

Breaking Barriers to Benefits



co-produced by:



As part of Inclusion Scotland's Rights and Resilience project.



Rights and Resilience

Introduction:

On 11th March 2016, we brought together people who access social security benefits, with support from Edinburgh based services, and representatives from a range of Edinburgh based services that offer support. We invited services which offer welfare rights information and advice, and services which provide independent advocacy.¹

We had two aims for the event:

- (1) To bring those who are in need of support together with the services that can support them;
- (2) To discuss what good practice looks like in terms of supporting people to access their welfare rights, and to identify what could be done better.

This was an important opportunity to think about the ways people who claim disability and sickness benefits are being supported. This is particularly pertinent when you consider existing claimants have been disproportionately disadvantaged by cuts to the social security system.² For example, evidence suggests that 60% of disabled people who receive Disability Living Allowance (DLA) are predicted to lose some or all of their award by 2018 in the transfer to Personal Independence Payment (PIP).

People with mental health conditions and learning difficulties have also experienced specific pressures with many reporting that their condition has deteriorated throughout the process. These groups are also sanctioned more frequently than any other group. DWP figures show that the number of 'adverse sanctions' between January 2011 and March 2015 against people described as having 'mental and behavioural disorders' was 48,153 compared to a total of 19,487 across all other impairment groups.

Within this current climate, support services are becoming ever more vital for people who are entitled to disability benefits. The Scottish Parliament describes, 'a whole

¹ We included organisations providing both individual and collective forms of advocacy.

² We take a 'social model' understanding of disability, where a disabled person is someone with an impairment or health condition who, in relation to this, experiences barriers to their participation in society. We also understand people with mental health conditions to be 'disabled' on the basis that they experience specific barriers in society – and the social security system offers some particularly stark examples of this. While we are mindful of wider debate in this area, there is not scope in this report to engage with it.

industry that has grown up to support claimants through the process'; while organisations providing welfare rights advice, information and support have experienced a spike in demand for their services.³ For example, the Lothian Centre for Inclusive Living's Grapevine service saw the number of enquiries they respond to leap from 2471 in 2012/13 to 4272 in 2014/15.⁴

Evidence suggests that services offering advice, information and independent advocacy are a crucial way in which welfare rights can be made accessible and obtainable to disabled people. For instance, no-one interviewed as part of Inclusion Scotland's 2015 report, *Second Class Citizens? How Welfare Reform Marginalises Disabled People* completed a benefits assessment form themselves, as this was seen as requiring specialist knowledge.⁵ Further, recent research suggests that independent advocacy plays a significant and positive role in the experiences and outcomes people have when being assessed for ill health and disability benefits.⁶

The Breaking Barriers event provided a space to reflect on the situation in Edinburgh and share the work that is being done locally. It also gave services a chance to learn from the people who need support from their services.

We based the event around three consultation questions:

1. What are good ways to support people to get benefits?
2. What would make advice and support more helpful and accessible?
3. What values would help to make advice and support accessible?

The report which follows is based on the responses to these questions. We hope that it will let professionals know what they are doing well, and offer some ideas for the continuous improvement of their practice. We also hope that it will be a useful sign-post to local and national policy-makers about the direction of travel we need as the Scottish approach to social security evolves

³ Welfare Reform Committee (2015) *The Future Delivery of Social Security in Scotland*, p.3

⁴ Kirstie Henderson (11 March 2016) Presentation: *The Benefits System: Benefits Who?*

⁵ Inclusion Scotland (2015) *Second Class Citizens? How Welfare Reform Marginalises Disabled People*: <http://inclusionScotland.org/wp-content/uploads/2015/08/IS-welfare-reform-impacts-guide.pdf>

⁶ Hopkins, N (2016): *Evaluation of Welfare Advocacy Support Project*

Findings:

1. What are good ways to support people to get benefits?

We asked participants to define the characteristics of 'good' support. The key characteristics identified included: quality relationships; knowledge and experience; and service accessibility. These are explained in this section.

