

# FIT FOR PURPOSE?

SAMH Redhall Trainees' Experiences of Welfare Reform

REDHALL

# Summary of findings

The story that emerged was of people being disbelieved by assessors who did not appear to be well trained or experienced in mental health.

"I went in with letters from a consultant psychiatrist, consultant psychologist, the then team leader here, and my GP, and these were overturned in twenty minutes by an unqualified nurse. I had to go to appeal."

# The assessment process does not work well for mental health and is in itself stressful

"As far as they're concerned, you're up on time, you're washed, you're dressed, therefore in their mind you've got washed, dressed, you're ready for work."

#### The fear of sanctions has a negative effect

"The fear of being sanctioned is enough to ruin your life without [actually] being sanctioned."

# The stress of being assessed or challenging those decisions made their condition worse

"... at the first stage I was in a really seriously bad financial position, and there was more riding on it and it was a lot more stressful. ... But it is still awful and it takes up my time and my energy, and my focus. It takes it all completely away from what I would be doing otherwise, which is focusing on my recovery."

# The Work Programme made trainees' mental health problems worse

"When I was referred to the Work Programme I ended up getting to the point where I had to start taking medication having actually never been on it before, and that was directly caused by the way the staff at the Work Programme treated me..."

# Challenging benefits decisions is stressful and confusing

"It takes it all completely away from what I would be doing otherwise which is focusing on my recovery"

People experienced ignorance and stigma on mental health both by Jobcentre staff and members of the public.

# The cumulative effects of sanctions and the whole assessment process take their toll

"When I got this letter from the DWP, I had to stop that [decreasing medication] and increase my medication again... Suicidal thoughts are massively increased. Urges for self-harm massively increased. Basically, when it comes to getting reassessed every other part of my life kind of shuts down because it just has a really bad effect on me. It's almost as if they were to design a process to make it as difficult as possible to stay alive, this is exactly how they would do it."

"if you find yourself going through a breakdown, depression, anxiety, it's more difficult to get the information [for the benefit claim] because you're not opening your mail, you're too anxious to."

## Recommendations

- People with mental health problems who require employment support should, by default, be referred to Work Choice, not the Work Programme.
- SAMH calls for the Scottish Government to ensure that when it takes over the Work Choice programme for disabled people in 2017, it also takes the opportunity to incorporate tailored support for individuals in order to support even more people into work and stay mentally well when there eg Individual Placement Support.
- SAMH calls on the UK Government for an end to benefit sanctions for people with mental health problems as this puts undue stress on vulnerable people.
- Both the UK and Scottish Governments should continue to commit resources to tackling stigma against people with mental health problems, with a particular focus on addressing stigma among front line staff in public services.
- The UK Government should introduce an assessment of the support people need to get back into work to the Employment and Support Allowance application process, and ensure that support is provided.
- The UK Government should expand the number and role of Disability Employment Advisers.



## Introduction

A growing body of evidence from charities and campaigning groups across Scottish civil society has shown that aspects of the present UK Government's programme of welfare reform has harmed the finances and wellbeing of disabled people and their families, particularly people with mental health problems.

In 2014, SAMH published the research report Worried Sick: Experiences of Poverty and Mental health in Scotland<sup>1</sup> which found that 79% of SAMH service users had suffered reduced finances due to welfare reform. The report also found that 98% of SAMH service users said their mental health had deteriorated as a direct result of the changes, with 48% less able to engage in social and community activities. We have also recently taken part in work with the Scottish Mental Health Partnership, which identified particular problems with Employment and Support Allowance (ESA) for people with mental health problems.

To further our understanding of the impact of both sanctioning and other issues relating to welfare reform on people in Scotland with mental health problems, SAMH held a focus group with trainees at our Redhall Walled Garden horticultural service in February 2015. Fifteen trainees shared their experiences. This visit was timely, given the UK 2015 General Election, the promise of further devolution of powers over aspects of welfare<sup>2</sup> to the Scottish Parliament, and the upcoming 2016 Scottish parliamentary elections.

