



Disability Agenda Scotland (DAS)
A New Future for Social Security: Consultation on Social Security in Scotland
October 2016

About DAS

DAS is an alliance of Scotland's leading disability organisations. The members of DAS are: Action on Hearing Loss Scotland, Capability Scotland, ENABLE Scotland, RNIB Scotland, SAMH (Scottish Association for Mental Health) and Sense Scotland.

There are one million disabled people in Scotland¹. Together our interests and expertise cover physical disability, sensory impairment, learning disability, communication support needs and mental health. Working closely with the thousands of disabled children, young people and adults, families and carers involved with the member organisations, DAS aims to: influence public policy and legislation; provide a forum for decision makers and influencers to obtain advice and information; and promote a better understanding of the experiences and needs of disabled people. DAS focuses on the issues that will have the most impact for disabled people.

DAS undertook some focus group research with a range of people supported by the member charities earlier this year for a DAS report, which will be published in the coming weeks. Social security was one of several topics discussed. Many people in the focus groups were upset and angry about changes to benefits over the last few years.

- They felt this made it more difficult to get by on a day to day basis.
- There was a desire for the system of support to be clear and understandable.
- There was a desire for the system to be more easily accessible for people.

Our response reflects input from these focus groups and members' own focus groups or other activities with people they work with and support, as well as welfare advisers, policy advisers and other members of staff to gather views and expertise. We have also had discussions with other disability organisations and the broader third sector. This response is particularly focused on the issues we believe to be of most importance to disabled people in Scotland on the social security powers being devolved, including:

- Advocacy and support
- Accessible communications
- Ensuring the stated principles are fully implemented throughout the system including improved training for staff
- Further exploration of greater automatic entitlement
- More appropriate assessments

¹ <http://www.gov.scot/Topics/People/Equality/disability>



As a pan-disability coalition of leading charities, DAS is well placed to provide insight into where it is possible to provide cross-sector, pan-disability support and where further specialist training or expertise will be needed.

Introduction and summary

For disabled people on benefits, there have been significant cuts, which have been well publicised. Yet, over half of the £1.63bn social security budget being devolved through the Scotland Act is currently spent on Disability Living Allowance (DLA) and Personal Independence Payments (PIP). This is a clear chance to improve key elements of the current system.

Reform of social security in Scotland must address the failure of the benefits system to adequately compensate disabled people for the **extra financial costs** they face to live an independent life. This is one of several reasons there are higher rates of poverty among disabled people. Another is that costs associated with disability average £550 per month². For instance, braille displays can cost thousands, £4,000 for a wheelchair, and/or additional costs for transport, cleaning, other support and equipment. A very recent report found that 39% of people in poverty are in a household with at least one disabled person³.

The changes to the social security system in recent years have undermined disabled people's **right to live independently** and their right to family life in contravention of articles 19 of the UN Convention on the Rights of People with Disabilities (UNCRPD) and Article 8 of the United Nations Convention on Human Rights (UNCHR). **This affects disabled people, carers and others around them and the wider society and economy.**

Disabled people being in work, where possible, can have economic and social benefits for individuals, the people around them and beyond⁴. And many disabled people wish to, and are able to, work. Yet, due to a range of barriers, only 43.8% of individuals with disabilities in Scotland are employed⁵, compared to 72.3%⁶ for the wider population. Social security is therefore vital to many disabled people.

² <http://www.scope.org.uk/campaigns/extra-costs/what-are-costs>

³ <https://www.jrf.org.uk/report/uk-poverty-causes-costs-and-solutions>

⁴ [https://www.researchgate.net/publication/221668849 Economic and social costs and benefits to employers of retaining recruiting and employing disabled people and/or people with health conditions or an injury A review of the evidence](https://www.researchgate.net/publication/221668849_Economic_and_social_costs_and_benefits_to_employers_of_retaining_recruiting_and_employing_disabled_people_and_or_people_with_health_conditions_or_an_injury_A_review_of_the_evidence)

⁵ <http://www.gov.scot/Resource/0048/00484492.pdf>

⁶ <http://www.gov.scot/Topics/Statistics/Browse/Labour-Market/LMTrends>



Improvements need to be made but in a well managed way, taking the time to get things right. The system is already complex and there will be two systems, with different expectations and cultures. **Any changes to social security should ensure there is no detriment to existing benefits.**

We recognise the challenges with the two systems, but DAS calls for a review of the system after 3 years of operation, including where possible, a longer term review of social security in Scotland. The benefits themselves are not being devolved, the powers to support them are. We need to not just replace like for like, but truly try to provide something better.

DAS believes the principles should be placed in legislation, and there should be a 'Social Security Charter' rather than a Claimant's charter – with rights and responsibilities on both sides.

Greater automatic entitlement built into the social security system would assist people to access the support they are entitled to, and would save some resource and also the impact on people, compared to the current system.

Assessments should be more personalised to a person's condition and avoiding irrelevant questions and repeat assessments for long term conditions. This would also reduce the number of assessments and the negative impact this process can have on people and those around them due to stress etc.

There is also an opportunity for social security to be **better coordinated** with other systems of support and referral, such as the Welfare Fund; and signposting people to other forms of advice and support. This, of course, does not mean using benefits to pay for social care and similar costs.

Other opportunities for a better approach would be **clear and respectful communications** about the changes being made and the **culture** throughout the social security system being introduced. **Accessible communications** has to be a core part of this.

DAS supports the proposed changes to **Carer's Allowance and a new Scottish Carer's benefit.**

We also call for greater funding for independent advice and advocacy. The recent Alliance report highlighted the evidence base for the benefits for people from advocacy.