Building quality relationships

All participants – including those providing as well as accessing services – agreed that the most effective support happens when there is a good relationship between a person and their supporting professional. The professional must demonstrate 'respect' for the person they are working with. They should show 'empathy' with their situation, and that they understand their needs. In doing so, the professional can become trusted by the person they are supporting, and the interaction between the two can be productive.

If trust and respect are important, losing contact with the professional who has been providing support can be challenging for a service user -trust needs to be rebuilt, and it is difficult to assume respect. Some participants were providing services, but with funding coming to an end, and expressed deep concerns about the fate of their clients. For example, the Recovery Essentials Financial Inclusion project hosted by Edinburgh Voluntary Organisation's Council (EVOC) has supported people with substance misuse issues since March 2014.⁷ However, as of April 2016 it is no longer funded. The project's staff reported concerns about the subsequent 'journeys' of clients, many of whom had previous negative experiences with mainstream services and who will struggle to re-engage with suitable support services.

Participants thought it was important that the journey of service users is as smooth as possible. They reported good practice such as accompanying clients to the first meeting after making a referral to another agency. This allows a transition whereby professionals can touch base with one another about the case, and the client experiences a continuum of support.

There was also agreement that projects need long-term funding in order to be properly effective. If services and their staff dissipate with their short-term funding, the good work they have done with particular individuals needs to be re-done elsewhere; and this means more resources and a more fractured journey towards positive outcomes.

⁷ <http://www.evoc.org.uk/networks/recovery-essentials/>

However smooth the process, accessing benefits produces considerable fear and anxiety for claimants.⁸ And professionals have a challenging role in terms of making people aware of their entitlements and guiding them through the onerous process of claiming them. It is therefore essential to be able to 'dispel myths', 'provide clear information and guidance', and to 'work through anxieties'. Having dedicated support from services that can take the time to explain what is going on and prepare the client for what they need to do pays dividends in terms of the client's understanding and ability to engage with the process.

It is also important to provide support to help the person say what they need to say. Many felt that they had been misunderstood during assessments or advice appointments which lead to them being wrongly assessed. The general consensus from all participants was that independent advocacy is vital for anyone who has difficulty claiming social security benefits.⁹ Several organisations committed, on the day, to signpost their clients to independent advocacy support where appropriate.

Participants also reported that some advice organisations are better than others at explaining benefits and entitlements in ways that people understand, and guiding their clients through the process. For example, FAIR, LCIL and The Action Group were specifically mentioned as examples of good practice here.¹⁰ This ability helps to de-mystify the process and makes the client feel more involved, informed, in control and, importantly, less anxious. Participants felt that the aim should be to empower the client and offer an alternative message to the disempowering, stigmatising narratives carried by politics and wider society.

⁸ This is generally well known. For example, see Inclusion Scotland (2015) *Second Class Citizens: How Welfare Reform Marginalises Disabled People*. The testimonies of event participants chimes with this.

⁹ For clarification on what Independent Advocacy means, see the explanation from the Scottish Independent Advocacy Alliance (SIAA) here: <http://www.siaa.org.uk/us/independent-advocacy/>

¹⁰ These organisations were mentioned frequently as examples of good practice, and were often contrasted with their 'mainstream' alternatives. While this remains anecdotal, it accords with what we have heard more widely.

Having the right knowledge and experience

Good support also relies on the knowledge and experience of staff. This involves providing the correct information about entitlement at the 'right point in time', and asking appropriate questions to understand the client's situation. As one participant put it, 'a complicated claiming system makes a hard time harder', and so feeling confident in the advice given is important. Professionals felt that regular updates on benefits changes help them to refresh their own knowledge, and remain confident.

Experience with filling in DWP forms was important to participants accessing support, especially since the 4 week window for receiving and returning forms can be highly pressured. Completing DWP forms was widely perceived to be a professional task, rather than something which individual claimants should be undertaking alone.