Redhall trainees reported some worrying findings, and while this report reflects the experience of only one group of people, making it impossible to draw universal conclusions, the trainees' experiences do add to a growing body of research which has identified similar concerns regarding the impact of welfare reform on people with mental health problems.<sup>3</sup>

## SAMH Redhall Walled Garden

Redhall Walled Garden is a SAMH service set within an 18<sup>th</sup> Century Walled Garden in Edinburgh. It offers emotional support and training in horticulture, conservation, maintenance skills and IT skills, for people with mental health problems. The service supports 50-55 trainees at any given time. The service is based on the working week and people who train there do this on a contractual basis. Placements are for a minimum of three days per week. People can self-refer to Redhall but also need a reference from a health professional.

The service aims to provide a safe environment where people can learn to deal with the challenges of recovering from enduring mental health problems, encouraging lifestyles which are positive, sustainable and health oriented.

#### Employment and Support Allowance and Personal Independence Payment

The two welfare changes most frequently highlighted by Redhall trainees were the introduction of ESA, which has replaced Incapacity benefit, and Personal Independence Payment (PIP) which is currently being rolled out to replace Disability Living Allowance (DLA).<sup>4</sup> Difficulties with both benefits were highlighted at the application, assessment and delivery stages.

PIP and DLA are benefits paid to help people with additional costs incurred due to disability. PIP is not dependant on a claimant's income, and is available for those both in and out of work.<sup>5</sup> ESA is a benefit for people who cannot work due to disability or illness. People found eligible for ESA are placed in one of two groups - the Work Related Activity Group (WRAG) or the Support Group. The WRAG is for people who, after assessment, are believed to be able to undertake employment in the future. Claimants in the WRAG must undertake activities to prepare them for future work, including 'work-focused interviews' and referral to Department for Work and Pensions (DWP) administered employability programmes. The Support Group is for people whose disability or illness is deemed to prevent them from being able to undertake employment in the future. People in the Support Group are not expected to undertake work related activities but can volunteer to do so.

### Assessments

The assessment of eligibility for both PIP and ESA generally involves a face to face assessment.<sup>6,7,8</sup> The Work Capability Assessment (WCA) for ESA and medical assessment for PIP are both highly contentious, particularly in how the assessments consider the impact of mental health and other fluctuating conditions.

<sup>&</sup>lt;sup>1.</sup>SAMH Worried Sick: Experiences of Poverty and Mental health in Scotland March 2014

<sup>&</sup>lt;sup>2</sup>. The Smith Commission Smith Commission report November 2014

<sup>&</sup>lt;sup>3.</sup> See: Scottish Parliament Welfare Reform committee, The Cumulative Impact of Welfare reform on Households in Scotland March 2015; Mind We've got work to do 2014

<sup>&</sup>lt;sup>4</sup>. PIP was introduced for DLA reassessments in Edinburgh, where Redhall Walled Gardens is located from January 2014. DWP Timetable for PIP replacing DLA January 2014

<sup>&</sup>lt;sup>5.</sup> DWP Personal Independence Payment Information leaflet 2013

<sup>&</sup>lt;sup>6.</sup> For SAMH's responses to the annual Independent Reviews of the Work Capability Assessment (WCA) see http://www.samh.org.uk/our-work/policy-campaigns/ financewelfare

<sup>&</sup>lt;sup>7</sup> House of Commons Work and Pensions Committee Employment and Support Allowance and Work Capability Assessments First Report of Session 2014–15 July 2014

Trainees were clear that the current format of the assessment did not allow them to fully express the impact of their mental health problems on their ability to work, with descriptors used in the assessment considered inadequate:

"The problem is that you've got PIP and ESA being assessed before you even go in the door. The other problem is with mental health it's difficult to assess, so the thing is with the descriptors ... if they say "Can you set up an alarm clock? How did you get here? Did you require someone to accompany you?" As far as they're concerned you're up on time, you're washed, you're dressed, therefore, in their mind you've got washed, dressed, you're ready for work."

This issue was raised by a number of the trainees, who felt their mental health and capacity to work was judged by their physical appearance at the assessment. A clean and punctual appearance was taken as evidence of the claimant's ability to work.

"You've got to look like a tramp .... people feeling like they've got to go and look like they haven't had a wash for five days, because otherwise, if they are turning up looking well then it's going against them."

