



Report

The future of social security in Scotland



1. Background

The Scottish Commission for Learning Disability (SCLD) is an independent charitable organisation and strategic partner to the Scottish Government in the delivery of Scotland's learning disability strategy, The keys to life .

The strategy defines learning disability as a significant, lifelong condition that started before adulthood, which affects development and means individuals need help to: understand information; learn skills; and cope independently. SCLD is committed to finding new and better ways to improve the lives of people with learning disabilities and is focused on sharing innovation and good practice so that those providing services and interventions can learn from each other.

SCLD also aims to be a knowledge hub and to build an evidence base, sharing how policy is being implemented and building on an understanding of effective methods of creating change.

2. Introduction

Recent reform to welfare at a UK level has impacted particularly severely on recipients of disability benefits. However, whilst there are problems with the design and delivery of disability benefits, they are vitally important to people with learning disabilities - helping them to participate in society and enabling them to take up opportunities that could be otherwise inaccessible. They provide financial support for independent living and meeting the additional costs of daily living faced by disabled people.

The Scotland Act (2016) devolves powers over the following benefits: Ill Health and Disability Benefits; Carer's Allowance; Best Start Grant; Funeral Payments and Winter Funeral Payments; Discretionary Housing Payments and some powers over Universal Credit. Ill Health and Disability Benefits include: Disability Living Allowance (DLA), Personal Independence Payment (PIP), Attendance Allowance (AA), Industrial Injuries Disablement Benefit (IIDB) and Carer's Allowance. Around half of the nearly £3bn of security expenditure being devolved is spent on Disability Living Allowance (DLA) and Personal Independence Payments (PIP).

The new powers included in the Scotland Act (2016) provide an opportunity to design a social security system specific to Scotland and to take a fresh look at accessibility and communication, eligibility criteria, assessment and evidence gathering processes. Given the extensive powers devolved over disability benefits, people with learning disabilities are likely to be particularly impacted by any changes to the social security system. It is essential that people with learning disabilities and organisations that work with them and represent them are able to positively influence this process.

Earlier this year SCLD held three consultation events in Edinburgh, Dundee and Girvan to hear the views of people with learning disabilities and their carers on their experience of the social security system to date and their suggestions for future improvements. These events helped shape our response to the Scottish Government's social security consultation and have informed this report.

Forty people attended the events: 65% were female and 35% male. There was a range of age groups from those who were still at school to those who were nearing retirement age. The feedback from these events was mostly qualitative in nature and is representative only of the views expressed by the individuals who attended. It does, however, highlight some of the issues that these individuals have encountered when interacting with the welfare system.

In this report we have also drawn on our considerable expertise and experience in the field of learning disability. This has been developed through extensive engagement with a wide range of stakeholders including: people who commission and provide services for people with learning disabilities; those who act as advocates or are working in research; as well as people with learning disabilities and carers.

3. Key points

SCLD believes the future social security system in Scotland should:

- Be co-produced with people with lived experience of learning disability and be underpinned by a human rights based approach;
- Prioritise inclusive communication and accessible information, with more streamlined application processes and local points of contact;
- Broaden the evidence base for decision making with minimum emphasis on assessments interviews;
- Consider the feasibility of more automatic entitlement and lifelong awards;
- Invest in a publicly funded service that offers holistic advice and advocacy to provide enhanced levels of support to those who need it;
- Be administered at a national level to increase certainty for claimants, to ensure quality of service, reduce complexity and avoid a postcode lottery;
- Integrate well with other services e.g. social care and support for employment, education and training;
- Include a review of the appeals and tribunal system.

4. Applications, assessments & eligibility

i) Applying for disability benefits

In order to make a claim for PIP, applicants must provide a Department of Work and Pensions (DWP) advisor with the following information by phone:

- contact details and date of birth
- National Insurance number
- bank or building society details
- doctor's or health worker's name
- details of any time spent abroad, or in a care home or hospital

On the basis of this information the DWP assesses whether someone meets the basic eligibility conditions and then sends a more detailed PIP2 form for claimants to describe how their disability impacts them. To support an application for PIP, claimants can submit additional written information from health and other professionals. The onus is upon the claimant to gather and submit this information.

At our consultation events people reported finding the application process difficult and complex. Some people found the phone call to initiate a claim for PIP challenging, particularly having to provide a lot of personal information on the spot. People also reported that PIP2 forms were confusing, too long and difficult to complete. Even with help from a support worker people said the form can take between two and three hours to complete.

