

# How social security can deliver for disabled people in Scotland

This new research looks at how disability assistance could reduce poverty in Scotland. In particular, it looks at how the Scottish Government and Social Security Scotland can look to maximise the power of social security to improve living standards and loosen poverty's grip on disabled people. The research was done in partnership with the Glasgow Disability Alliance, Dundee Fighting for Fairness, and Inclusion Scotland bringing the voices of disabled people and those who work to support them to the fore. It finds that while the Scottish Government and Social Security Scotland's approach, which is rightly based on dignity, is a welcome change, there are concerns that this will not be reflected in practice.

**Shelagh Young**

## Key Findings

To ensure our social security system works better for disabled people, the next Scottish Government and Social Security Scotland should:

- Continue to recognise disabled people's distrust of the social security system, and determinedly reiterate their commitment to disabled people receiving the payments they are entitled to through a system with dignity at its core.
- Work to raise broader public awareness of people's entitlement to disability assistance benefits, because the lack of awareness is causing stigma that is discouraging people from applying. One specific goal should be to re-establish the fact that Disability Assistance is for the additional costs of living incurred by disabled people.
- As a key underpinning of that, incorporate the rights of the UN Convention on the Rights of Persons with Disabilities into devolved law.
- Ensure meaningful scrutiny of the new disability assistance benefits by disabled people and Disabled People's Organisations.
- Ensure that sufficient funding is provided to third sector organisations and support agencies including Disabled People's Organisations for advice and advocacy to assist disabled people in accessing the payments they are entitled to.
- Work with the Department of Work and Pensions (DWP) and local authorities to provide a one-stop shop for disabled people to access all support they are entitled to.
- Bring forward the review of disability assistance to review adequacy of payments and ensure they reflect the real cost of living for disabled people.

## Executive Summary

Disabled people are significantly more likely to experience poverty than the general population and children in families with a disabled person are more likely to be in both relative and absolute poverty after housing costs, compared to children in families without a disabled person. This is an unacceptable situation that limits disabled people's ability to enjoy the quality of life that we all deserve.

Nearly a quarter of Scotland's adult population are disabled, and almost half of the people in Scotland that are in poverty live in a household where someone is disabled. (Scottish Government (B), 2021)

This report looks at ways to improve the poverty-reducing impact of devolved Disability Assistance payments for working-age people in Scotland. It draws on the experience, insights and expertise of disabled people and disabled people's organisations (DPOs).

Adult Disability Payment (ADP), which replaces Disability Living Allowance and Personal Independence Payments for working-age adults, is one of three new benefit entitlements for disabled people that are in the process of being devolved to, and delivered by, Social Security Scotland.

ADP is set to be launched without major changes to levels of payments or eligibility criteria. However, significant changes are promised in the way the assessment system will work in line with the Scottish Government's commitments to take a human rights approach to social security, treating all claimants with dignity and respect. However, our research shows that there is concern that current financial arrangements will undermine this promise, and that without formally incorporating economic and social rights in Scottish law there is a serious risk of these values and principles being eroded. Although the recent report by the National Taskforce for Human Leadership (Scottish Government (A), 2021) shows promise that this concern may be put to rest in the near future.

The new Disability Assistance payments remain age-banded, meaning that people who have reached state pension age before they claim Disability Assistance will continue to be denied the mobility component which represents a significant loss of potential income. Neither are there any significant new measures being put in place to help people transition from one life stage to another or into work. The Scottish Government have committed to an independent review of the payment in summer 2023 which is welcome. That will, however, mean a long wait for any possible changes for the thousands of disabled people who struggle to make ends meet now.

Structural issues that trap disabled people in poverty or put them at an unjust additional risk of living in poverty also need to be addressed; these include low-paid

work, discriminatory attitudes and lack of awareness. These things can restrict disabled people's opportunities to secure paid employment and gets in the way of people accessing social security payments and other entitlements or forms of assistance.

Promoting uptake of Disability Assistance and improving the ways in which additional entitlements can be accessed by disabled people is therefore crucial. This includes ensuring there is adequate funding to allow all disabled people easy access to high-quality independent advice and advocacy.

The good work of engaging with disabled people and disabled people's organisations in designing Disability Assistance should be followed through, ensuring they have an ongoing meaningful scrutiny role in relation to the performance of Social Security Scotland.

## 1. Introduction

“I can’t afford to heat my flat. I can’t afford to put the hot water on. For washing dishes, it’s cheaper for me to boil a kettle. I have a blanket and thermals on now, as I can’t afford to put the heating on. I’m waiting on the winter heating allowance.”

Disabled Person

Will Scotland’s new social security system for Disability Assistance payments make a significant contribution to ending poverty for disabled people living in Scotland? This question matters because families in Scotland with at least one disabled person are far more likely to live in relative poverty after housing costs than those without. Almost half of all people in poverty live in a household where someone is disabled (Scottish Government, 2021).