The discussion with the trainees also highlighted a lack of confidence in the accurate reporting of assessments by staff. Participants provided examples of assessors not correctly recording what the claimant had stated:

"They just absolutely make up outright lies, and all that kind of thing, which happened to me. My decision [came] back and probably more than 50% of what they said was an outright lie about what I'd said at the assessment. And a lot of it just doesn't have any logic to it whatsoever, they just, kind of say, any random stuff that disqualifies you."

Trainees had a number of suggestions to avoid inaccurate reporting and build trust in the assessment process. These including a claimant 'sign off' of the assessment paperwork on the day of the assessment and wider promotion of claimants' existing rights to be accompanied at an assessment and option to ask for an audio recording.<sup>9</sup> "I'd asked [WCA assessors] previously to check the report and then sign it to say I verified this is true. And they said "no, this is sent to DWP." I think it'd be good if DWP and the new medical, whoever it's going to be, allowed you to actually read what was written on the day, and then to sign and certify this is a true copy."

The first Independent Review of the Work Capability Assessment (2010) compiled by Professor Malcolm Harrington<sup>10</sup> recommended that audio recording of the WCA be piloted to determine if it would be helpful. The DWP assessment of the pilot found that universal audio recording of assessments would not improve assessment quality, a finding supported by Professor Harrington in his third independent review.<sup>11</sup> The current position is that requests for audio recording should be accommodated where possible, but that there is no legal right to have the WCA recorded.<sup>12</sup> We would suggest that the DWP should make claimants aware of their right to request an audio recording of their Work Capability Assessment, given that there is clearly some enthusiasm for this.

In the fourth Independent review of the Work Capability Assessment, Dr Litchfield recommended that claimants should have the opportunity to 'sign off' assessment transcripts or reports.<sup>13</sup> This was accepted in principle by the UK Government but has not been acted on to date, with the DWP expressing concerns that this would add to the time an assessment takes, and have additional implications for people with a learning disability.<sup>14</sup> We suggest that the DWP should fully implement this recommendation as soon as possible.

Participants in the focus group stressed the need for accessible information to be sent to claimants outlining their rights and sources of support, including welfare rights advice.

"People are not aware of what their rights [are] because they're not told, and when someone's going through the process of waiting for the assessment and filling the forms [they have to] take it upon themselves to go and seek out welfare rights advice at the same time. This just isn't a practical thing for them to be able to do that. So if there's some way that people can be informed of their rights about the process that would make it a lot better."

This reflects a recommendation in our Worried Sick

<sup>9.</sup> For further details of the claimant rights to ask for an audio recording see DWP Employment and Support Allowance - Work Capability Assessment Audio Recording of face-to-face assessments - Policy

<sup>&</sup>lt;sup>10.</sup> Prof Malcolm Harrington An Independent Review of the Work capability Assessment November 2010

<sup>&</sup>lt;sup>11.</sup> Prof Malcolm Harrington An Independent Review of the Work Capability Assessment – year three November 2012

<sup>&</sup>lt;sup>12</sup> DWP Employment and Support Allowance - Work Capability Assessment Audio Recording of face-to-face assessments - Policy

<sup>&</sup>lt;sup>13.</sup> Dr Paul Litchfield An Independent Review of the Work Capability Assessment – year four December 2013

<sup>&</sup>lt;sup>14.</sup> Dr Paul Litchfield An Independent Review of the Work Capability Assessment – year five November 2014

<sup>16</sup> House of Commons Work and Pensions Committee Employment and Support Allowance and Work Capability Assessments First Report of Session 2014–15 July 2014

report (2014), in which SAMH called for the DWP to provide information signposting people to sources of support at the beginning of the ESA application process.<sup>15</sup>

Another concern raised by participants was the lack of mental health training that assessors undertook, compounded by assessments routinely undertaken by non-mental health medical professionals:

"I went in with letters from a consultant psychiatrist, consultant psychologist, the then team leader here, and my GP, and these were overturned in twenty minutes by an unqualified nurse. I had to go to appeal."

