they don't open letters related to their benefits at all.

Very worryingly a number of people taking part in the event explained how the process of accessing PIP had led to suicidal ideation; some were still traumatised by their experiences, despite having received a long term award. Others spoke about living in fear about losing their support.

Someone who was planning to attend the event but couldn't due to ill health sent SAMH details of her experience which are included in this submission. These highlight the negative impact the PIP process has had on her long term mental wellbeing and echo's the experiences of others we heard from at the event:

"I am one of those people who had not recovered from the DWP process, even though I have been awarded PIP following Mandatory Reconsideration. I find myself continuously worrying about having to go through this process again in 4 years' time.

The insight that came to me was that parts of the PIP process (medical examination and initial DWP report) were, for me and perhaps for others, an echo of my childhood abuse and trauma within the family. [I have recently been diagnosed with Post-Traumatic Stress Disorder – PTSD]. My rights were not explained to me at any stage and my statements were apparently disbelieved. The assessor's behaviour during the examination was, at times, abusive.

For anyone with PTSD (myself included), the PIP procedure is likely to trigger memories of past trauma, which will require help to process."

Session 2 – Improving the PIP process

The second discussion session focused on what can be done to improve the process and experience of applying for PIP, in the context of the creation of a Scottish Security System with the devolution of aspects of the UK social security system to the Scottish government and parliament.

Themes running through all the suggestions were:

- The need for a rights based process, respecting claimant's dignity
- Improved communication to claimants of expectations on them; the PIP process; and how to access support
- The need for a more personalised approach
- The need for mental health expertise throughout the process
- Co-production with people using the social security system in designing a Scottish approach

Specific suggestions from those taking part in the discussion are broadly grouped below:

➤ **Application Form and Supporting Evidence**

- One discussion table suggested that there should be a separate form for claimants where their primary disability was mental health. This reducing unnecessary questions about physical functionality where they are not relevant
- No cost to individual for supporting evidence, it should come from the Government.
- Co-production of the design of application forms including people with mental health problems
- A reduction in repetition on the application form
- Clear guidance included with application forms including claimants rights and where/how to access support. The current DWP helpline was not seen as adequate
- Guaranteed access to welfare advice or advocacy to assist in completing forms and attending assessments
- Information should be provided at the point of application about other benefits that you may be entitled to, with instructions how to access them
- All supporting evidence must be used in considering someone's PIP application

➤ **Assessments**

- Where a face to face assessment is required and the claimant has a mental health problem the assessment should always be conducted by a mental health clinician
- Assessments must be more personalised. For example where a claimant's primary disability is mental health the assessment should solely focus on this rather than asking unnecessary questions on physical functionality
- Clarity on the terms of face to face assessments should be provided to claimants. Informal observation at the assessment should not be part of the assessment criteria i.e. a person's ability to arrive on time / be clean and tidy should not be used as proof that they are not disabled
- To improve trust one discussion table suggested claimants be given a copy of the completed assessment form at the end of the assessment for sign off
- Assessment times and locations must take into consideration the circumstances of the claimant to a much higher degree. Examples provided by participants included offering afternoon assessments to people impacted by medication side effects which make it difficult to fully function in the morning; provision of taxi's to assessments to ease anxiety about travel on public transport
- Greater use of supported written evidence to reduce the need for face to face assessments
- Clarity is needed over the use of previous ESA awards/submitted evidence in determining a PIP claim

➤ **Other and general suggestions**

- Waiting times for assessments and award decisions must be shortened. Participants felt that the emotional and financial impact of waiting for a PIP award was not currently recognised

- Long term or life time awards should be introduced for significant mental health problems
- The system from application to award/appeal must be made clear – currently it is very complex and confusing. Accessible language and different methods of communication are urgently required. One person suggested current leaflets for Bowel cancer screening were an example of good practice in clear understandable communication
- Advocacy support and welfare advice must be better resourced to increase timely access
- The third sector should be supported to up skill their staff on benefits and avenues of support to signpost clients to
- Assessors and decision makers must be more accountable for their practice
- A national and consistent approach is required to ensure equal treatment, rather than devolving disability benefits to local authorities

A number of people, who took part in the discussion, while welcoming the approach of the Scottish Government in regard to highlighting the need for dignity and respect as the cornerstone of a Scottish social security system, stressed the need to make radical change not just ‘tweak’ the current PIP system. Related to this was a fear that due to current negative perceptions and practices of the DWP system minor improvement in Scotland could be viewed as a success where fundamental change embedding a rights based system is required.

If you have any queries please contact:

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