People also expressed concerns that communications at present are not inclusive and complained about a lack accessible information. Examples of this included unfriendly and disrespectful staff, as well as written communication which is complicated, difficult to understand and sometimes does not make sense. Some said they found the system confusing and hard to engage with and cited frequent errors and delays in correspondence. There was even an impression amongst some that DWP communications are designed to confuse people or catch them out.

The Scottish social security system must ensure that accessible information and guidance, appropriate to an individual's needs, is available at all stages of the application process.

People may:

- Require information in alternative formats for example easy read, large print, audio or DVD.
- Have difficulty using a phone and may prefer a one-to-one meeting.
- Need the support of advocacy services.
- Require specialist tailored advice to deal with complex enquiries.

At our consultation events suggestions on what could improve the application process for disability benefits included:

When people first get in touch

- More inclusive communication and better accessible information.
- A range of communication options e.g. online, face to face, telephone.
- A funded advice sector with specialist provision for people with learning disabilities.

- More provision for face-to-face contact with advisors.
- More training for advisors in working with people with learning disabilities.
- A role for health visitors, GPs and other professionals in signposting people.

When they are in the processes of applying for a benefit

- A range of options when making applications e.g. online, face to face, over the telephone or by filling out a form.
- More streamlined, accessible and straightforward applications forms.
- Statutory assistance to support people to complete application forms.
- Support to help people use computers.
- Signposting and improved advice or linking in with other services e.g. Welfare Fund, the Independent Living Fund or other support.
- Acknowledgment of an application once it has been received.

When a decision is made (for example, about whether they receive a benefit)

- Ensure written correspondence can be easily understood.
- More time to act after someone receives a letter.
- Greater transparency in the decision making process.
- Availability of advocacy support.

When they are in receipt of a benefit

- Inclusive communication and accessible information before and after mandatory reassessment.
- Greater clarity and transparency of processes.

We believe that to be genuinely inclusive it is important that the new system includes local points of contact with well-trained frontline staff who have an understanding of disability and some staff who specialise in working with people with learning disabilities. Involving people with learning disabilities in the design, development and testing of new systems is vital to ensure that any methods of contacting people used do not create communication barriers.

ii) Assessments

Personal Independence Payments (PIP) which were introduced in 2013 to replace Disability Living Allowance (DLA) introduced face to face medical assessments for the vast majority of claimants and an end to indefinite or lifetime awards. Some of the biggest concerns for those who attended our consultation events were around medical assessments and the constant threat of having entitlement reassessed and losing their benefits. The on-going migration from DLA to PIP and the mandatory reassessment this entails was described as a difficult and negative experience. The following criticisms of assessments were made at the events:

- The period leading up to an assessment is stressful and nerve racking.
- The process of attending assessments can be traumatic.
- Assessments are impersonal and can make people feel vulnerable.
- Sharing private information with a stranger is embarrassing and degrading.
- Having an interview to prove someone has a disability is humiliating.
- Assessment centres can be difficult to get to.

The quality of the assessor was thought by some to be a key factor in the outcome of the assessment interviews. People reported feeling that they were not always believed or that their views were dismissed as irrelevant. Support workers made the point that individuals with learning disabilities often need to have developed a trusting relationship with someone in order to feel comfortable divulging personal information.

A number of issues were raised relating to a lack of faith in those conducting assessment interviews. Examples included assessors:

- Being unfriendly, impolite and impatient.
- Showing a lack of understanding of learning disability (it was questioned whether physiotherapists are suitably qualified).
- Asking leading questions and paying insufficient attention to the person being assessed.
- Not appearing to be familiar with the details on the applicant's form.

There were some views which supported the case for assessment interviews in certain circumstances:

- They can be beneficial if the person has not had a lot of previous engagement with primary care.
- Some people with learning disabilities may overstate their capabilities on the form and an interview can provide checks and balances for this.
- An assessment interview can provide an opportunity for people to explain their situation more fully and could be available on an opt-in basis.
- One-to-one assessments in a home environment are less stressful and can allow an assessor to learn more about a person's day-to-day life.

A 65% success rate for those who appeal decisions to reduce or cancel their PIP award points to a high rate of inaccurate decision making . In our opinion there are a number reasons why PIP assessments do not always give an accurate picture of someone with learning disabilities capabilities:

- They tend to produce a snap shot of a person's life rather than a long term picture.
- They also focus overly on physical and health needs and take little account of an individual's level of understanding or level of support they required to attend the interview.
- People with learning disabilities can struggle to communicate their difficulties clearly and effectively in an interview situation, and may also underplay their difficulties or not fully understand the questions.
- They may not always understand the criteria on which they are being assessed or the particular significance of the answers they give.