The Scottish Government has inspired hope in disabled people and disabled people’s organisations by stating that it regards social security as a human right. It has committed to regulations which will form the foundation for a new relationship between disabled people and the social security system; the Adult Disability Payment “will be delivered in-keeping with our values of dignity, fairness and respect”. (Scottish Government, 2020).

These promises have started to tackle the immense cynicism and fear amongst disabled people that are legacies of the current benefits system administered by the Department for Work and Pensions. However, the disabled people and DPOs who contributed to this report do not believe that Scotland’s new social security system for Disability Assistance will go far or fast enough in reducing poverty.

“You can’t overstate people’s anxieties and fears about making applications [...] there’s years and years of negative experiences and people feeling humiliated, you know, embarrassed and challenged about applying for benefits and that now permeates the culture.”

Welfare Rights Advisor

Scotland’s suite of new Disability Assistance payments is its most ambitious programme yet in the devolution of social security powers. Starting with the Child Disability Payment, to replace Disability Living Allowance for children from Summer 2021, it will introduce the Adult Disability Payment in 2022. This will replace Personal Independence Payment and Disability Living Allowance for disabled people of working age. No date has yet been set for the transfer of Attendance Allowance, which will be renamed as the Pension Age Disability Benefit.

The Equalities act describes a disabled person as someone who has “a physical or mental impairment which has a substantial or long-term adverse effect “on their ability to “carry out normal day-to-day duties”. In this report the terms disability and disabled are used in line with this definition. However, it also recognises the social model of disability in which people are disabled by barriers in society, for example discrimination by employers or lack of accessible public transport, rather than by differences in abilities.

For working-age adults with a disability, the social security system is supposed to compensate for the additional costs of living with a disability, whether the person is in or out of paid work, by providing non-means-tested payments. It is clearly not working as it should.

When taken with the fact that in the period 2017-20, the poverty rate in Scotland after housing costs for people in families with a disabled person was 23% compared with 17% in a family where nobody has a disability, it is clear there is much more to be done to loosen poverty’s grip on disabled people (Scottish Government, 2021).

The signs are also that this has worsened during the global pandemic (Glasgow Disability Alliance, 2020). DPOs such as Glasgow Disability Alliance (GDA) point out that while they support the £20-a-week temporary uplift in Universal Credit (UC) and Working Tax Credit (WTC), which has been a lifeline for many people, and want to see it continued, there has been no similar additional cash assistance specifically for disabled people. The exclusion of legacy benefits from this lifeline is a significant and unacceptable flaw in the UK Government’s response to the pandemic.

Levels of Disability Assistance payments clearly do matter but they are not the whole story. In our research most people felt hopeful that the new Scottish system would do much to repair the harm they feel is caused by current methods of assessment. But they were concerned by the proposed “level” transfer which will exclude many people by retaining controversial barriers to access, such as the infamous 50-metre walking distance rule, as well as maintaining a level of benefits which has not kept pace with the costs of living.

Above all they feared that the Scottish Government’s aims to treat all claimants with dignity and respect could end, as Peter Drucker famously put it, in “culture eating strategy for breakfast”. The fear is that Social Security Scotland will fail to live up to the principles and values outlined at its inception in a document called “Our Charter” (Social Security Scotland) without adequate ongoing training and development of all staff, and the continued engagement of disabled people as advisors and critical friends with more than token powers of scrutiny. Clearly this is a legacy of the DWP’s approach over the last few years, but it is a timely reminder to Social Security Scotland to hold firmly to the values they have rightly espoused.

Other factors hold disabled people back from accessing social security; underclaiming of disability benefits, though extremely difficult to estimate, is a significant problem. So too is the uptake of additional forms of assistance which are often linked to, but not

automatically triggered by, a successful claim for disability assistance. These so-called “passport” benefits include concessionary fares on public transport, council tax discounts, help with home adaptations and a TV licence discount for people with severe visual impairments.

Avoiding making claims for disability assistance is often attributed to the fear of entering what has been described repeatedly as an intrusive and dehumanising assessment process, and the stigma and embarrassment of claiming benefits in what disabled people perceive to be a hostile culture. When it comes to low take-up of “passport” benefits people refer to the system’s complexity and lack of transparency as well as the difficulty many have in accessing good-quality advice and accessible information, meaning that many are unaware of what they are entitled to. Lack of access to good-quality independent advice and advocacy was raised as a necessity which is referenced but not clearly provided for within current Scottish Government proposals.

Low-paid work and barriers to accessing paid work, such as discrimination and unconscious bias, or lack of accessible transport, affect disabled people disproportionately. These structural drivers of poverty were often mentioned along with the unjust ways in which some companies extract a poverty premium from the disproportionate number of disabled people in poverty, ranging from pre-payment meter rates for utilities to the high cost of basic aids for independent living.

