

RESPONDENT INFORMATION FORM



Consultation on Social Security in Scotland to determine how best to use the new social security powers which will be devolved by the Scotland Act 2016.

Please Note this form **must** be returned with your response.

Are you responding as an individual or an organisation?

- Individual
 Organisation

Full name or organisation's name

Scottish Commission for Learning Disability (SCLD)

Phone number

0141 248 3733

Address

5th Floor Suite 5.2, Stock Exchange Court, 77 Nelson Mandela Place, Glasgow

Postcode

G2 1QY

Email

Lorne.b@sclld.co.uk

The Scottish Government would like your permission to publish your consultation response. Please indicate your publishing preference:

- Publish response with name
 Publish response only (anonymous)
 Do not publish response

We will share your response internally with other Scottish Government policy teams who may be addressing the issues you discuss. They may wish to contact you again in the future, but we require your permission to do so. Are you content for Scottish Government to contact you again in relation to this consultation exercise?

- Yes
 No

Background

The Scottish Commission for Learning Disabilities (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*¹. 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.

We are committed to finding new and better ways to improve the lives of people with learning disabilities and are focussed on sharing innovation and good practice so that those providing services and interventions can learn from each other. We also aim to be a knowledge hub and to build an evidence base, sharing how policy is being implemented and building on an understanding of what really works.

To inform this response 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. A total of forty people attended the events, 65% were female and 35% male and there was a range of age groups. Almost a third of participants described themselves as having a physical impairment as well as a learning disability, and almost half said they also had mental health condition. 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 compiling this response we have also drawn on our considerable expertise and experience in the field of learning disabilities. 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.

We welcome the opportunity to respond to the Scottish Government's consultation on the future of social security in Scotland.

¹ <http://keystolife.info/>

Introduction

The Scotland Act devolves around £3bn of social security expenditure. Over half of this (£1.6bn) is spent on Disability Living Allowance (DLA) and Personal Independence Payments (PIP). Whilst there have been problems with the design and delivery of these benefits, they have been important to people with learning disabilities, helping them participate in society and enabling them to take up opportunities that could be otherwise inaccessible. They have provided financial support for independent living and meeting the additional costs of daily living faced by disabled people. Recent reform to welfare at a UK level, however, has impacted particularly severely on recipients of disability benefits.

SCLD believes the devolution of the new social security powers to Scotland provides an opportunity to improve accessibility and communication, review eligibility criteria and reform assessment and evidence gathering processes to create a system that genuinely offers improved life chances for all.

Key points

We believe the future social security system in Scotland should:

- Be underpinned by a human rights based approach with key principles embedded in legislation;
- Support people with learning disabilities to be as independent as possible and support their right to live well;
- Prioritise inclusive communication and accessible information and processes
- Invest in a publicly funded advocacy service to provide enhanced levels of support to those who need it;
- Broaden the evidence base for decision making with minimum emphasis on assessments interviews;
- 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.

Part 1: A Principled Approach

1. Fixing the Principles in Legislation

Which way do you think principles should be embedded in the legislation?

~~A. As a 'Claimant Charter'?~~

~~B. Placing principles in legislation?~~

C. Some other way, please specify

At our consultation events we held a discussion on the Scottish Government's suggestions for fixing the principles in legislation and asked participants to vote on their preference for: a claimant charter, having principles written into law or a combination of both. The results were as follows:

A claimant charter	Writing principles into law	Combination of both
9% (3)	14% (5)	77% (27)

A charter that is well written and clearly worded was generally seen as important. It was felt this would make the principles more accessible and easier to understand but there were concerns that the principles would lack clout and offer little protection unless they had a basis in legislation. Enshrining the principles in law was seen as offering greater accountability and giving people the option to challenge in the courts. There was also a view that people with learning disabilities should have a role in writing and designing the charter.