Professionals at the event had good knowledge of the benefits system, and highlighted good practice, such as checking for entitlement to other benefits (besides that which the client was originally enquiring about) and undertaking home visits where resources allow. Both help to ensure that as much relevant information as possible is passed on, and that people get their maximum entitlements. Participants also noted that knowledge should be passed on in a way which 'encourages' and gives 'impetus' to pursue entitlements. This could mean taking a human rights based approach, for example.¹¹ This is important as dominant narratives and DWP administrative processes tend to be obstructive to pursuing entitlement.

Ensuring services are accessible

The accessibility of advice services, although alluded to in the above comments, emerged as a distinct concern for good advice and support. Participants saw a need for more information about benefits and entitlements to be available to claimants in Easy Read format, for example.¹² They also noted the need for interpreters – including British Sign Language (BSL) interpreters - to be more easily available when required.

In addition to clear information, participants talked about the value of not feeling rushed when accessing a service – 'quality over speed' was important. However, this might depend on the time and resources of different information and support organisations. It was important that appointments are available. For example, drop-ins were noted as good practice where they save people from waiting too long for a booked appointment. However, there can be a real issue where people receive forms to fill in when organisations are – or are shortly due to – close for holidays. The four week window to receive and return forms is then too short to access appropriate support.

Participants also suggested having different access points for information and support in the community – for example, at the local post office, the GP surgery, or even the Job Centre. Two points might be made about different access points for welfare rights. First, in some cases this may help to overcome the fear associated

¹¹ <http://www.scottishhumanrights.com/careaboutrights/whatisahumanrightsbasedapproach>

¹² <http://www.learningdisabilities.org.uk/help-information/learning-disability-a-z/e/easy-read/>

with visiting a Job Centre.¹³ Where support is offered in a community setting, people are able to fit their 'benefits' discussions around other aspects of their day. This could help to provide better transitions from thinking about benefits to thinking about other things, and thereby reduce stress. Second, accessing welfare rights in different settings can bring marked benefits. For example, studies have shown that integrating welfare rights in GP surgeries / primary care settings can help to better facilitate patient access to welfare rights advice. And this advice is often very relevant to health outcomes.¹⁴

2. What would make advice and support more helpful and accessible?

More joined up working between different information / support organisations

There was unanimous agreement that information and support organisations need to work together more effectively to achieve positive outcomes for service users. Suggestions about how this could be done varied – from a 'one-stop-shop' to a regional online referral system and working partnerships between specific organisations. Despite different practical solutions, participants identified some key aims they would like to see accomplished:

- Service users not having to repeat information in various different places.
- The same information not being duplicated by different service providers.
- Reduction in the number of repeat referrals, because the initial referral was incorrect or the issue was not effectively dealt with.
- Better transitions between services for service users.
- Clearer pathways towards independent advocacy support.

Better resourcing of services

Having adequate resources would help immensely with the provision of information and support. It would also help to ensure that information and support is accessible. For example, better resourcing could help to reduce waiting lists so that service users are less frequently 'stuck' in the system thereby unable to access support where there is a high demand for it

Consistent funding for services provides professionals with an environment where they can get to know their service users and provide support for as long as they need it. In an immediate sense, under-resourcing can mean that, workers are having to limit the time that they spend with people. Job security, equipment, and decent wages were all found to be conducive to staff well-being and improve the standard of service provided.

¹³ We heard during our 2014 research into the impact of welfare reform on disabled people, and in subsequent consultations, that disabled people become very worried at the prospect of going to the Job Centre or being assessed because they are scared of being 'caught out' and believe their entitlement will reduce or disappear entirely. This holds true even when there is no reasonable ground to believe that, and the idea of a person losing entitlement is absurd.