We suggest there is a need to broaden the evidence base for decision making with more use of existing medical and other reports (e.g. social care or education) to support an application and inform the assessment process. This should involve greater use of evidence from professionals who know the claimant e.g. GPs, community psychiatric nurses, consultants, social workers, occupational therapists, physiotherapist, support workers. Placing less emphasis on individuals to repeatedly provide information will also reduce the stress of the application process and speed up decision making processes.

SCLD is open to limited use of assessment interviews in certain circumstances where it has not been possible to obtain crucial information by the ways described above or where an individual specifically requests one. In such cases, assessors must be equipped with the communication skills and competencies to be able to support the person to give an accurate representation of themselves and that interviews should take place in locations that are familiar to people and fully accessible.

iii) Eligibility

At our consultation events it was suggested that people are not always opposed to having a medical assessment in principle but what they object to is constant reassessment. Unnecessary assessments are also a drain on resources and cause significant turmoil and stress for people with learning disabilities and their families. One way to reduce this is through the inclusion of automatic entitlement and lifelong awards for certain conditions. There is a strong argument for looking at the feasibility of granting people with learning disabilities lifetime awards following assessment.

Establishing the criteria to determine who qualifies for these entitlements and awards will be critical. This process should involve extensive consultation with claimants of disability benefits and organisations and professionals that support them. Automaticity is unlikely to apply to everyone with a learning disability and where this is the case decision making should be informed by a wider evidence base with more information provided by professionals who know the claimant. Face-to-face medical assessments should only be used in the last resort.

5. Co-production, delivery and advocacy

i) Co-production

People who attended our consultation events felt strongly that the skills and experience of those with lived experience of learning disabilities should inform the design of the new social security system. SCLD believes it is important that people have the opportunity to share their experiences and opinions on the advantages and disadvantages of the present system and to participate in the process of planning and designing the new one. This process should involve active and constructive dialogue with people with learning disabilities and be underpinned by a human rights-based approach using the PANEL principles. It is important that dialogue continues after the system is set up to feed in to continual improvement processes.

There is an opportunity to engage with existing structures such as The keys to life Expert Group as well as other forums led by and for people with learning disabilities. The Expert Group comprises around twenty people with learning disabilities from different parts of Scotland and was established to provide a means of eliciting the voices of people with lived experience in the delivery of The keys to life and related policy issues.

ii) Scottish social security agency

The Scottish Government has recognised the need to change the stigmatising and discriminatory language associated with welfare. The creation of a Scottish social security agency presents an opportunity to embed a new ethos and culture, and a more positive approach to social security recognising the way it supports self-determination and the human rights of people with learning disabilities.

In terms of delivery of social security the views expressed at our consultation events generally supported a single national agency which administers all social security benefits in Scotland. This mainly related to the importance people placed on consistency of service delivery and quality of decision making across different areas.

People pointed to varying levels of entitlements and quality of service for national schemes delivered locally such as the Scottish Welfare Fund and National Concessionary Travel Scheme. There was some support for local authorities and third sector organisations to provide advice, information and support but a widely held view that the administration and delivery of benefits should be the responsibility of a national agency.

Based on our knowledge of welfare delivery models we believe a single national agency has the following potential advantages:

- Promoting consistency and uniformity.
- Allowing for minimum standards to be established.
- Reducing communication difficulties between agencies.
- Facilitating the development of specialist expertise.
- Supporting integration at financial, policy and operational levels with other public services.

It is paramount that the new social security agency guarantees continuity of support, services and payments to minimise any confusion or accessibility issues that may arise.

iii) Alignment with other devolved services

It is important that the new social security system is well integrated and works effectively with other services at national and local level such as:

- Social care
- Employment support
- Health services
- Independent Living Fund
- Welfare Fund
- Housing and homelessness services
- Business, employment conditions and pay, childcare
- Independent advice and advocacy, including money and debt advice

With regard to social care, many recipients pay a contribution to the cost of their care based on the amount they receive in benefits. In designing the new system the Scottish Government should be cognisant of the interaction between social security and social care funding and the possible implications for individuals. For example, it would make little sense to increase benefit levels only for this increase to be absorbed by increases in local authority care charges.