SCLD believes that the involvement of claimants in designing this process will be important to ensure that the principles of the social security system are understood by those who use the system as well as those who administer it. We would like to see a co-produced charter built on active and constructive dialogue with people with learning disabilities and set within a human rights-based framework. In our opinion, this type of detailed consultation with people who use the system is vital to ensure effective scrutiny of the extent to which the social security principles are upheld within the legislation. A process which takes account of the experiences of people with learning disabilities will also help to promote continuous improvement and transparency.

We recommend that the Scottish Government applies a human rights-based approach using the PANEL approach²:

- **Participation** – people take part in decision-making and have a voice
- **Accountability** – organisations and people are accountable for realising rights
- **Non-discrimination** – everyone has the same rights, regardless of their status
- **Empowerment** – people have the power to know and claim their rights
- **Legality** – all decision answer to human rights legal standards

² <http://www.scottishhumanrights.com/humanrights/humanrightsbasedapproach>

These rights-based PANEL principles should be used to put rights into practice in every part of the new social security system.

2. Outcomes and the user experience

Are the outcomes the right high level outcomes to develop and measure social security in Scotland?

SCLD welcomes the high level outcomes to develop and measure social security in Scotland. They set out clearly what people can expect from the new system and reflect the potential for social security to be a key determinant of well-being. The extensive powers in relation to disability benefits included in the Scotland Act 2016 mean that people with learning disabilities are likely to be particularly impacted by the new system. It is essential, therefore, that disability benefits under the new system are fit for purpose and empower people to lead full, active and independent lives.

How can the Scottish social security system ensure all social security communications are designed with dignity and respect at their core?

People who attended our consultation events expressed concerns that communications at present are not inclusive and fail to treat people with dignity and respect. 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 Department of Work and Pensions (DWP) communications are designed to confuse people or catch them out.

The Scottish Government has statutory duties under the Equality Act 2010³ and responsibilities under the United Nations Convention on the Rights of Disabled People⁴ (UNCPRD) to guarantee that disabled people are not disadvantaged by communication barriers. We welcome the recommendations in the Scottish Parliament's Welfare Reform Committee report on the Future of Delivery of Social Security in Scotland⁵ that all social security communications should be clear, accessible and written in plain English.

Accessible information and guidance, appropriate to an individual's needs, should be available at all stages of the application process. People may:

- Require information in alternative formats for example easy read, large print, audio or DVD.

³ <http://www.legislation.gov.uk/ukpga/2010/15/contents>

⁴ <http://www.un.org/disabilities/convention/conventionfull.shtml>

⁵ [The Future Delivery of Social Security in Scotland, 6th report 2015 \(session 4\)](#)

- Have difficulty using a phone and may prefer a one-to-one meeting with communication support.
- Need the support of advocacy services.

Some individuals may require additional support or equipment and specialist tailored advice should be available to deal with more complex enquiries. If information is not accessible a person with learning disabilities may:

- Avoid services completely.
- Not turn up for an appointment.
- Respond to only some of the advice given even after saying or nodding they understand.
- Give irrelevant, unclear or rambling responses to questions.
- Have difficulty paying attention.
- Become frustrated, embarrassed, anxious or angry.
- Have difficulty describing feelings, events or needs in words that make sense.⁶

The Scottish Government has a duty, therefore, to prioritise inclusive communication as well as a responsibility to ensure that the language and tone of communication is respectful, considered and does not stigmatise people. SCLD believes a system based on dignity and respect will engender a more positive opinion of social security amongst people with learning disabilities in Scotland

With whom should the Scottish Government consult, in order to ensure that the use of language for social security in Scotland is accessible and appropriate?