¹⁴ <http://www.ncbi.nlm.nih.gov/pubmed/12509370>

It was also important to participants that there are clear pathways between services so that service users can reach appropriate services - and service providers know how to get them there efficiently. This may help to reduce the number of referrals which are wrong or ineffective, and create less protracted routes through services. In this sense, participants wanted to see more funding for partnership working and the creation of links between different organisations serving Edinburgh. They also pointed out how useful it would be for organisations to have a means of sharing client information in confidence; and of tracking referrals so that they know what works, and how to enhance the quality of sign-posting. There were additionally calls for 'roadmaps for newly diagnosed people', i.e. people with newly acquired impairments or health conditions, who need to discover where to begin their journey.

Finally, participants pointed out the need for ongoing, good quality training for professionals. Anecdotally, a few stories were shared about people being given inaccurate, inconsistent or conflicting advice. It was felt that this was largely an issue with training or with staff not having the most up-to-date information.

People who need to access services are empowered to do so

Although perhaps obvious, no service is accessible if people do not know that it exists and that they are entitled to access it; and understand *how* to access it. This point resounded around the room at the event. Participants felt that we should be working to empower communities with knowledge about their welfare rights so that people seek out support in the first place. As was noted in a presentation from the Lothian Centre for Inclusive Living's Grapevine service during the day, this may mean a fundamental change in the way we think about social security: social security should be about 'helping people to make their contribution to society, rather than highlighting their deficits and making them dependent'.¹⁵

3. What values would help to make advice and support services better?

For the final workshop question, we asked about the values which would help to make advice and support more accessible. The most commonly cited values were 'respect', 'compassion' and 'empathy'. Chiming with those key values, 'non-judgement', 'decency' and 'person-centred' were additionally suggested. In part, this reflects the importance which participants placed on good relationships between staff and the people they are helping (see section 1 above). It is vital that the power relations between professionals and service users are not deployed in such a way as to patronise, reprimand or degrade service users because of their circumstances. A spirit of common humanity and genuine compassion should instead characterise relationships. It is important to recognise that none of us are immune to genuine hardship, and we should treat others as we would hope to be treated ourselves.

It was clear during discussion that this also reflects the values which participants want to see more broadly in a Scottish social security system. The current cultural and political narrative is at odds with values such as 'respect', 'compassion' and

¹⁵ Peter Beresford (16 Feb 2016) *The Guardian* (cited by Kirstie Henderson (11 March 2016)).

'empathy'.¹⁶ Additionally, there is a constant stream of anecdotal evidence suggesting the assessment and delivery of benefits to eligible people, and the negative coverage the media gives to benefits recipients, often evades such values. With the UK Government currently the subject of a confidential United Nations (UN) investigation into the detrimental impact of welfare reform on disabled people's human rights.¹⁷ the values our participants are looking for are very much 'missing in action' in the current welfare system.

Others points that were discussed helped to solidify some of the earlier points raised. For example, it was important to people that 'confidentiality' should be a key value underpinning support. Participants also wanted more effective information sharing between organisations in order to ease the pathways through benefits claims and support – and hence, 'holistic' was also suggested by numerous participants. However, they were wary about the uses of personal data and felt that a principle of confidentiality should be in place for the relevant professionals.

Accessibility emerged as being an important value to participants. Points were raised about the lack of information provided in formats which widen accessibility – for example, Easy Read, braille and British Sign Language (BSL). Keith Lynch, Vice Chair of People First Scotland, told participants that he and others with learning difficulties he has consulted feel that 'the quicker [they] understand what is happening, the more reassured [they] feel. He said,

Welfare rights and benefits entitlement is a complex area. Especially during a period of change, it can be difficult to understand the system and what it can deliver in individual cases. This is often true for professionals as well as claimants. While efforts to simplify the system necessarily bring unfairness, as broad stroke rules overlook individual circumstance, the system becomes particularly incomprehensible to those who fall foul of its rigid stipulations. People are often left feeling confused, out of pocket and, crucially, lacking a proper understanding of their situation.