This report focusses on disability assistance payments for working-age adults in Scotland, but there are other social security payments that people may be entitled to, not least Universal Credit and Employment and Support Allowance. When we talk about disability benefits in this report, though, we are talking about disability assistance payments rather than those other entitlements.

Overall people shared the same aspirations for the Adult Disability Payment as has been stated by Scottish Government. This is that, as a rights’-based non-means-tested entitlement, it should make a significant positive difference to the quality of life for disabled people. Based on the testimony of disabled people, DPOs and the Scottish Government’s own analysis of what needs to be done in line with the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD) to create a Fairer Scotland (Scottish Government, 2015) this report shows that changes are needed to the current plans for there to be any significant short or medium-term triumph of hope over experience when it comes to the role of Disability Assistance in ending poverty.

- 24% of Scotland’s adult population have a disability (Scottish Government (A) 2019).
- The older you are the more likely you are to have a disability. It is estimated that, in 2019, over half (51%) of the population aged 75 or over had a disability (ibid).
- Disability also varies with socio-economic status. In 2019, 15% of those in the least deprived SIMD quintile report having a disability, compared to 43% of those in the most deprived quintile (ibid).
- 29% of working-aged adults with a disability are living in poverty in Scotland and this increases to more than a third of disabled adults (38%) when you exclude disability benefits, for example, benefits provided to cover the additional costs of living with a disability.
- Disabled people were significantly more likely to experience food insecurity than the general population (18% compared to 5%) (Scottish Government (A) 2019).
- Children in families with a disabled member are more likely to be in both relative and severe poverty after housing costs, compared to children in families without a disabled member.
- In 2019 the additional monthly living costs faced by disabled people were estimated at £583 (Scope, 2019).
- The employment rate for disabled people aged 16-24 was 35.8% in 2018. At the same time, among the population as a whole, the youth employment rate (population average for 16 to 24-year-olds) was much higher (57.2%), as recorded on page 21 of A Fairer Scotland for Disabled People: progress report 2019 (Scottish Government (A), 2019).

## 2. Preventing culture eating strategy

“The thing that came out very strongly was staff attitudes, and the difficulties of dealing with staff who have either consciously or otherwise got really discriminatory attitudes towards people in poverty [...] people said, the worst aspect of poverty was being judged, and people looking down their nose at you and people making assumptions about your lifestyle, and people treating you differently because you were having to apply for financial support.”

Welfare Rights Advisor

“I think ultimately [...] it will be entirely about culture and leadership. So, actually, the nitty gritty of what happens, will be entirely directed by the culture that you set and the leadership.”

DPO staff member

Disabled people and DPOs attribute many known problems which contribute to causing poverty to how people working in and for the Department for Work and Pensions behave, as well as to the rules which govern the system and the levels of benefits available.

These problems include underclaiming of benefits due to fear, stigma and embarrassment, exacerbation of mental health problems and the high rate of refusals of applications for disability benefits which are overturned on appeal. Disabled people are more likely to feel embarrassed about claiming benefits, and more likely to feel they are not treated with respect when claiming benefits. As a result, disabled people are twice as likely to delay making a claim due to concerns about how they will be treated by DWP/Jobcentre staff compared to non-disabled people (Geiger et al, 2020).

This argument that the working culture matters, not just the regulations, has clearly been heard by the Scottish Government and Social Security Scotland. There is much evidence that they have listened and responded positively to the advice of stakeholders including from the Disability and Carers Benefits Expert Advisory Group (DACBEAG) which was set up in 2017 to provide recommendations and advice to Scottish Ministers.

This learning is reflected in the introduction to the consultation on the regulations for Adult Disability Payment opened in December 2020. In this document, Shirley Anne Somerville MSP, Cabinet Secretary for Social Security and Older People, confirmed the Scottish Government's commitment to forming a new relationship between the social security system and disabled people. She emphasised the need for disabled people to have confidence in a system which works for them not against them writing that:

**“We believe that we can make bold choices to create a real difference to the whole client journey – a journey that has trust embedded throughout and reflects our core values. I fully recognise the distress and anxiety that people describe when talking about the dreaded brown envelope, assessments and having to repeatedly tell their story. I am determined that we will listen, we will learn and we will do better.”**

Scottish Government, December 2020.

Her introduction also highlighted two further key points:

- The Scottish Government's commitment to designing Disability Assistance in partnership with disabled people and disabled people's organisations.
- That the regulations are only part of the story – it also matters how the new benefit will be delivered.

We have also had recent discussions with Social Security Scotland that showed the importance of culture is at the front of their minds, at the most senior level. This emphasis on the culture of the new agency and ways of working in the system is welcomed by disabled people and DPOs, but there are concerns about the extent to



which Social Security Scotland will live up to the commitments being expressed by Ministers.