SCLD's report⁷ on the progress of implementation of the UNCRPD highlighted the importance of the direct involvement of people with learning disabilities in creating appropriate accessible information and language. As mentioned previously, we advocate a process of co-production in the design of the new system. It is important that people with learning disabilities have the opportunity to share their experiences and opinions on the advantages and disadvantages of present system and to participate in the process of planning and designing the new one. We propose the Scottish Government consults with *The keys to life* Expert Group⁸ as well as with 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. The

⁶ [Principles of Inclusive Information \(2011\)](#)

⁷ [SCLD Parallel Report to the United Nation Committee on the Rights of the Person with Disabilities on the Progress of the Implementation of UNCRPD in the United Kingdom](#)

⁸ [The keys to life Expert Group](#)

group is facilitated by SCLD. A number of other service provider and advocacy organisations within the third sector also have long established forums.

The Scottish Government's social security 'user panels' should also inform the language of the new system. It is important that these include learning disability claimants with a range of support needs and backgrounds.

How should the Scottish social security system communicate with service users? (For example, text messaging or social media)?

SCLD recognises the potential of technology to reach people more efficiently and effectively. We are, however, cognisant of the risk that some groups may be inadvertently excluded. The rates of digital exclusion are higher amongst people with learning disabilities⁹. Many people do not have access to the internet or require equipment to be specially adapted to their needs. We believe that it is essential that the methods of communication used by the new system are as inclusive as possible. 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.

What are your views on how the Scottish Government can ensure that a Scottish social security system is designed with users using a co-production and co-design approach?

The Scottish Co-production Network has produced a guide to integrating co-production into public service design and delivery¹⁰. It emphasises four key elements:

- **Co-commissioning** - service commissioners working with people who use services and local communities in the prioritisation and planning of services.
- **Co-design** - service providers and citizens redesigning public services to improve outcomes and reduce costs
- **Co-delivery** - service providers working with citizens who use services to improve the service delivery process and take preventative action with local communities to improve outcomes
- **Co-assessment** - public service providers working with citizens as evaluators of public service quality and outcomes

We believe co-production has the potential to be a key driver of reform. The skills and experience of all stakeholders including the lived experience of people with learning disabilities should inform all stages of the process. We urge the Scottish Government to conduct on-going dialogue with people with learning disabilities to

⁹ http://www.litrg.org.uk/sites/default/files/digital_exclusion_-_litrg_report.pdf

¹⁰ <http://www.coproductionsotland.org.uk/resources/the-co-production-star/>

inform the design and delivery of the new system. This dialogue should continue after the system is set up to feed in to continual improvement processes.

3. Delivering social security in Scotland

Should the social security agency administer all social security benefits in Scotland?

The views expressed at our consultation events generally supported a single national agency which administers all social security benefits in Scotland. These 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.

A common theme to emerge from the consultation events was the complex and disjointed nature of the current system. The devolution of the new social security powers in the Scotland Act 2016 has the potential to add to this complexity and there is a risk this could make the process more inaccessible for people with learning disabilities. It is paramount, therefore, that the new social security agency guarantees continuity of support, services and payments to minimise any confusion or accessibility issues that may arise.

Should the social security agency in Scotland be responsible for providing benefits in cash only or offer a choice of goods and cash?

There was a mixture of views expressed on this at our consultation events. We asked people to vote on whether they would like choice of some of their benefit being used to purchase goods 'in-kind', such as reduced energy tariffs or adaptations to their homes. The result was as follows:

Yes	No	Don't Know
35% (9)	42% (11)	23% (6)

Some people stressed the importance of choice and said they would prefer to be able to purchase goods themselves than to be restricted to a certain supplier or manufacturer. In our view, it is important that any alternative to cash arrangements are offered to individuals as a free choice, without any pressure placed on the claimant to select the form of support most cost effective to the Scottish Government.

We also asked participants at our consultation events to vote on whether a one-off, lump sum payment would be more appropriate than regular payments in some situations. The result was as follows:

One big payment	Small and regular payments	Don't know
8% (2)	85% (22)	8% (2)

The underlying theme that emerged was that people appreciate frequent payments as this makes it easier to budget and meet some of the extra day-to-day costs of living with a learning disability.

Should social security make some provision for face to face contact?