However, it is important that we manage expectations about what can be undertaken by the Scottish Government with the devolved powers and how far things can be improved. The system is complex and there will be two systems, with different expectations and cultures.



There will therefore need to be ongoing coordination with Westminster and reserved powers and benefits. There needs to also be ongoing explanation of rights and the functioning of the system to people in Scotland as the system beds in, and indeed beyond to ensure clear understanding and in fitting with the principles outlined in the consultation document.

Part 1: A Principled Approach

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

A 'Claimant Charter' could be a useful way of ensuring that the Scottish Government's stated principles are understood by members of the public as well as by staff administering social security benefits in Scotland. There is a perception that a number of other 'charters' in recent years have not lasted or brought effective change to people.

DAS does not agree that the Charter should be called a Claimant Charter, and instead calls for a 'Social Security Charter' (or another name) that is for recipients and also staff as there are rights and responsibilities on both sides, and there needs to be recourse where the service and principles, for instance, are not met.

We believe it would be best for there to be one charter – rather than two separate charters – to encapsulate claimants and assessors to reflect different rights and responsibilities together in one document, given that they are mutually interdependent and also to reduce the number of documents in an already complicated system.

In terms of developing the Charter, there should be meaningful co-production on this and all aspects of the system for it to work effectively and an advisory group could be involved. It will be key to involve service users and organisations representing them. One comment highlights this: "If we do have a Charter then we really must have disabled people on there. That is of the greatest importance."⁷

As well as being expressed in a Charter, the principles should also be embedded in legislation. The legislation should allow for a review - "a proper review by the stakeholders every few years"⁸. We believe that it is important that the new social security system be reviewed (within three years of its establishment and regularly thereafter) and that disabled people and the organisations that represent them should be involved in the review procedure.

It has been difficult for all concerned to look at this with a 'blank slate' as only some powers are being devolved and we will be working with two systems but even so, it would be useful –

⁷ RNIB focus group, 2016

⁸ RNIB focus group, 2016



as is suggested in the consultation document – to look at this in a more longer term way in the future.

On whom would you place a duty to abide by the principle that claimants should be treated with dignity and respect?

At the operational level, the Chief Executive of the Social Security Agency would have an obvious duty. However, the responsible Minister also has a duty to uphold the principle that claimants should be treated with dignity and respect.

Do you have any further comments on placing principles in legislation?

We believe that placing the principles in legislation is essential. The advantage of legislation is that it gives clear reference points. Where legislation can embody the values of dignity and respect it should do so, rather than placing a general duty that is open to interpretation. The Mental Health Care and Treatment (Scotland) Act 2003, for instance, has the ‘10 Millan Principles’⁹ which were thought to have been effective, in part because they are spelt out in the legislation; and legislation also gives ‘teeth’ which is needed.

The principles will need to be brought to life and promoted throughout the service and beyond. And there will probably need to be several things to properly implement culture change. For instance, it will be important to promote rights through advocacy and family support etc. and there could be a public awareness campaign, given the success with raising the profile and understanding and commitment for the living wage.

People with learning disabilities and indeed others may need people to help them understand a Charter.

These principles should be about ensuring all people have the same rights and not just that those people who are able to get advice or advocacy can understand the system and get what they are entitled to, as is currently what often happens at the moment. We are aware that the Government wishes to move away from a culture of stigma for people on benefits. More could be done to achieve a greater culture of rights-based entitlement and reduce stigma. Much of this may be achieved through the new system but it will need reviewing and potentially more action in the future.

Outcomes and the user experience

The outcomes identified in the consultation are a very good starting point to develop and measure social security in Scotland.

⁹ <http://www.legislation.gov.uk/asp/2003/13/section/1>



Are there any other outcomes that you think we should also include (and if so, why?)

We believe that the principle that the changes will have 'no detriment' to existing benefits and people entitled to them, should also be enshrined in the legislation. While there have been reassurances from Westminster and the Scottish Government, DAS would like to see this in legislation and a clear outcome to prevent unintended consequences in a very complicated system. We appreciate this would need further discussions between Westminster and the Scottish Government.

We would also suggest other outcomes could be consistency and getting the right decision as much as possible in the first instance; and access to information and advice in a preferred format; are also important outcomes.

The level of poverty among particular groups, such as disabled people, is very high – 39% of people living in poverty have at least one disabled person in their household¹⁰. Given that poverty is measurable, and that a key outcome for social security should be to ensure people do not have to live in poverty, DAS recommends this is an additional outcome.

DAS also believes it would be helpful for all outcomes to be reported on in a transparent manner.

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

To provide information that can be accessed by as many people as possible, and ensure dignity and respect, it will be crucial that a range of communication options should be available in accessible formats. The Scottish Government should not choose the 'digital by default' option for the new Scottish social security system. There are some cost implications involved as accessible communications e.g. note takers or British Sign Language (BSL) interpreters do require additional resource, and are essential for some people.

“It can be difficult to book interpreters and things need to be put off to different dates because there are so few interpreters in Scotland.”
(Action on Hearing Loss Focus group)

There is currently a lack of communication about rights and entitlements and a sense that people have to be aware of their rights and know to ask the 'right questions'. It would be positive and support equality if we moved away from this to more of a culture of assisting people to claim what they are entitled to.

¹⁰ <https://www.jrf.org.uk/report/uk-poverty-causes-costs-and-solutions>



Access to independent advice and advocacy is also vital. The level of successful appeals¹¹, particularly when advocacy is provided, highlights this. Additional information is also drawn from the detailed interviews and evaluation undertaken during the Welfare Advocacy Support Project¹². Again, this does require some additional resourcing but is invaluable to the people who need it and these are often the most vulnerable. And there are costs – economic and social – from not providing this support, including greater costs to the state from supporting disabled people who, if they do not have sufficient funds to live an independent life, such as higher healthcare costs, will result in a lower likelihood that they will (re-)enter the jobs market or volunteer work, for example.