The relevant principles and values are contained in Social Security Scotland's Our Charter. This is the founding document which the Social Security (Scotland) Act 2018 required the Scottish Government to create, and which was co-produced with people who have lived experience of claiming welfare benefits. Although the charter is required by the regulations its content does not have the force of law behind it. As a result, there is a concern that a change in administration could lead to the swift undermining of these principles without Parliamentary oversight.

The specific concerns about culture stated by disabled people and DPOs can be summarised under three main headings:

- Staff bringing dominant discriminatory ideas into Social Security Scotland.
- Good intentions being undermined by budgetary challenges.
- Lack of clarity about ongoing independent scrutiny by disabled people.

## **2.1 Staff bringing dominant discriminatory ideas into the institution**

The Our Charter document states that Social Security Scotland will 'recruit people who care about delivering a service based on equality, respect, dignity and human rights'. Despite this, disabled people and DPOs have expressed concern about the potential negative impact on the culture at Social Security Scotland of the employment of staff who formally worked within the disability benefits system at the Department for Work and Pensions (DWP).

The harm done by an organisational culture within the DWP and, a wider general culture, which is thought to display hostility and resentment towards people claiming benefits, is not easily forgotten by those who describe their experiences as claimants as degrading, humiliating and stressful.

This point was made more broadly in relation to the general issue of stigma and how staff in several organisations often respond to disabled people.

*"What's coming up very strongly from members is the personal relationship aspect of it – how people feel and experience stigma in the way staff within organisations talk to them. And that applies to a range of public sector organisations. It applies to social work and housing as well as benefits but it is particularly the case in benefits that people feel stigma in how they are addressed and how they are spoken to, in the kind of attitudes and judgement of the staff who are actually dealing with the claim."*

DPO spokesperson

Negative experiences linked to people's attitudes and beliefs are too frequently stated by disabled people to be ignored. In 2018 the charity Scope reported that one in three disabled people said they faced a lot of prejudice, whereas only one in five non-disabled people said there was a lot of prejudice against disabled people (Dixon, Smith and Touchet, 2018). But the report revealed disabled people experienced multiple incidents of what could be called 'microaggressions' such as not being served on their turn in shops, or having doors left to swing shut on them as if they are invisible.

It also revealed serious misunderstandings about the scale and nature of disability. For example, 32% thought that disabled people were not as productive as non-disabled people at least some of the time. The report picked up on the importance of relationships. It noted closer alignment between views on levels of prejudice between disabled people and non-disabled people when the latter said they knew or had close relationships with disabled people.

Based on this evidence, it is perhaps not the potential negative impact of staff who have previously worked in what disabled people regard to have been a toxic system that matters, as much as ensuring the right training, awareness-raising and performance monitoring systems are in place and sustained in the long-term to help combat general prejudice and ignorance. Disability equality training delivered by disabled people is one option which should be considered. Welfare benefits advisors stressed the importance of staff understanding the impacts of their decisions by hearing from disabled people themselves.

Public attitudes also matter. Fear of losing benefit entitlements if they are perceived by others as not being sufficiently disabled and being 'reported' to the authorities is commonplace amongst disabled people. This has been linked to low uptake of opportunities such as volunteering and willingness to access services and opportunities designed to address challenges such as social isolation, loneliness and under-employment.

Some disabled people believe negative attitudes to benefits claimants exist due to deliberate attempts by UK Governments to stigmatise claimants, deter claims and drive more people into insecure, low-paid work.

## **2.2 Good intentions being undermined by budgetary challenges**

DPOs raise a specific concern about the ability of Social Security Scotland to adhere to the principles in Our Charter in the face of budgetary pressure. Their experience in observing and lobbying for changes in the delivery of social care gives credibility to this concern. Not all disabled people need social care but the well-known challenges in this sector loom large for DPOs because the route to independent living for disabled people is often dependent on being able to access suitable person-centred social care support.

Derek Feeley, chair of the recently concluded Independent Review of Adult Social Care in Scotland, showed there were solid grounds for this concern in his report (Feeley, 2021). He referenced many ground-breaking policies and examples of legislation worthy of celebration in Scotland while stating that:

“Social workers and their representative organisations told us about their frustrations [...] which put social workers in the position of gatekeeping budgets on behalf of cash-strapped Local Authorities, and prioritising cost and eligibility considerations above working with people to plan their support and to ensure access to high-quality support. As one social worker put it to us: it’s the equivalent of NHS staff having to make a case for funding every time someone needs a blood test.”

Disabled people and DPOs perceive the impact of this in ways which suggest the financial pressures have a bearing not just on decision making but also on culture. The most generous view is that stressed social work staff are simply unable to do their jobs as they would prefer, and everybody suffers harmful fallout from that in terms of poor relationships and sub-optimal services and outcomes. There is a harder-edged view of what is happening in some local authority social work departments which is that social work staff adapt to stressful budgetary pressure by reframing the purpose of their work and/or their opinions of those who are seeking or relying on social care support, to the detriment of disabled people.