# Mandatory Reconsideration and Appeals

Some Redhall trainees discussed the process of challenging an initial ESA or PIP decision and the impact this had on their wellbeing. It was clear that to challenge a decision and gather additional medical evidence to support their appeal was very stressful.

Before an applicant can appeal against a decision on ESA, they must now request a mandatory reconsideration. This involves another DWP decision maker examining the ESA claim. Importantly, claimants cannot receive ESA at the assessment rate during this period and will have to try to claim Jobseeker's Allowance if they have been found for work. The House of Commons Work and Pension Committee, while welcoming the policy intention of mandatory reconsideration, warned that this additional process might deter claimants from challenging decisions, even where they had a high likelihood of success.<sup>16</sup>

The following quote is from a trainee who is, at the time of writing, contemplating challenging an ESA decision after the original decision was upheld after a

#### mandatory reconsideration:

"It's very difficult for me to even decide whether to do it or not because the impact that it has... It's not as bad as the first level of the process [mandatory reconsideration] because I did get some money through, and now I'm no longer in the position where there's not so much riding on the money that I get ... I just didn't get as many points as I think that I should have got. So it's not as stressful as the first stage because at the first stage I was in a really seriously bad financial position, there was more riding on it and it was a lot more stressful. ... But it is still awful and it takes up my time, my energy and my focus. It takes it all completely away from what I would be doing otherwise which is focusing on my recovery."

## Jobseeker's Allowance and Employability

Trainees also discussed their experience of accessing Jobseeker's Allowance (JSA) and their experiences of employability programmes, particularly the Work Programme.

### **Conditionality and Sanctions**

JSA is an-out-of-work benefit for people who are fit to work and actively seeking employment. A number of trainees reported being inappropriately advised to apply for JSA rather than ESA despite living with significant mental health problems. As a result trainees reported real difficulties in complying with the job seeking conditionality of JSA, resulting in a threat of benefit suspensions and sanctions:

"I was finding it hard to travel, finding it hard in interviews, finding it hard with applications for jobs and everything... I was very close to getting sanctioned and that really scared me. It blew me out the water a bit, really. I'm a bubbly, cheery person, and I was really, really low."

#### <sup>15.</sup> SAMH Worried Sick 2014. See recommendation 3 p18:

SAMH calls upon DWP to provide clear, accessible information to each applicant, via letter, at the beginning of the Employment and Support Allowance application process on: organisations which can support them through the process, including welfare rights advice, mental health and wellbeing support and financial advice; the process for securing supporting medical statements; the applicant's rights and entitlements throughout the process. This must be proactively communicated to each individual applicant. For each applicant placed in the Work Related Activity Group (WRAG), further information must be communicated regarding organisations and sources of accurate information on: the conditions to be fulfilled and consequences of not fulfilling these; organisations which can support the individual during WRAG activity, including support for their mental health and wellbeing.

Figures from the DWP show that benefit sanctions, particularly for ESA, have disproportionately affected the most vulnerable claimants, with 58% of all ESA sanctions in the first six months of 2013 being applied to people with a mental health condition or learning difficulty.<sup>17</sup> The damaging impact that the threat and fear of sanctioning has on an individual's mental wellbeing was clear:

"The fear of being sanctioned is enough to ruin your life without [actually] being sanctioned."

The conditionality associated with receiving ESA and JSA and complying with the Work Programme was described as being "threatening" and a barrier to recovery. Many of the trainees discussed the importance of attending Redhall as part of their recovery from mental ill health, while others expressed the desire to undertake voluntary work. But benefit conditionality was seen as a strong disincentive to undertake such opportunities as it was feared this would be perceived by the DWP and Jobcentre as showing fitness to undertake paid employment:

"You are legally allowed to volunteer. And coming to Redhall is neither volunteering nor work, it's support for mental health recovery. But it goes back to that question of perception. If he's a big strong guy, clean shaven, and he's been volunteering, of course he can work."

"It's the fear that if you're trying to, as part of your recovery, progress to get yourself better, each time you try to get better they just take the rug from under your feet and then you're back in that vicious cycle of mental health again."