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?

The Scottish Government should consult with disabled people and the organisations that represent them to ensure that the use of language for social security in Scotland is accessible and appropriate.

In focus groups DAS undertook with people supported by all six members, this was a crucial theme that came up:

There was a desire for the system of support to be clear and understandable.

“People need a clearer and simplistic benefit system so they know what they can get and what they can’t get.” (RNIB Focus Group)

“Things need to be clearer. The package that I was given needed to be fought for.” (RNIB Focus Group)

“You’re looking at all the negativity in your life on a piece of paper – then they’re asking you how this affects your life? It’s stripping you of your dignity.” (SAMH Focus Group)

There were concerns about the cuts to benefits in recent years

“Lots of us have concerns that our benefits have been cut.” (Sense Scotland Our Voice Group)

“You are relying on your benefits as that is the only income you have coming in. What are you going to do? You’re snookered.” (ENABLE Focus group)

¹¹ <http://news.scotland.gov.uk/News/PIP-failing-disabled-people-2b29.aspx>

¹² <http://www.alliance-scotland.org.uk/what-we-do/our-work/policy/welfare-advocacy-support-project/>



There was a desire for the system to be more easily accessible for people.

“You spend a lot of your time proving to social services that you can’t do this stuff without someone coming to help you. You need a realistic process and an honest and transparent process.” (RNIB Focus Group)

“You can walk, you can talk, you can do lots of different things and because you can communicate really well then it gives you less ability to access things because people think you are more capable.” (RNIB Focus Group)

“Absolutely no account of mental health problems... Asking you if you can lift a cardboard box and how many stairs you can walk up.” (SAMH focus group)

Are there any particular words or phrases that should not be used when delivering social security in Scotland?

Language is important and DAS believe we should avoid using the words ‘customers’ and ‘claimants’. Some people liked talking of ‘citizens’, ‘rights’ and ‘entitlements’.

RNIB Scotland focus groups also suggested that "conditions should not be diseases"; "recipients should not be sufferers" and that "welfare" should be replaced by "social security". Language like "If you don't attend this meeting and or fill in this form, your benefit will be stopped" should not be used. We also need sensitive wording for special rules applying to people with terminal illnesses applying for benefits. Indeed, how people regard themselves or a loved one is usually not in terms of their impairment(s) so sensitive and considerate wording generally would be best. Similarly, many people with a mental health problem, who would meet the criteria for disability benefits, do not identify themselves as disabled. A holistic approach, designed in partnership with people with lived experience and mental health support services is required to increase benefit uptake from this group.

What else could be done to enhance the user experience?

A range of communication options should be available in accessible formats.

Consideration should be given to what could be done to simplify the procedures including the length of application forms (for example, the current PIP forms are 50 pages long). SAMH service users reported that the forms were confusing and focused upon physical impairments, lacking relevance to their mental health. The majority of questions cover factors such as ability to dress, mobility, preparation of food and toileting with only a limited number asking directly about cognitive functions. The form also does not make it clear where a



person's mental illness may impact on activities such as dressing or eating due to a lack of self-care.

DAS welcomes plans to pilot the new system.

We want to see an emphasis placed on conducting assessments, where they are necessary, locally. This was particularly highlighted as an issue in SAMH focus groups, where people reported having to travel significant distances to assessment centres, often at substantial cost.

One person using a SAMH service had to travel from the Isle of Cumbrae to a PIP Assessment Centre in Kilmarnock, requiring a ferry and 2 buses, costing over £15 in total. Some assessment centres are not signposted, which creates further distress.

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

The best means of communication should be checked with people applying for / receiving benefits and different options available where needed.

Within the current benefits system there is not much consistency. Universal Credit has to be applied for online and communications about the claim are online too; PIP is applied for by phone; the DLA form is 50 pages long and Attendance Allowance (AA) applications are either made online or by downloading the claim form or requesting a claim form is sent out.

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 Government must consult with disabled people and the organisations that work with, and represent, them in meaningful co-production.

We are considering whether or not to adopt the name "User Panels". Can you think of another name that would better suit the groups of existing social security claimants which we will set up?

RNIB Scotland focus groups found that the name "User Panels" was very unpopular. "User" was thought to have negative connotations - "druggy", "sponging". Another comment was "User panel is a consultative forum and implies homogeneity of all users. We need to be recognised as individual recipients of social security." The term "claimant" was preferred and "group" rather than panel, ergo, "Claimant Group". However, others have said they dislike the words 'claimant'.



Delivering social security in Scotland

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

DAS and our members believe it is important to ensure a national service to ensure consistency and prevent disparities in provision across the country. Given the size of the population in Scotland, a national approach for delivery also seemed sensible in terms of efficiencies.

Delivering social security through a single national agency has a series of advantages:

- Promoting consistency and uniformity (in both front facing assessment processes but also back office functions such as training, HR, IT etc.)
- Minimum standards can be established
- Reducing the opportunity for communication issues between agencies
- Allowing for specialist expertise to develop, particularly in relation to communications and support for particular groups' needs.

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

Yes, cash only. Members, particularly ENABLE, have explored this with the people they work with and support. While there was some interest and discussion of possible opportunities, we are in favour of providing benefits in cash as offering a choice of goods and cash could create further complexities and inequalities. For instance, the worth or cost of a service or good could vary over time. Other than in carefully defined and restricted circumstances, social security benefits should be monetary rather than in kind. This provides independence to the recipient, and the benefit will also be felt by the local communities, as the funding will be spent in local businesses and community assets. We believe there is a risk that any other approach could be contrary to the Scottish Government's stated principles of promoting dignity and respect.