This was described as follows:

“It’s all about money but it’s dressed up as maximising independence. [...] It is the complete opposite of the UN CRPD Article 19 [...] a definition of independence that’s saying disabled people are independent if they can do everything by themselves [...] but none of us bake our own bread, none of us grow all our own bloody vegetables [...]. That’s not independence. Independence is really about interdependence. It’s about the support that we all need.”

DPO spokesperson

Research into current attitudes, beliefs and working practices in social work in Scotland is lacking. However, research exploring the challenges encountered in embedding Self-Directed Support (SDS), a keystone policy designed to help facilitate independent living by placing care users in the driving seat in terms of choice in how their care is delivered, in social work practice draws attention to the risk of a lack of financial resources undermining a human-rights based approach:

“SDS may be getting used as a means to implement budget cuts, thus bypassing transitional arrangements between existing organisational structures and newer, flexible, more user-focused arrangements via a wholesale shift of responsibilities to users, driven primarily by fiscal imperatives.”

Eccles and Cunningham, 2016

Derek Feeley's (Feeley, 2021) analysis of the severe problems in Scotland's social care system indicates that concerns expressed by disabled people about the power of culture to undermine policy are certainly not groundless. His report shows just how far the system has drifted from the principles upon which the much-celebrated ground-breaking legislation and policies he cites were founded.

The potential parallels with Social Security Scotland and Disability Assistance are clear. If staff are to take a "human rights" approach to Disability Assistance they must have the means to do so and not become frustrated in that duty by unrealistic budgets. The Feeley review concluded in relation to social care that increased spending is not only an investment in wellbeing but also "warranted on the human rights basis we have set out".

Clearly as the payments are yet to start, there is no evidence that this will be the approach taken to spending on Disability Assistance. What is clear, though, is that the disruption to support services resulting from the COVID-19 pandemic, and talk of a looming further crisis in public finances, has increased the level of anxiety for many disabled people. DPOs are monitoring the situation carefully and report early signs that this supposedly temporary withdrawal of services will become more permanent if disabled people are considered to have 'managed' well without them.

### **2.3 Lack of clarity on ongoing independent scrutiny by disabled people**

The power and value of lived experience for informing and influencing policy and practice is well-established in Scottish Government rhetoric and increasingly evidenced in policy making processes in national and local government. Despite this, the scepticism of disabled people is understandable. Recent relevant experiences include the abrupt withdrawal and slow restoration of social care services during the pandemic. These are cited to illustrate their concerns that change can happen swiftly in systems, and it is not always for the benefit of disabled people, or as a direct result of engaging with them or with DPOs.

There is anxiety about statements, which appear to be clear commitments to continued co-production, being disregarded or overtaken by events. Such events include the pandemic or the election of a different government, financial or political pressures, or by wider cultural shifts that lead to the guidance being interpreted in ways not intended originally.

For example, Our Charter states that the Scottish Government and Social Security Scotland will:

**'...involve people using the service in measuring how well it works - including the commitments in Our Charter.'**

It is easy to see how such a commitment could, at worse, be reduced to a cursory box-ticking exercise. This might not be intended but what, if not the ongoing meaningful involvement of disabled people and DPOs in guiding and governing the system, would prevent it?

Similarly, Our Charter commits the Scottish Government to involving: '...people with diverse lived experiences of social security in developing policy.' But involvement can take many forms and it is not always experienced as meaningful. It can also be experienced as an unwanted pressure to take on unpaid work. This note of caution on the topic of 'consultation fatigue' is noted in Glasgow City Integration Joint Board's Participation and Engagement Strategy.

When it comes to Social Security Scotland several groups, variously described as stakeholder, reference, and advisory groups, have been set up and these do include some disabled people and DPOs as members. However, the Agency's Chief Executive is not accountable formally to any of these groups but, as is normal for such Agencies, to the Scottish Government via the relevant Minister. Real power resides, as ever, out of the hands of the people the system was set up to serve.

It would be wrong to say there will be no scrutiny of Social Security Scotland's performance at all. The Scottish Parliament's Social Security Committee has been formed to enable parliamentarians to play their part in this. But this brings us back to the central point which is that much of the well-informed good intentions signalled in the Charter, which was itself co-produced with people using the Social Security system, and in the guidance which will accompany the relevant Disability Assistance regulations, are open to interpretation.

This includes, for example, the meaning of the term 'dignity'. What exactly does it mean to treat people claiming Disability Assistance with dignity and how will staff or the organisation's leadership be held to account if, in the opinion of disabled people, it fails to do so?