Accessibility however is not only about offering information that people can understand. It is also about that information being provided when it is needed, and providers being identifiable. Participants talked about difficulties with knowing where to go, and suggested a need for 'road maps' at key contact points when they are newly diagnosed or it is apparent they need support.

There are also problems for those who have difficulty in explaining their conditions or lack insight into how their condition effects them. All the advice services available are little good to a person who lacks the ability to speak up and explain their situation to the advice worker. That's where Independent Advocacy can play a vital role. A recent survey conducted by Inclusion Scotland and AdvoCard around pathways to independent advocacy support, indicated that people do not always have the right information at the right time. For example, one person said:

¹⁶ See, for example, Brian, Watson and Philo (2011) *Bad News for Disabled People: How the newspapers are reporting disability*: http://www.gla.ac.uk/media/media_214917_en.pdf

¹⁷ See recent newspaper coverage: <http://www.theguardian.com/society/2015/oct/20/un-inquiry-uk-disability-rights-violations-cprd-welfare-cuts>

“When I left my job due to severe depression I was in contact with DWP for help and advice. No one seemed to be able to tell me what I needed to know. I was concerned about how I was going to live and pay my mortgage. I went into the job centre, I phoned the DWP and the Citizens Advice Bureau phoned the DWP several times on my behalf but got nowhere, a friend suggested I seek advocacy and that’s what made the difference”

For those who have difficulty in explaining their circumstances or have communication problems then advocacy can make the difference in getting the right advice. Those who participated in the survey made several suggestions about where the route to independent advocacy could be initiated, including: clinicians, care workers, community psychiatric nurses, doctors, the Job Centre, Citizen’s Advice Bureaus, the library, places of worship, community centres - even ‘the DWP itself could alert people with poor mental health that such a thing as advocacy exists’.

Conclusion

Overall, there is a desire for a Scottish social security system built on the ideals of administrative coherence, professional competence and compassionate support. The majority of event participants, as well as those we have consulted beyond the event, are only able to gain proper access to the social security system by engaging with local information and support services. This local infrastructure is the lens through which people come to understand their entitlements; and it provides the pathways through which entitlements are accessed. At the very least, our local services are a key to social security.

In the context of our findings, the Scottish Government’s ambition for a system where ‘the need for advocacy and support disappears for the vast majority of claimants’ must be treated with caution.¹⁸ No matter how simple a system, there will always be those who have difficulty being heard and who will need support. The people who are effected most by the changes, those who claim these benefits, have said that they need services which can take the time to explain what is happening and how this will impact them. Until we have a system which can respond efficiently and fairly to the complexity of individual circumstance, we need services which can support people when they engage in, or fall foul of, the process. Until the system is itself able to listen properly to claimants and have a nuanced and compassionate understanding of their needs, we need advocacy to ensure that people are heard. And while there are some benefits delivered by the DWP and others from within Scotland, and their interaction remains complex, we need advice services to help people navigate those systems. Overall, the bar is high.

¹⁸ Scottish Parliament Welfare Reform Committee (2016) *The Future Delivery of Social Security in Scotland*: p.3
http://www.parliament.scot/S4_Welfare_Reform_Committee/General%20Documents/6th_Report_Future_Delivery_of_Social_Security_in_Scotland.pdf

When our local service infrastructure plays such a key role in allowing people to access their entitlements, it is only right that we shine a light on it. Within the 'sector', we have found a lot of passion, knowledge, and a desire to learn and to do better. We feel that this needs to be encouraged and invested in. Support needs to grow in tandem, and as part of, a new 'Scottish' approach to social security. While every effort should be made to ensure best practice within the state's social security delivery mechanisms, it will be important to work in partnership with local support services. The quality and range of professional experience and local knowledge they offer is not something we should aim to move away from, but a resource we should lean in to and grow alongside.

Recommendations:

As a result of this consultation event, and the wider discussions and research which preceded it, we make the following recommendations about the future delivery of services which support welfare rights. It should be noted that these recommendations are based on consultation work anchored in Edinburgh. However, we do feel that they have relevance more broadly across Scotland.