A strong message to emerge from our consultation events was the need for a range of different ways for people to engage with the system. SCLD is clear that in order to be genuinely inclusive, the new social security system must make some provision for face to face contact. We agree that the creation of a new agency presents an opportunity to embed a new ethos and culture around social security, and we think that one way to effect this is to create local points of contact with well-trained frontline staff. In our experience it is vital that staff should have an understanding of disability including some staff who specialise in working with people with a learning disability.

4. Equality and low income

What does the Scottish Government need to do, as it develops a Scottish social security system to ensure that any implications for those on low incomes are fully taken into account?

PIP and DLA are not income replacements but provide support for additional costs of living with a disability such as heating, transport, clothing, diet, promoting independent living and social inclusion. The UK Government is a signatory to the UN Convention on the Rights of Persons with Disabilities¹¹, which states that every disabled person has the right to an adequate income to meet the basic needs that arise. Despite this, there are unacceptably high levels of poverty among disabled people some of which is related to the additional costs of living with a disability.

¹¹ <http://www.un.org/disabilities/convention/conventionfull.shtml>

Research by the New Policy Institute has found that 48% of all those living in poverty in the UK are either disabled people or people living with disabled people¹². Furthermore, the impact of welfare reform legislation at a UK level is still to be fully felt. From April 2017, those who claim the Work Related Activity Group (WRAG) element of Employment Support Allowance (ESA) will get the same as Job Seeker's Allowance (JSA)¹³. This will reduce payments from £103 a week to £73 a week for someone over the age of 25. We anticipate these changes will impact significantly on the incomes of people with learning disabilities who are one of the largest groups in the WRAG. We urge the Scottish Government to take account of the levels of poverty among people with learning disabilities and consider the extent to which the benefits delivered in Scotland contribute to an adequate income for people with learning disabilities.

5. Independent Advice and Scrutiny

Do you think there is a need for an independent body to be set up to scrutinise Scottish social security arrangements?

SCLD is in favour of an independent body to provide mandatory scrutiny of the new social security arrangements. We see a critical role for this function in overseeing standards, particularly in assessment processes. We believe this would allow for the development of a new culture built on the concepts of fairness, transparency and respect. We think this body should draw on the expertise of a panel of people who use the social security system to allow for effective on-going scrutiny.

¹² [Disability and Poverty, New Poverty Institute \(August 2016\)](#)

¹³ <http://www.disabilityrightsuk.org/how-we-can-help/benefits-information/timetable-forthcoming-welfare-benefits-changes#April2017>

Part 2: The Devolved Benefits

6. Disability Benefits

Thinking of the current benefits, what are your views on what is right and what is wrong with them?

At our consultation events people in receipt of DLA and PIP people generally felt that these payments made a huge difference in helping them to lead full lives and live independently. However, areas of concern for people included the complicated process of application, poor communication and assessment interviews.

Applying for a disability benefit

Some of the views expressed at the consultation events included:

- The system is confusing and the application process is complicated.
- There is a lack accessible information and advice.
- The phone call to initiate a claim for PIP can be challenging.
- The forms are too long and some questions are difficult to answer.
- Even with help from a support worker or social worker the form takes between 2-3 hours to complete.
- The process is not transparent enough and it is difficult to know on what basis decisions are being made.

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 benefits

- A range of options when making application 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 to attend assessment interviews and appeals.

When they are in receipt of a benefit

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

Assessments/Consideration of the Person's disability

Some of the biggest concerns for those who attended our consultation events were fear of losing their benefit and being under the constant threat of having their entitlement reassessed. The 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.
- Attending assessments is traumatic and emotionally and physically draining.
- 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. 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. People also reported feeling that they were not always believed or that their views were dismissed irrelevant.

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.

SCLD believes it is imperative that the new system is better equipped to accurately assesses people's support needs and determine levels of entitlement. In our view, the overreliance on PIP assessments in the current system leads to poor decision making, and we believe this is reflected in the 65% success rate for those who appeal decisions to reduce or cancel their PIP award¹⁴. Assessments are also resource intensive and place avoidable stress on individuals and their families.