How best can we harness digital services for social security delivery in Scotland?

Technology can provide excellent opportunities for people with particular disabilities to get on to a level playing field. However, the cost of such technology can be very high so the new social security service should look at the cost of technology for particular groups. Moreover, we have to be aware of the digital divide that exists in Scotland. Many disabled and/or lower income people do not have access to digital services. As stated already, there should be a range of communication options.



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

Yes – the option for face to face contact can be the best and preferred option for some people, including the most vulnerable. Communication should be tailored to individual needs and access. Within that there should be the option for face to face to contact, in a person's home if necessary. As we will elaborate in greater detail, introducing more automatic entitlement in the social security system should reduce the need and costs for some elements of the assessment process.

Who should deliver social security medical assessments for disability related benefits?

There was a strong consensus across the DAS members that current assessments are not being undertaken by people with sufficient training to understand a range of conditions, from learning to physical to mental health to other disabilities including fluctuating conditions, and they should also be more able to better judge how impairments might impact on an individual's life.

SAMH focus group members were clear that the medical assessment did not allow them to fully demonstrate the debilitating impact of their mental ill-health, particularly where it fluctuates, both due to the assessment focusing on physical functionality and an apparent lack of assessor knowledge or understanding of mental health. A number of people also reported facing negative and stigmatising attitudes from assessors.

Some members supported a return to something like the former system of medical assessment by an Examining Medical Practitioner (EMP) in the claimant's home although others had concerns about this, as there had been problems with this too.

Should any aspect of social security be delivered by others such as the 3rd sector, not for profit organisations, social enterprises or the private sector?

The third sector could play a valuable role in providing specialist advice and advocacy support, as well as employment and other services, but it is crucial that the third sector maintains an independent role. The Alliance Welfare Advocacy pilot, funded by the Scottish Government, was an example of where the third sector can provide meaningful added value to the social security system. The evaluation of the pilot¹³ found that the provision of advocacy decreased the stress felt by claimants during assessment, empowered claimants to remain engaged with the process and more fully communicate to assessors the issues they face. The evaluation also found that the presence of advocacy positively impacted the behaviour of assessors.

¹³ ALLIANCE [Evaluation of Welfare Advocacy Support Project Evaluation Report](#) 2016



Organisations and groups, such as the 'Open Doors' consortium, which supports young disabled people into employment, also have a crucial role to play.

Independent advice and scrutiny

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

Yes. DAS is in favour of the establishment of a statutory Scottish Social Security Advisory Committee (SSSAC), following a similar model to the current UK SSAC¹⁴. However, we appreciate that the exact role of such a committee would have to be adapted to reflect the Scottish context. Consideration would have to be given to cross-border issues and interactions with UK social security.

The body would have to be established in law. The existing Social Security Advisory Committee (SSAC) is an independent statutory body that provides impartial advice on social security and related matters. It scrutinises most of the complex secondary legislation that underpins the social security system. The operation of the existing SSAC could provide a model. It has a Chair and Vice Chair and up to 13 other members who have experience in social security law, academia, policy, business, employment and the voluntary sector. It would be best to include service users.

Should there be a statutory body to oversee Scottish social security decision making standards?

Yes. Given the very great problems that currently affect decision-making standards around, for example, PIP and Employment and Support Allowance (both of which have very high success rates on appeal) further consideration should be given as to how such a body should be constituted and operated to ensure the quality of decision making in Scotland.

¹⁴ <https://www.gov.uk/government/organisations/social-security-advisory-committee>



Part 2: The Devolved Benefits

Disability Benefits

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

Disability Living Allowance

DLA is a benefit that is paid to cover the additional costs that arise due to disability or illness. Rather than cover these costs directly through goods/services or by an expense reimbursement system; DLA calibrates disability based on the level and type of help required and then attaches a financial figure to the result. DAS supports this type of approach as a cash benefit gives flexibility to claimants across the spectrum of disabilities to choose the support, services or goods they feel will help them most. Due to the broad range of disabilities/illnesses and care and support needs experienced by people with disabilities, it would be very difficult to provide support other than a direct monetary benefit which would bring this flexibility.

We accept that calibrating and attaching a financial figure to disability/illness is an inherently difficult task, and that we are unlikely to ever achieve a perfect system; the accuracy of evidence gathering and decision making has been clearly lacking. This is supported by the continually high success rates at appeal.

DAS suggests that many of the perceived problems with DLA could have (prior to the introduction of PIP) and can be (going forward for children under the current system) be resolved by improving the standard of decision making.

The current system of regular re-assessment is also very stressful and unnecessary when someone has a condition that is very unlikely to change, such as a learning disability, is registered blind or have some types of physical disabilities, for instance.

DAS would also suggest that the Scottish Government consider changes to the criteria for an award of the higher rate of the mobility component of DLA, particularly for children with learning difficulties.



Personal Independence Payment

Through focus groups and a survey of 60 service users and staff, SAMH has identified and analysed particular issues with PIP¹⁵, which are supported by the findings of other DAS members:

- The application form (PIP2) and face to face medical assessment did not adequately assess the impact of mental health, with a focus on physical functionality
- Claimants felt disbelieved and at times stigmatised by assessors
- There was an overwhelming breakdown of trust in the application and assessment process
- Claimants' rights were not communicated adequately
- The experience of assessment had a negative and often long term impact on claimants' mental health
- The quality of evidence gathering and medical evidence

Many members and service users have not yet migrated from DLA to PIP. For those who had, some people had found PIP to be favourable, for instance if they are registered blind, but less so, if they are visually impaired, for example.