One answer lies in the moves Scotland is making towards embedding human rights in Scottish law. Human dignity is an overarching concept in human rights law. The European Social Charter and International Covenant on Economic, Social and Cultural Rights protect rights to social security, social assistance and an adequate standard of living at international level. Incorporating either one of these, as recommended by the Human Rights Leadership Group, in Scottish law would strengthen the ability of all Scottish people to ensure Our Charter's principles are upheld by enabling them to go to the Scottish courts if they believe a piece of legislation, or an act or decision by a Minister or public authority, contravenes their human rights.

### 3. Promoting take up and tackling prejudice

“We need to look at the kind of messaging around benefit take up and benefit awareness that it doesn't kind of sometimes unconsciously reinforce the idea that you have to be a poor soul to get this. The messaging should be much more around: if you have a health condition or disability, you're likely to encounter additional costs, it's not fair to expect you to meet them on a limited income [...] that's a very different way of framing things.”

DPO spokesperson

“There's also maybe people who think my health conditions aren't very bad. I don't want to take something that someone else could get. That's not how it works. You know, you're either entitled or you're not.”

Welfare Rights Advisor

Placing a figure on the underclaiming of disability benefits is very difficult. DPOs and other agencies which offer welfare rights advice draw on the numbers of people they advise, and the amounts of entitlements claimed successfully following that advice, to illustrate the value of their services and the scale of the problem.

Scottish Government has itself drawn on figures provided by Citizens Advice Scotland (CAS) in developing its 2019 take-up strategy for social security benefits (Scottish Government (C), 2019). One method of monitoring this as the Scottish Social Security system develops is to establish the size of the eligible population and set that against actual expenditure. However, the difficulty of estimating the scale of the problem is exacerbated when eligibility is based on case-by-case assessment as it is with Disability Assistance.

However, the Scottish Government accepts that underclaiming is a real and significant problem and has pledged to work on exploring methods of assessing this. In the March 2019 consultation on the three new benefits, it stated:

‘These forms of Disability Assistance will provide financial support to over 350,000 people in Scotland and it is anticipated that all of these individuals will be impacted directly by the delivery of Disability Assistance. Further work on developing a benefit uptake strategy is being undertaken and it is likely that the total caseload will increase as a result of the implementation of the strategy.’

In the December 2020 consultation (Scottish Government (C), 2020) on the Adult Disability Payment this envisaged increase remained unquantified, but readers were reminded that:

**‘The Social Security (Scotland) Act 2018 sets out the duty on Scottish Ministers to promote uptake of benefits for eligible individuals, and the Act requires Ministers to set out in parliament a benefit uptake strategy.’**

The reasons why people do not always claim everything to which they are entitled are easier to establish than the number. Some of these reasons were addressed in Section 1. The leading ones identified by disabled people and DPOs are:

- Fear of being subject to an intrusive and insensitive assessment system.
- Lack of knowledge and understanding of various entitlements.
- Stigma and embarrassment related to perceptions of public attitudes to disabled people and to benefits claimants.

This is reflected in submissions to a 2019 Scottish Parliament Social Security Committee inquiry into benefits take-up, in which the most common reasons mentioned were complexity and lack of knowledge, followed by administrative barriers, lack of accessible information, previous bad experience and stigma. It also noted that difficulties are increased where well-being, health issues or complex lives reduce people’s energy to engage with a complex system (Scottish Parliament Social Security Committee, 2019).

It is important to remember that disability benefits are not means-tested and are supposed to address the additional costs of living with disability. The much higher rate of disabled people experiencing food insecurity than in the general population (18% compared with 5% (Scottish Government (B) 2019), and the high number of children living in poverty in households with a disabled person present, demonstrate how crucial it is to ensure uptake is maximised if Scotland’s targets on child poverty and overall wellbeing are to be met.

DPOs do not believe increased uptake can be achieved simply by advertising and signposting. Alerting people to the availability of Disability Assistance will not be enough because lack of knowledge and awareness is only one dimension of the problem.

Their experience of having to actively persuade people that their poverty can be alleviated to some extent by making a claim underpins this view. Examples of the fears which deter people from claiming or from taking action likely to help them avoid becoming trapped in poverty are not hard to find.

One destitute man was described by his welfare rights advisor as having turned to sex work rather than try and claim Universal Credit because he attributed his friend’s suicide to the way he was treated by the DWP. Another described people feeling so afraid and disempowered by the fact that their income appeared to depend on the ‘whim’ of the DWP that they avoid opportunities which might help improve their wellbeing and employment opportunities:

“We're trying to address underrepresentation of disabled people in volunteering, and something that comes up time and time again, is a fear of, well, if I volunteer, my health-related benefits will be reassessed, my work capability will be assessed. I'm not going to risk losing benefits. [...] there's actually very, very few cases where that's actually happened, that somebody has had the benefit reassessed because of volunteering, the fact that the fear is so prevalent here, is an indication of just how strongly people feel about that.”  
DPO spokesperson

Social Security Scotland's Our Charter signals a healthy recognition of what needs to be done in terms of addressing unhelpful attitudes and beliefs in stating a commitment to:

‘Publicly challenge the myths and stereotypes about social security to help reduce stigma and negativity.’