- Services offering welfare rights information and support, including independent advocacy, need sustained funding. Even if a Scottish social security system was significantly fairer and easier to access than the current structure, there is a need to support people as they try to articulate their needs and deal with what is easily perceived as a daunting process with far reaching implications.
- Funders must fund existing projects. This will help to capitalise on good work already being done, and limit potentially regressive disruption to service users. While new projects and initiatives have a certain gloss, good existing work brings consistency and enables services to grow and improve.
- Information, advice and support organisations should invest in staff training where possible. Training should be aimed at improving welfare rights knowledge, and challenging perceptions about service users. Disability Equality Training should be a core part of this.
- Increased opportunities for people to engage in collective advocacy around welfare reform issues are needed to enable those who are being effected the most to have a voice in the changes ahead.
- Safe spaces where service providers and service users can discuss issues and co-produce solutions are useful. Again, a positive consequence of our consultation was the opportunity for differently positioned people to discuss shared concerns and learn from each other. This could also help to reduce stigma and foster more of a collective spirit around mitigating the impacts of welfare reform.
- Services in Edinburgh would benefit from a shared referral system. This would help to generate clearer pathways through services; and reduce the time professionals spend locating appropriate referral destinations for clients. It may also have the benefit of enabling organisations to track their referrals and gain a better understanding of the impact of their work.

Appendix:

About the Organisations which Co-Produced the Event –

AdvoCard

AdvoCard is an independent advocacy service, providing individual and collective advocacy for mental health service users in Edinburgh. As part of their service they have a dedicated Welfare Reform Advocacy Worker who provides advocacy for those who are being effected by the current reforms. This includes attending benefit assessments, helping complete benefit questionnaires, contacting the DWP and City of Edinburgh Council and helping with reconsideration requests.



They accept referrals from other organisations and self referrals. As Independent Advocacy providers they remain independent of other mental health services which are provided by the statutory and voluntary sectors. This enables them to stand alongside the people they work with and support them without any conflict of interest.

Inclusion Scotland

Inclusion Scotland is a consortium of organisations of disabled people and disabled individuals.



Through a process of structured development it aims to draw attention to the physical, social, economic, cultural and attitudinal barriers that affect our everyday lives as disabled people in Scotland. It aims to encourage a wide understanding of those issues throughout mainstream thought in Scotland.

In short, Inclusion Scotland wants to reverse the current social exclusion experienced by disabled people through civil dialogue, partnerships, capacity building, education, persuasion, training and advocacy.

People First (Scotland)



People First (Scotland) is a member controlled disabled people's organisation (DPO). This means that it is open only to people who have a learning difficulty, or what services call a learning disability. That means that no-one else has any say at all in what the organisation does.

It was established in 1989 and works to support people with learning difficulties to have more choice and control over their lives. It works for change on 3 levels:

- The way members see themselves
- The way other people see members
- The laws and policies that affect members
-
- ***Lothian Centre for Inclusive Living (LCiL)***



The Lothian Center for Inclusive Living (LCiL) is a user controlled organisation which supports disabled people, people with long-term conditions and older people, to live independently in their communities. LCiL has various services which enable disabled people to live more independently, including Grapevine.

Grapevine provides information and advice on all disability matters on a free, confidential and impartial basis. The service is funded to work with people living in Edinburgh and Midlothian. It specialises in providing up to date, accessible and local based specialist knowledge and advice on matters such as:

- Disability benefits (including help with Personal Independence Payment forms and Attendance Allowance forms);
- Older people's benefits;
- Transport concessions;
- Rights at work and learning opportunities;
- Accessing community care services and self-directed support;
- Health and personal issues, including where to get emotional support, self-management classes;
- Grants and trust searches;
- Holidays and respite opportunities;
- Access issues and where to get help with legal matters;
- Housing and adaptations;
- Local suppliers for aids and equipment;
- Accessible publications and factsheets (check out these on our E-library).