Under DLA, those with lower levels of care requirements could still be entitled to the lower rate of the care component of DLA. Under PIP, this is no longer possible with the standard and enhanced rates being equivalent to middle/high rate DLA. In practice, this can make it much more difficult for those with less profound care and support needs to access the benefit leaving them without proper support. We call on the Scottish Government to consider two options to resolve this:

- Option 1: introduce a lower rate of the daily living component where a claim can be accepted with a lower points score than the current threshold or by satisfying certain activities (i.e. entitlement via the cooking activity under PIP would be comparable to the cooking test in DLA).
- Option 2: Introduce a regulation similar to that which exists in Employment and Support Allowance (Regulation 29(2)(b) the exceptional circumstances regulations) where those who do not meet the points threshold could still be entitled to an award if they met "exceptional circumstances". We would suggest that exceptional circumstances would be given a definition similar to "would otherwise be unable to live independently without support".

Majority of the time rule: Under PIP, a claimant must require support with an activity for the majority of the time. This is a departure from DLA where a more rounded picture of the claimant's life could be used to decide on entitlement. The impact of a learning disability can

¹⁵ Personal Independence Payment: what's the problem, SAMH, October 2016
<https://www.samh.org.uk/our-work/public-affairs.aspx>



often be complex, meaning that the majority of the time rule places some, such as significant numbers of people with learning disabilities at risk of no award as they only require support in specific areas of their life.

DAS does not feel that the PIP qualification criteria provide an accurate calibration process for young people reaching 16. The PIP test looks at areas such as cooking, budgeting and social interaction. These are areas where many young people still require assistance and/or they may not do so at all (e.g. budgeting if living with parents). This means that the test being applied is often hypothetical and therefore unlikely to produce accurate results. DAS suggests the age for transitioning from DLA to PIP be moved from 16 to 21 in order to accommodate this, should PIP be continued in the longer term. This would have the benefit of postponing an area of concern for young people with a disability and their families while they are likely to also be transitioning in areas such as social work involvement, education and/or health services.

Attendance Allowance

It is important to have a benefit in place for the over-65s. AA is simpler to apply for than other benefits and decisions are made more quickly (within four weeks). However, AA is supposed to help with the extra costs of disability but there is no recognition of mobility issues. It is for care needs only.

Under current AA rules, claimants must have experienced their care needs for six months (the “backwards test”) and be expected to have them for a further six months, before an award of benefit can be made. The reasoning behind this is that they want to preclude awards for those experiencing relatively short term needs. Whilst we understand this thinking, we would suggest that a better way to manage this would be to increase the “forwards test” to twelve months rather than preclude those with conditions that may come on suddenly but with great impact, such as a stroke. This issue also affects some people under DLA and PIP but we have raised it here as it affects a broader group.

A comment from the RNIB Scotland focus groups reflect other views on issues around the lack of a mobility component: "If you claim Attendance Allowance there's no mobility component attached to that at all, so there's no acknowledgment that your sight loss might be causing you difficulty getting outside. So if you're over 65 you've got a higher test to satisfy. To get a higher rate you need to satisfy night time need."

How should the new Scottish social security system operate?

- Application – The process of applying for a disability benefit should be as straight-forward and accessible as possible. It should be possible to claim a disability benefit by telephone, online or using a paper claim form depending on individual preferences and capabilities.



- Eligibility – We would like the forthcoming Scottish social legislation to include a schedule of conditions that automatically qualify for benefit.
- Assessment – In determining the impact of the disability, the decision maker should go beyond considering the person's ability to complete simple day to day tasks. Instead the decision maker should consider the individual's ability to fulfil their basic rights and live independently, including their ability to work, to form relationships, to participate in society and to raise children. The former system of medical assessment by an Examining Medical Practitioner in the claimant's home should be restored.
- Provision of awards – The default position should be that all disability benefit payments are monetary. Awards should also be made for an appropriate length of time in order to avoid excessive re-assessment. Indefinite or extended awards should be made in all cases where the person's condition is highly unlikely to improve, is degenerative or terminal.
- Appeals – The position should be maintained where there is at least one tribunal wing member with a knowledge of disability. In-person hearings should be available on request

With this in mind, do you think that timescales should be set for assessments and decision making?

Yes, but with some flexibility.

The experience of introducing PIP highlights the need to set timescales for assessments and decision-making. In a report published on 27 February 2014, the National Audit Office (NAO)¹⁶ said that "poor early operational performance" had led to "long uncertain delays" for PIP claimants. On 18 March 2014, a Work and Pensions Committee report¹⁷ said that the length of time disabled people were having to wait for a decision on PIP claims was unacceptable. Noting that some claims were taking six months or more to process, the Committee recommended that DWP invoked penalty clauses in the assessment providers' contracts if necessary, and cleared the backlog of PIP claims before extending reassessment. It also recommended that resources be concentrated on meeting a seven day target for processing claims from terminally ill people.

We are also aware that currently requesting information/application details in alternative formats can add six weeks to an application procedure. This should not be the case. The current timescale for PIP applications is around 16 weeks. Decisions on AA are much quicker – within three to four weeks. We recommend an eight week timescale

However, some flexibility allows for deadlines to be extended should people need extra time for evidence to be gathered, particular communication needs to be met and/or other difficulties that could arise during the time periods.

¹⁶ <https://www.nao.org.uk/report/personal-independence-payments-pip-2/>

¹⁷ <http://www.publications.parliament.uk/pa/cm201314/cmselect/cmworpen/1153/115302.htm>



What evidence and information, if any, should be required to support an application for a Scottish benefit?