And

‘Ensure that disabled people who need help with the application process can get independent advocacy.’

DPOs welcome these commitments but are concerned that the challenge won't be tackled with sufficient imagination, ambition or a full understanding of the scale required. For example, another issue raised by disabled people is concern that the default position will be over-dependence on digital channels for awareness campaigns which would further compound the problems of people who are digitally excluded. With trust looming so large as a key issue in tackling underclaiming there is a lot of enthusiasm for ensuring trusted organisations, especially membership-based and local grassroots community support groups, are supported to help stimulate positive word-of-mouth communication to help reassure as well as to inform people.

DPOs want to see the ambitions outlined in Our Charter realised in two main ways:

- For disabled people to benefit from long-term investment in a See Me-style national initiative, designed to achieve for disabled people what the See Me campaign set out to achieve for mental health stigma (See Me, 2021). Its mission to transform public understanding of mental health issues and to reduce ignorance, stigma, discrimination and prejudice mirrors many of the barriers to be overcome in increasing uptake of Disability Assistance. One specific important goal should be to re-establish the fact that Disability Assistance is for the additional costs of living incurred by disabled people. It should also move beyond the particular challenges facing disabled people in order to transform attitudes to the welfare system so that 'benefits' are perceived as entitlements not 'help' and money spent on these entitlements is understood to be a positive investment in the wellbeing of all Scotland's people.



- Increased and longer-term investment in independent advice and advocacy support. Changing hearts and minds takes time and so it is envisaged that the work of helping people both to understand what they can claim and to overcome their fears and anxieties so that they are willing to trust the new system will continue for some time.

The current lack of clarity about how the provision of independent advocacy will be realised is of concern:

“Advocacy is a wee bit murky right now, we're not quite sure what's happening with advocacy, because it's written into the legislation, and the guidance [...] and I believe that's a good intent. We're just not quite sure who's going to be delivering on that. And I would suggest it should go through the Scottish Independent Advocacy Alliance, they should have a role in it [...] and that advocacy organisations should be resourced.”

DPO spokesperson and disabled person

Resourcing the Third Sector to sustain a truly accessible independent advocacy and advice service is challenging. There are strong feelings that generalist services such as CAS are not fully accessible to disabled people right across Scotland due to basic issues such as the buildings in which they are housed not always being easily accessible to all disabled people. However, the biggest weakness cited in the current system is lack of availability of services staffed with trained and knowledgeable specialist advisors, which means there is not universal local availability, and there are long waiting times for good-quality advice and advocacy support. This is attributed primarily to short-term and inadequate funding.

There is a relationship between the prejudice disabled people perceive to exist in society and their willingness to claim benefits. DPOs feel a strong, positive promotional campaign around the new Disability Assistance system is a prime opportunity to change and improve public understanding and attitudes to both disabled people and benefits claimants in general, which could have a much wider positive impact than simply boosting uptake.

They point out that several key challenges which the Scottish Government has committed to tackling could be assisted by a systematic drive to change attitudes and raise awareness which would help reduce stigma. These include increasing paid employment and volunteering by disabled people, reducing social isolation and loneliness, and supporting initiatives designed to help reduce the number of people experiencing poor mental health.

There is also some enthusiasm for more radical changes which would build on the knowledge that universal benefits are often not even perceived to be ‘benefits’. As one person put it:

“A universal basic income, with add-ons for disability costs, could remove the stigma of having to claim benefits and would change the culture and shift attitudes”.

Disabled person

#### **4. Will Adult Disability payments be adequate to prevent disabled people living in poverty?**

“ [...] do the benefits actually allow people to live as we were describing the model of independent living? Or are they just giving people enough to stop them from falling into abject poverty and able to feed themselves? And my sense is that the rates at the moment, are much more towards that end of the spectrum, just helping people to keep their heads above water, rather than actually, what could potentially be the case of allowing them to do things they aspire to do.”

DPO spokesperson

“I am in a lot of debt because I’ve had to buy a lot of equipment for my visual disability. Paying interest on these debts means I am really struggling. I’ve had to spend thousands of pounds on equipment. Recently I had to get a new TV that has voiceover built in. Torches, headlamps, batteries that I need to buy cost hundreds of pounds and there is equipment that I would like to have but I have to do without.”

Disabled person

A growing number of households in which people are in full-time employment fall below the Minimum Income Standard (MIS) (Hirsch et al, 2020). However, under-employment is a major issue for disabled people, and people who are not working in paid employment have the highest risk of living in households which fall below the MIS.