In our opinion there are a number reasons why PIP assessments do not 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.

Given our view of the inadequacy of PIP assessments for effective decision making we believe 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. We recommend greater use of evidence from professionals who know the claimant e.g. GPs, community psychiatric nurses, consultants, social workers, occupational therapists, physiotherapist, support workers. We would also like to see less emphasis placed on individuals to repeatedly provide information. This would reduce the levels of stress the application process places on people and speed up decision making processes.

SCLD is open to the use limited 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, we urge the

¹⁴ <http://news.scotland.gov.uk/News/PIP-failing-disabled-people-2b29.aspx>

Scottish Government to ensure that assessors are equipped with the communication skills and competencies to be able to support the person to give an accurate representation of themselves and that interviews take place in locations that are familiar to people and fully accessible.

Eligibility criteria set for disability related benefits

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. We believe that there is a place for more automatic entitlement and lifelong awards in the new system and therefore welcome the Scottish Government's consideration of greater automaticity for certain conditions. Additionally, we believe that 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. SCLD believes this process should involve extensive consultation with claimants of disability benefits and organisations and professionals that support them. We recognise, however, that automaticity is unlikely to apply to everyone with a learning disability and as previously stated, we think 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.

Mobility component

Should the new Scottish social security system continue to support the Mobility scheme?

A theme that emerged at our consultation events was the importance of the mobility element of disability benefits for some people with learning disabilities. For some people the mobility scheme makes a fundamental difference to their ability to live independently and participate fully in society. Some people, however, reported that their higher-rate mobility had been reduced from in the transfer from DLA to PIP. There was a fear that losing higher-rate mobility would reduce their access to independent living. SCLD understands the difference the mobility scheme makes to people's lives and to achieving the strategic outcomes in *The keys to life* and we urge the Scottish Government continue to support it.

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. We urge the Scottish Government to 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.

We believe it is vital that the new social security system works 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 population¹⁵. 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.

Finally, people with learning disabilities do not always claim all the benefits they are entitled to. We believe there is an opportunity for the Scottish Government to look at ways to ensure maximum take up. This should involve alignment with other services to consider the range of passported benefits a person may qualify for.

7. Carer's Allowance

The UK Government currently pays Carer's Allowance at a rate of £62.10 per week. We agree with the Scottish Government's proposal to increase Carer's Allowance so that it is paid at the same level as Jobseeker's Allowance (£73.10 per week for jobseekers aged 25 and over). We also welcome the Scottish Government's commitment to embedding financial support and recognition for carers into the wider strategy for supporting carers set out in the Carers (Scotland) Act 2016.

¹⁵ [Mapping the Employability Landscape for People with Learning Disabilities in Scotland, SCLD \(August 2016\)](#)

We agree with the briefing produced by the National Carers Organisations¹⁶ which recommends:

- The removal of the earnings limit for Carer's Allowance or ensuring that it increases in line with the National Minimum Wage.
- Allowing people to combine caring with full time studying, by making Carer's Allowance available to full time students.
- Allowing people to claim a greater amount of Carer's Allowance if caring for more than one person, recognising the financial impact of multiple caring roles.
- Replacing Carer's Allowance with a two-tier benefit for carers which:
 - Pays a Carer's Allowance equivalent at the same rate as Jobseekers Allowance, with the opportunity to earn small amounts in a paid job in line with the permitted earnings rule.
 - Includes a premium payment available to all carers in intensive caring roles but payable to all qualifying carers to compensate them for the additional costs of caring and/or to enable them to buy in help, goods or services to ease their caring situation.

¹⁶ http://www.carerstogether.org/wp-content/uploads/2016/06/Carers_Allowance_position_paper_final.pdf

Part 3: Operational Policy

14. Advice, representation and advocacy

What role should publicly funded advice providers play in the development of a new Scottish social security system?