Once an application is received, the decision maker should have responsibility for seeking additional evidence. The evidence required will obviously depend on the eligibility criteria used. If entitlement were based on the impact a disability has on the claimant's ability to live independently, for example, the cornerstone of any evidence should be the claimant's own testimony and the views of those who know and support them. Where it is felt that further detailed medical information is required, consideration should always be given to whether appropriate evidence already exists before further information is requested from either professionals or claimants themselves.

The claimant should be given adequate guidance and opportunity to choose who they think would be the most appropriate person or people to provide evidence. This could be a specialist doctor, GP, community nurse, support worker or even friend or family member, depending on the nature of the evidence required. Where, however, entitlement is automatic based on an applicant's condition, the relevant person/ professional should only have to confirm the diagnosis.

The evidence required to support a claim must be proportionate and necessary for the purposes of the claim. Decision makers need to have adequate training and support to allow them to be flexible in gathering the information and evidence that they feel is required to support the processing of a claim. The present DLA/PIP/AA systems have very little flexibility and we feel that this contributes to the issues they have in the standard of decision making and the claimant experience.

In terms of the administration of claims, we should only request the information that is necessary. For example, if identities can be verified using existing systems that the new agency may have access to information from (DWP/local authorities) then there should be no need to ask for this again in writing.

Should the individual be asked to give their consent (Note: consent must be freely given, specific and informed) to allow access to their personal information, including medical records, in the interests of simplifying and speeding up the application process and/or reducing the need for appeals due to lack of evidence?

Yes. DAS is calling for advocacy and communication support to be available at application stage to ensure understanding and proper consent.

If the individual has given their permission, should a Scottish social security agency be able to request information on their behalf?



Yes.

Do you agree that the impact of a person's impairment or disability is the best way to determine entitlement to the benefits?

Yes. We do not want to lose any of the progress made in terms of people recognising the values of the 'social model' of disability, but the impact of an impairment is a helpful proxy for the extra costs of disability.

What do you think are the advantages and disadvantages of automatic entitlement?

DAS supports the Scottish Government in further exploring how a greater level of automatic entitlement could work, as it would reduce the resource currently used in assessing people unnecessarily and reduce the impact on people who have to go through assessments and find the process stressful.

A starting point might be to consider reinstating the automatic entitlements lost in the transfer from DLA to PIP, such as for claimants undergoing dialysis. Factors to be taken into account in identifying additional automatic entitlements might include the predictability of a condition's impact, the likelihood of an improvement in the condition over time and the severity of the condition. We do not want to undermine a culture of recovery, particularly in mental health where people may return to full health or experience years without any problems. However, automatic entitlement should be used where appropriate.

Where an individual has been diagnosed with a condition, it does seem unnecessary to require them to undergo further assessment. Not all people will be covered by automatic entitlement, and some assessment would probably be needed to understand the level of impairment and/or the impact on that person's life, but this would likely still reduce assessment.

We have been considering this further as a coalition and certainly support greater automatic entitlement in principle but work would need to be done by the Government to work this through and develop the criteria and ways to ensure assessment for people whose impairments are not included in the list. DAS would be happy to be part of these discussions

Along with automatic entitlement, there should be greater use of 'passported benefits' so that if someone is eligible for a benefit e.g. PIP or DLA, they don't need to show evidence again for other relevant benefits, such as a bus pass etc. In practice, this means they could just tick a box for which eligible benefit they receive and can show evidence that they receive it.



There should also be a return to longer term and lifetime awards as for some conditions, whether physical disabilities like cerebral palsy, learning disabilities like Down Syndrome, or schizophrenia in terms of mental illness for instance, and other types of conditions, they are unlikely to change unless there is a significant technological or medical breakthrough. And longer awards would reduce assessments and the pressures this puts on people.

Would applicants be content for their medical or other publicly-held records, for example prescribing and medicines information or information held by HMRC, to be accessed to support automatic entitlement where a legal basis existed to do this?

We considered this very thoroughly and consulted with service users and found that people were very much willing for information to be shared about their condition if it assisted the application process and meant more joined up decision making. Clearly, safeguards and scrutiny would need to be in place, especially as some information can be particularly sensitive.

Should there be additional flexibility, for example, an up-front lump sum?

It would be useful to have some flexibility. There were concerns among some members about some people managing a lump sum, but it could be useful for other recipients and allow benefits for adaptations and in particular fluctuating conditions.

In the longer term, do you think that the Scottish Government should explore the potential for a consistent approach to eligibility across all ages, with interventions to meet specific needs at certain life stages or situations?

Yes. DAS considers that the devolution of disability benefits provides an opportunity to review the existing benefits and a more strategic review in the future would be useful. There is a strong argument for examining whether one disability benefit might be more appropriate than the current set of three different types of benefit. DAS would like to see a more consistent approach across disability benefits.

We recognise that this might not be possible in the short term, but even if they are not replaced with a universal benefit at this point, consideration should be given to the transition stages.

What would the advantages and disadvantages of a single, whole-of-life benefit be?

A single, whole-of-life benefit with age-related payments is worth further consideration. There may be disadvantages to having a single, whole-of-life benefit in the case of fluctuating conditions. However, more consistent criteria across the benefits and the life of a person



would seem fairer as it can be confusing for people who move from one benefit to another, and this impacts the level of benefits they receive, simply because they are a year older.

In addition, the advantages of a single, whole of life benefit would include:

- Greater consistency across the benefits in terms of criteria and who is eligible for what award
- There would not be the challenge of people having to transition at 16 and 65, for instance
- Reduce unneeded administration
- Along with greater automatic entitlements and lifetime awards, this would reduce some assessments and also stress for people and their families

For some conditions, in the context of lifetime awards, it would need a significant technical and/or medical breakthrough for there to be a change.