#### Employability

The Redhall trainees were asked about any experience they have had with DWP and third sector employability programmes, including the Work Programme and Work Choice. All of those who had participated in an employability programme had been referred to the Work Programme, despite Work Choice having a significantly higher success rate for people with a mental health problem. Indeed DWP figures from April 2014 show that only 5% of Work programme participants receiving ESA attained a Job Outcome within a year<sup>18</sup>, whereas 39% of Work Choice starts with a 'mild to moderate mental health condition' achieved a job outcome in 2013/14.<sup>19</sup>

Disability Employment Advisors (DEAs) can refer ESA and JSA claimants to Work Choice but referrals are aimed at people who are expected to be capable of a minimum of 16 hours' work per week within six months of referral.<sup>20</sup> This results in a low rate of ESA referrals.<sup>21</sup> The result of this is that people with more serious barriers to entering the workplace are either given no support or provided with the generic support of Jobcentre Plus and the Work Programme.

"Knowing that the sanction process exists is enough to ruin your life. The fear of being sanctioned is enough to ruin your life without being sanctioned."

17 UK Government Freedom of Information request 2014-79 March 2014

18 Department of Work and Pensions Work Programme Official Statistics to Dec 2013 April 2014

19 Department of Work and Pensions Work Choice Official Statistics August 2014

20 Department of Work and Pensions The disability and health employment strategy: the discussion so far December 2013

21 Department for Work and Pensions (2014) Work Choice: Official Statistics November 2014

The individual experiences of Redhall trainees attending the Work Programme were universally negative. They reported that employability advisors lacked an understanding of the impact of mental health and made excessive demands on claimants to undertake work related activity. One trainee described the experience of the Work Programmes in the following way:

"When I was referred to the Work Programme I ended up getting to the point where I had to start taking medication having actually never been on it before, and that was directly caused by the way the staff at the Work Programme treated me..... At one point it got to the stage where I had five job interviews arranged for one week. And on the days when I was not going to them she [employability advisor] was phoning me three times a day telling me about other opportunities. I was not answering the phone and she was leaving me angry voicemails saying "Why don't you ever answer the phone? I have to be able to contact you." She refused to take my health issues into consideration, because I wasn't comfortable talking about them in detail with her because she wasn't qualified whatsoever to speak to me about my mental health issues. I didn't know her, and she was asking me very intrusive questions and it was extremely stressful."

#### Stigma

A theme that emerged throughout the discussion from a majority of participants was the high levels of ignorance and stigma that people with mental health problems faced when navigating the welfare system,

"You can see the face and the face looks happy and whatever else but underneath it could be like a car wreck, you just put a brave face on it." from Jobcentre and employability staff as well as the wider public. The interaction between stigma related to mental health and stigma related to claiming benefits was expressed by many of the Redhall trainees.

#### Front Line Jobcentre and Employability staff

Trainees reported that they frequently encountered negative attitudes related to their mental health from Jobcentre staff when applying for and accessing benefits. The hidden nature of many mental health conditions in comparison to physical disabilities was cited as one reason for this:

"You can see the face and the face looks happy and whatever else, but underneath it could be like a car wreck, you just put a brave face on it."

Beyond benefit assessment staff, trainees reported widespread ignorance of the impact of mental health problems on the ability to work among other Jobcentre and Work Programme staff:

"Anyone I speak to in the Job Centre, anyone that assesses me, anyone in the Work Programme, not only do they seem to be not qualified, but their attitude very often seems to be almost aggressive."

While the majority of experiences with Jobcentre staff were negative, one trainee outlined her constructive experience with a specialist Disability Employment Advisor (DEA), highlighting the real positive impact that such a relationship can have. The trainee was receiving JSA and the DEA recognised the decline in the trainee's wellbeing and consequently, how inappropriate JSA was for the trainee during that time:

"She's the disability officer, and she's been really good with me, very patient. She tried to understand my problems but she couldn't really help me with them because I was on Jobseeker's ... She saw it was affecting me, I started losing weight, I was getting really grumpy. I was horrible to people. The complete opposite of what I generally am... Yeah, she advised me to do that [apply for ESA]. And she's advised me to go for this PIP as well. So she's given me really good information."