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.

At our consultation events there were complaints about a lack of available advice and information. People reported that Citizens Advice Bureau (CAB) services were overloaded and people gave examples of having to travel significant distances to access advice services. Some felt that claims may be unsuccessful not because they are undeserving but because there has not been the appropriate help and support.

SCLD believes 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, we urge the Scottish Government 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.

Do you think that independent Advocacy services should be available to help people successfully claim appropriate benefits?

We believe there is scope for independent advocacy to play a significant role in the support that is available to people claiming disability benefits. In our view, advocacy has the potential to make the 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 learning from the Welfare Advocacy Project¹⁷ suggests that advocacy can be of significant assistance in providing one-to-one tailored support for people undergoing assessments. The pilot project which ran from May 2015 to May 2016 in four areas of Scotland (Dundee City, Forth Valley, Glasgow, Midlothian/City of Edinburgh) was specifically tailored to support people with mental health problems, neurological conditions and learning disabilities; over 900 people used the project. During the

¹⁷ [Evaluation of the Welfare Advocacy Project \(2016\)](#)

project significantly greater numbers of people who received advocacy support had successful claims than the national average. The project also had a positive impact on individuals' understanding of the process, their ability to communicate and preparation levels.

At our consultation events people expressed the following advantages to having someone to support them during the interview process:

- 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 advocacy should be available to anyone who is asked to attend an assessment interview as part of their application. We urge the Scottish Government to plan for investment in advocacy as an essential element of the new system. At the same time, we believe it is the Scottish Government's responsibility to make sure the new system is easier to navigate without professional support and is more responsive to the requirements of people with learning disabilities.

15. Complaints, reviews and appeals

How can we ensure that our values underpin the appeals process for a Scottish Security agency?

For people with learning disabilities the appeals and tribunal process can be a daunting experience and most people have very limited understanding of the process involved. One person at our consultation event gave the following account:

“The tribunal process is daunting, nerve racking, stressful. There is the fear of the unknown. It is upsetting. People are afraid to say the wrong thing. There is the fear of going in front of someone you don't know. You don't know what information your doctor has submitted. It feels humiliating...a form of mental torture”.

We believe it is essential that the complaints, review and appeals process is based human rights principle 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 urge the Scottish Government to review the appeals and tribunal system. We suggest that benefits should remain in place until an appeals process is completed and a judgement made. There must also be a clear timetable for the review and consideration of appeals.

19. Safeguarding your information

Should the individual be asked to give their consent to allow their personal information, including medical records, in the interests of simplifying and speeding up the application process and/or reducing the needs for appeals due to lack of evidence?

At our consultation events there was broad support expressed for measures to reduce bureaucracy. People complained about having to explain their conditions, symptoms or level of independence numerous times. However, confidentiality remained a concern for some.

SCLD recognises that sharing information between public sector organisations offers significant advantages to the application process i.e. reducing the burden on applicants, and developing a more integrated and efficient approach to delivering services. However, information sharing must be appropriate and should always be done with the person's consent. We believe the person themselves is the best guardian of their data and the level of sharing needs to be based on the view of the person themselves. We urge the Scottish Government to ensure the system is flexible enough to enable the individual to give consent to open up access to their data to whatever level they stipulate.

What are your views on having the option to complete social security application forms online?

At our consultation events some people felt that being able to complete an application form online would speed up the decision making process. However, people also highlighted the importance of ensuring that it is possible to save online applications, and to add supporting documents. Others were concerned that not everyone has access to a computer or the internet. We urge the Scottish Government to ensure that there are a range of accessible ways to complete social security applications forms and that any online version is user friendly.

20. Uprating

What are your views on the best way to ensure that devolved benefits keep pace with the cost of living?

It is important for the living standards of people with learning disabilities that disability benefit levels do not lose value as the cost of living increases. We recommend that the newly devolved benefits system should be uprated in line with the Retail Prices Index.