Could the current assessment processes for disability benefits be improved?

Yes. The assessment process could be improved if people were made aware of their options at the outset, including being able to take someone with them; that their companion can take an active part in the assessment; and assessments can be undertaken in their home.

The existing assessment process could be improved by introducing automatic entitlement to disability benefits where it can be established that a person has a long term condition that is unlikely to improve. Where assessment may be necessary, DAS recommends returning to something like the DLA system of home assessments by Examining Medical Practitioners (a pool of retired General Practitioners).

In addition, assessments should be more personalised to a person's condition, carried out by medical professionals with expertise in the person's condition and avoiding irrelevant questions. In particular, the assessment criteria need to be less focused on functionality and more towards looking at the whole person.

If the individual's condition or circumstances are unlikely to change, should they have to be re-assessed?

No. Where an individual has a condition or circumstances that are unlikely to change, they should not have to be re-assessed.

If their condition was to change – whether an improvement or deterioration – the onus should be on the individual to notify the Scottish Social Security Agency of their change in circumstances.



What evidence do you think would be required to determine that a person should / or should not be reassessed? Who should provide that evidence?

The evidence should be provided by the applicant in the first instance, verified by health professionals and/or others if needed.

Do you think people should be offered the choice of some of their benefit being given to provide alternative support, such as reduced energy tariffs or adaptations to their homes?

No. We do not think that benefits should be reduced and replaced by alternative support. This could be the thin end of the wedge, whereby benefit is siphoned off to help fill funding gaps elsewhere. It could also lead to confusion / error about the liquidity of the person's assets when dealing with local authorities for care services etc.

Would a one-off, lump sum payment be more appropriate than regular payments in some situations?

No. On balance, we do not think this would be more appropriate.

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

Yes. The Motability scheme is sometimes the only way disabled people can travel around and it promotes social inclusion.

What kind of additional support should be available for people who need more help with their application and during assessment?

A number of people have highlighted difficulties in being able to access the application process and being aware of communications about their benefits. Face-to-face advice was valued as was being able to take someone to the assessment with them. The support of reputable advice services is essential. It should be possible to be assessed at home and not have to travel long distances and where people do travel to an appointment, it should not be perceived that this counts against them, something that has been raised anecdotally a number of times to us. There is a greater need, as mentioned previously, for funding for advice and advocacy and the outputs from the Alliance project highlight the evidence for this.

How could disability benefits work more effectively with other services at national and local level assuming that legislation allows for this e.g. with health and social care, professionals supporting families with a disabled child.



DAS firmly believes that there could be greater signposting between services. So, health and social care refer people to social security services, or if someone isn't eligible for a particular benefit, they could be referred to the Independent Living Fund, for instance, or to other advice and support if needed.

Carer's Allowance

Do you agree with the Scottish Government's overall approach to developing a Scottish Carer's Benefit?

Yes. DAS welcomes the proposal to bring Carer's Benefit into line with Jobseeker's Allowance and to develop a Scottish Carer's Benefit. However, in line with the "no detriment" principle, entitlement to Carer's Benefit should be disregarded in relation to other benefits.

DAS strongly believes that there should be no detriment to existing benefits and that the increase in carer's allowance should be disregarded in terms of assessing for other benefits and support, including Universal Credit, housing benefit and social care charging etc. There have been assurances on this from Westminster and the Scottish Government but we believe it needs to be clearly placed in legislation to prevent unintended consequences.

Winter Fuel and Cold Weather Payments

Do you have any comments about the Scottish Government's proposals for Winter Fuel and Cold Weather Payments?

DAS welcomes the Scottish Government's review of winter fuel and cold weather payments.

Funeral Payments

DAS has not responded to the detailed questions on funeral payments but welcome the attention that we know the question is receiving from other third sector organisations. The current UK average payment of £1,375 per funeral is demonstrably not enough to cover costs.

Job Grant

What should the Scottish Government consider in developing the Job Grant?

DAS would like to see the Job Grant interacting with Access to Work programmes. This should not be a detrimental link.

We understand the Scottish Government is exploring the links between health, disability and employment, to improve the pathway from illness to work, and there could be benefit in including access to the Job Grant within this pathway.



There should also be better links with colleges and universities, working with disabled students to support them into work.

Universal Credit flexibilities

Should the choice of managed payments of rent be extended to private sector landlords in the future?

Yes. Offering choice is key. DAS supports extending the choice of managed payments of rent to private sector landlords. We also think that direct payments should be set up on an ongoing basis rather than for initial short-term payments for both the public and private sectors.

Should payments of Universal Credit be split?

Split payments should not be the default position but provision should be made under certain circumstances, as in the case of a couple claim, where one of the couple has a record either of addiction and/or mismanaging budgets. Sensitive consideration needs to be maintained for any split payments, given the risk of abuse by one member of a couple, for instance.

Part 3: Operational policy

Advice, representation and advocacy

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

Yes. This is vital. These should play an active role as recognised specialists and we find that people find the process less stressful and much clearer where they have support. Advocacy services should be given sufficient resourcing to provide these services as they are vital to the successful outcomes of the new social security powers. Consideration should be given to introducing an automatic right to independent advocacy for people engaging with the social security system. Scottish mental health law provides a model for this as currently anyone in Scotland with a mental health condition has the right to independent advocacy.

When the new Scottish devolved benefits are in place, advisers will be dealing with the interactions of the UK and Scottish systems. In dealing with these complexities, the need for advice is likely to increase. Advocacy could also help reassure people claiming the benefits that they are able to get the support they are entitled to, setting a different approach to the DWP system.