All Jobcentre Plus offices have an attached DEA, but there are concerns that there are not enough numbers to meet demand.<sup>22</sup>

22 Mind We've got work to do December 2014

## Wider Public

Stigmatising attitudes to mental health, and claiming welfare more generally, were also reported outside the confines of the Jobcentre. One issue which highlighted the impact of this was the use of concessionary travel passes. A large number of the trainees were eligible to receive a concessionary travel pass due to being in receipt of DLA, but felt embarrassment and faced hostility from public transport staff when using them:

"If you don't look like a pensioner, or you've got both your legs and both your arms, then they think you're scamming them ... And that can blow you out the water because it's the beginning of the day... Putting my pass on the bus, getting attitude from the driver and I've just come back off it again. You know, because you're just inflamed with anger and you've got nowhere to go with it. I tend to just walk it off and get another bus."

A number of trainees described how important their travel passes are in allowing them to access medical appointments and wider community supports, including attending Redhall. Unfortunately trainees highlighted how the design of the local pass 'advertised' their disability making them less likely to use them:

"It is a big issue for me because it looks different from the normal bus pass that you would buy. The average person knows what a bus pass looks like and if you have a different one then they might ask you about it. And I've found myself in social situations paying for the bus even though I have a bus pass because I don't want the people I'm with to see it. That's happened to me quite a lot. And also even if the driver doesn't do anything, it's two times a day at least you're presenting yourself with a card being like "I am disabled." And obviously I don't look physically disabled. And so then I think people may assume I have mental health issues."

# Cumulative Impact of Changes on Mental Health

Looking beyond the impact of individual welfare changes, participants were clear that the large scope and ongoing nature of the reforms, including recurrent assessments for ESA and PIP, were a serious impediment to recovery. One trainee outlined the "relentless" nature of the changes:

"The biggest change since the new benefits and new government has come in is that the process is now relentless.... three years ago I was getting reassessed for DLA. The next year I was migrated from Income Support onto ESA. Last year was meant to be my year off. I was not due to be reassessed for any of that, but then they sent me a letter saying I had to get reassessed anyway. This year my DLA runs out again so I'll have to be reassessed for PIP. And then the year after that is when my ESA is due to run out so I'll have to be reassessed."

The trainee described how this has impacted on her mental health:

"Well, last year my psychiatrist was reducing my medication when I got this letter from the DWP, so I had to stop that and increase my medication again... Suicidal thoughts are massively increased. Urges for self-harm massively increased. Basically, when it comes to getting reassessed every other part of my life kind of shuts down because it just has a really bad effect on me. It's almost as if they were to design a process to make it as difficult as possible to stay alive, this is exactly how they would do it."

Another participant described the bewildering experiences of engaging with the welfare system for the first time following the development of mental health problems:

"I was extremely close to suicide. I was at my lowest ebb of my life, and having to go through this dehumanising, utterly humiliating process. I think it's hell for anyone with mental health problems or not... if you find yourself going through a breakdown, depression, anxiety, it's more difficult to get the information [for the benefit claim] because you're not opening your mail, you're too anxious to. So it's a double whammy, you can't pick up or concentrate and get what you need to know, and then when you're treated appallingly it just further confirms your view of yourself as a useless human being because that's what you're being told."

## Conclusion

While this report outlines the experiences of only one small group of people with mental health problems, it does add to the growing body of evidence highlighting inadequacies with the current welfare system in its treatment of people with mental health problems. The trainees described a social security system that is difficult to navigate, dehumanising and incapable of taking account of, or responding to, the complexities and fluctuating nature of many mental health conditions. Beyond structural deficiencies in the system, the experiences outlined above reinforce the importance of misconceptions about mental health and ongoing stigma, within the benefit system but also across society more generally.

Despite the overwhelmingly negative experiences outlined in this report, the conversation with the trainees highlighted the positive impact that well placed and well informed support can have, such as the role played by disability employment advisors. Indeed the focus group highlights that often small, or procedural, changes could have a significantly positive impact. The idea of a claimant 'sign off' during an ESA or PIP assessment, as suggested by one trainee, is one such example, as is the timely provision of accessible information to claimant's signposting them to source of support when engaging with the welfare system.