The new social security system must also work in tandem with other new powers such as employability support. The employment rate for people with learning disability is between 7-25% compared with 73% rate for the general population . Many people with a learning disability can work, however they may require support in order to be able to enter, sustain and progress into employment. Addressing the employability gap in part requires overcoming the low expectations of (some) parents, teachers and college lecturers; and challenging employers' preconceptions of what people with a learning disability are able to do in the workplace.

It is essential that the social security system does not create barriers to entering work, provides people with the means and support to access employment opportunities, and allows people to move in and out of the system without being penalised.

iv) Advice services

At our consultation events there were complaints about a lack of available advice and information to support the application and assessment process. People reported that Citizens Advice Bureau (CAB) services were overloaded and people gave examples of having to travel significant distances to access advice services. The creation of the new social security system means there will be two systems each with their own rules and processes. This will place new requirements and demands on the advice sector in Scotland, who may face increased pressure in the absence of additional resources.

We believe there is a requirement for a publicly funded advice service that offers holistic advice and supports people to navigate the system. There could also be a role to offer advice in other important areas such as energy efficiency measures or debt management. The service should make provision for one-to-one advice in local offices as well as accessible information and advice freely available online. In developing such a service, it will be important to prioritise the user experience and to ensure processes and services are evidence based and co-designed with claimants including people with learning disabilities. It will also be important to encourage proactive signposting and develop links between the service and a wide range of organisations e.g. providers of health and social care services as well as learning disability organisations.

v) Independent advocacy

Professional advocacy support has been shown to be 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 .

At our consultation events some people felt that claims may be unsuccessful not because they are undeserving but because there has not been the appropriate help and support. People expressed the following advantages to having someone to support them during the PIP interview assessment:

- It made them more likely to attend.
- It increased their confidence levels.
- It helped them to communicate.
- It reduced stress and improved overall wellbeing.
- It increased their preparedness.

The presence of an advocate in an assessment interview can also ensure that people do not forget to raise key issues, and have a positive influence on the approach of the assessor. We believe there is scope for independent advocacy to play a significant role in the support that is available to people claiming disability benefits. Advocacy has the potential to make the new system more accessible and responsive to the needs of people with learning disabilities, help people navigate the claims process and provide an enhanced level of support for people during assessment process. The future Scottish social security system should recognise this and be funded to provide the necessary provision.

vi) Complaints, reviews and appeals

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.

At our consultation events people with learning disabilities reported that the appeals and tribunal process can be a daunting experience and most people have very limited understanding of the process involved. We believe it is essential that the complaints, review and appeals process is based on human rights principles and treats people with dignity, respect and compassion.

At present the appeals process is formal and off-putting and the tribunal process is overburdened and expensive. We advocate a review of the appeals and tribunal system. We suggest that benefits should remain in place until an appeals process is completed and a judgement made. There should also be a clear timetable for the review and consideration of appeals.

6. Conclusion

The Scottish Parliament has an opportunity to make radical changes to the nature of disability benefits in Scotland and the way they are delivered. A strong message which emerged from our consultation events was that the present system creates a number of barriers for people with learning disabilities and the application and assessment process can be stressful for individuals and their families.

We believe, in order to be genuinely inclusive, the Scottish social security system must include a range of different ways for people to engage with the system. This should include local points of contact with some staff who specialise in working with people with a learning disability. Accessible information appropriate to an individual's needs should also be available at all stages of the application process.

The overreliance on PIP assessments in the current system is stressful for people with learning disabilities and leads to poor decision making. It is imperative that the new system is better equipped to accurately assess people's support needs and determine levels of entitlement. In our view, this requires an assessment process which minimises the need for face to face interviews and reduces the need for unnecessary reassessment. Making more use of existing medical and other reports (e.g. social care or education) as well as increased safe information sharing between professionals would broaden the evidence base for assessment.

Advocacy has the potential to make the new system more accessible and responsive to the needs of people with learning disabilities. We propose the Scottish Government should plan for investment in advocacy together with holistic advice services as an essential element underpinning the design of the new system. However, the Scottish Government also has a responsibility to ensure the new system is easier to navigate without professional support and is designed to be more responsive to the requirements of people with learning disabilities.

A process of co-production involving active dialogue with people with learning disabilities at every stage is vital to ensure that the new Scottish social security system is fully inclusive and accessible, and is built on a rights-based approach.

References

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