Advocates have an important role in making people aware of their rights. For example, just 16% of people who completed SAMH's survey knew that they had a right to ask for a home assessment, with just 40% aware they could be accompanied to a medical assessment.

People taking part in SAMH focus groups highlighted the positive impact of independent advocacy, but pointed out that it is often unavailable due to high demand. Additional investment in advocacy and advice is needed. Article 12 UNCRPD on supported decision making may also be relevant here.

Complaints, reviews and appeals

Do you agree that we should base our CHP on the Scottish Public Services Ombudsman's "Statement of Complaints Handling Principles"?

Yes.

How should a Scottish internal review process work?

A review process that is prompt, courteous and efficient.

Currently, claimants have 28 days within which to challenge any decision that they are not happy with. It would be reasonable to expect reviews to be carried out within the same timescale, that is, 28 days.

The tribunal process can be traumatic for individuals. However, the process gives access to a resolution process that is independent of the social security provider. The independence of the tribunal process is necessary but the formal nature of the proceedings can deter people from continuing an appeal. This is an issue that the Scottish Government should address.

How could the existing appeals process be improved?

Signposting available help and advice would improve the appeals process. Provision of information should be clear and comprehensive at the outset of a process. The inclusion of evidence from carers as well as the individual at a tribunal, such as already happens in the Mental Health Tribunal of Scotland, could also be considered.

We do not want to see the importation of the "mandatory reconsideration" process. This is a barrier to getting the right benefit and is often too stressful for people to contemplate.

"The lawyer said, "You missed out on 10 points, I think you should appeal, I would do it". I said I can't go through this again." (SAMH Focus Group participant)



Residency and cross-border issues

Should Scottish benefits only be payable to individuals who are resident in Scotland?

Benefit eligibility should be dependent on having main residence in Scotland.

What factors should Scottish Government consider in seeking to coordinate its social security system with other social security systems in the UK?

Inter-governmental exchange as through the Joint Ministerial Working Group on Social Security is essential. Day-to-day contact and understanding of the two systems in Scotland; and to some extent, an understanding or at least signposting and support to social security / related systems in England, Wales and Northern Ireland will be crucial.

Managing overpayments and debt

DAS has found that most over-payments have occurred in relation to tax credits which will be absorbed into Universal Credit, which is a reserved benefit.

Fraud

DAS has responded to the detailed questions but hopes that robust anti-fraud measures will be put in place, while also maintaining the principles outlined in the first part of the consultation. DAS notes that fraud rates for DLA were amongst the lowest of all fraud rates for benefits. Knowing that people with disabilities have experienced stigma about their rights to claim benefits, especially for people with less visible conditions, it is important that the messages from the Scottish Government do not feed into this perception, but instead inform people of their entitlement to support.

Safeguarding information

Current security questions that advice providers must answer - even in implicit consent cases – are stringent. Annoyingly, however, the level of stringency and reaction varies from official to official. DAS would support having a Scottish Government public consultation on the Privacy Impact Assessment. Security of the data management system and strict compliance with data protection legislation would mitigate the risks posed by data security breaches. We can see the benefits of sharing information but safeguards also need to be in place.



What are your views on having the option to complete social security application forms online? Can you foresee any disadvantages?

Online application forms will work well for some people. But given the digital divide – that hopefully will improve with time – and also some people’s communication challenges, there should always be other options and a range of accessible communication format. This applies to disabled people but other groups too, such as the digitally excluded, people with literacy issues, older people and others. DAS believes there would be disadvantages with online only applications and communications on benefits. Simply applying for benefits and getting communications can be a real problem and additional expense for disabled people.

Currently, Universal Credit has to be applied for online and communications about the claim are online too. The Scottish Government should make any changes it can to the Universal Credit process and not choose the "digital by default" option for the new Scottish social security system.

In reality we have a digital divide. A Royal Society of Edinburgh (RSE) Inquiry¹⁸ into digital inclusion concluded that "If the gap between these extremes of exclusion is not addressed, the digital divide will exacerbate existing social divides."

A range of application/communication options should be available in accessible formats and there should not be undue delays in providing these. Currently, asking for accessible formats can take up to six weeks delaying claims and adding to the claimant’s money worries.

What are your views on the new agency providing a secure email account or other electronic access to check and correct information for the purposes of assessing applications (noting that any such provision would need to be audited and regulated so that the security and accuracy of the information would not be compromised)?

DAS understands that welfare advisers have experienced great difficulties in dealing with secure email accounts for customers. DAS believes the key point here is the line in the consultation document that: "[t]here is no doubt that alternatives to online applications and communications must be made for those who are unable to use or access a computer or mobile device."

¹⁸ https://www.royalsoced.org.uk/1058_SpreadingtheBenefitsofDigitalParticipation.html



Uprating

As the consultation document notes, six devolved benefits – AA, Carer’s Allowance, DLA, PIP, Severe Disablement Allowance (SDA), and Industrial Injuries Disablement Benefit (IIDB) – are currently uprated. Retaining the link to the rate of inflation for devolved benefits would ensure that they kept pace with the cost of living and help to deliver the "no detriment" principle outlined by the Smith Commission.

Any other comments / supporting evidence?

DAS members are calling for a review of social care charging as this is impacting significantly on people’s income and would potentially also ensure greater consistency across Scotland.

RESPONDENT INFORMATION AND CONTACT DETAILS

For more information, or to discuss the contents of this submission, please contact:

Layla Theiner

Disability Agenda Scotland (DAS)

Layla@disabilityagenda.scot

07876 865342

c/o INSPIRE House, 3 Renshaw Place, Eurocentral, N Lanarkshire, ML1 4UF