In a recent study it was found that most single, economically inactive, working-age adults reported being permanently or temporarily sick, which should qualify them for social security support and, in some cases, disability benefits (Padley and Stone, 2021).

Scottish Government has made several commitments, expressed in Our Charter and elsewhere, to tackle poverty through the social security system. There are three main statements relevant to the perceived adequacy or otherwise of Adult Disability Payments. These are that it will:

- Use social security powers to contribute towards tackling poverty.
- Review the payment levels of Scottish benefits every year.

- Increase the value of disability, employment-injury, carers' and funeral expense benefits every year in line with inflation.

The Social Security (Scotland) Act 2018 places a duty on Scottish Ministers to publish a report each year that sets out the impact of inflation and what they intend to do for the next financial year. There is also a duty on Scottish Ministers to bring forward legislation to uprate carers', disability, employment-injury, and funeral expense assistance by inflation.

In fulfilling this duty the Scottish Government laid a report before the Scottish Parliament in February 2020 stating that it will use the Consumer Price Index (CPI) as the measure of inflation for uprating devolved social security assistance in the short-term. This keeps uprating in line with the measure used by the UK Government for reserved benefits.

There was support for alternative measures, such as the Retail Price Index (RPI) which tends to be higher than CPI, but the Scottish Government (Scottish Government (A), 2020) have rejected this as RPI is generally considered to be an unreliable measure. The Scottish Government has committed to continue exploring and monitoring the development of emerging inflation measures, but while inflation is running at low levels this is clearly not the most important tool for unlocking disabled people from poverty's constraints.

The key issues raised by disabled people and DPOs in relation to adequacy of Disability Assistance are:

- payment levels,
- eligibility criteria,
- longevity of awards,
- difficulties around transitions,
- the complexity and lack of transparency around add-on 'passport' benefits.

#### **4.1 Payment levels**

The main concern about levels of payments is that people have lost sight of the original purpose of non-means-tested Disability Assistance, which was to cover the additional costs of living for disabled people. This matters because, according to UK Government 2021 statistics, only one in three Personal Independence Payment (PiP) claimants received higher rate awards (DWP, March 2021). The lower rates of payments, even when combined with the mobility component, fall short of the estimated £583 average additional monthly living costs for disabled people (John et al, 2019).

The Scottish Government is proposing many changes in assessment procedures and other changes which might well both broaden eligibility for the higher rates as well as increase uptake. However, in terms of the rates of Adult Disability Payments there are no changes proposed for when the new benefits start in 2022. A commitment to a substantial independent review of Adult Disability Payment in summer 2023, a year after it is rolled out, signals a long wait for any action on the adequacy of payment levels.

The Scottish Government's position is that it does not wish to create a two-tier system in which new claimants receive different, possibly higher, rates than existing claimants. This is not sitting well with DPOs who point out that there is already a two-tier system because people receiving Disability Living Allowance already exist alongside people stuck with its successor, Personal Independence Payments.

## **4.2 Eligibility criteria**

Disabled people and DPOs mostly recognise there are reasons why it is proposed that Scotland transitions into the devolved system of Disability Assistance without making major changes to eligibility. They do not accept that a transformative human-rights-based approach to the new system should be much delayed after that transfer is achieved.

One of the reasons why so many disabled people are excluded from the current system, or receive less than the highest rates, are the substantive changes to eligibility criteria which were made when Disability Living Allowance was replaced by Personal Independence Payment. People who could not walk, aided or unaided, for more than 50 metres had previously qualified for the highest rates of benefits. This distance measure was more than halved to 20 metres, and this is the measure that Social Security Scotland will maintain.

Another aspect of concern is the plight of older people which is addressed under the section on Transitions below.

There is hope that changes to the assessment and appeals process, especially if the promised positive culture is cultivated alongside systemic changes, will bring more positive outcomes for more people. However, there are concerns that the eligibility criteria remain unfair and will continue to have a particularly inequitable impact on people with fluctuating conditions characterised by 'good' and 'bad' days, meaning they often fail to meet the criteria while still incurring additional costs of living and finding it difficult to secure and sustain paid employment.

## **4.3 Longevity of awards**

Many disabled people believe that there should be lifetime awards for people whose condition will not improve or cannot be improved significantly from whatever point of

life this can be established. Any re-assessment of lifetime awards would be triggered by a disabled person's request rather than by a one size fits all assessment timetable. This is not to say that disabled people want to be told what they will or won't be able to achieve in life. There are far too many examples of well-meaning assessments that have the unintended consequences of crushing hopes and aspirations. However, it is hard to see how a system based on dignity and respecting human-rights is compatible with asking that a person with a lifelong condition repeatedly proves that they are still disabled. The Scottish Government's commitment to explore lifetime awards in their recent consultation is, as a result, welcome.

## **4.4 Difficulties around transitions**

There are three main areas of concern:

### **4.4.1 Awards based on age**

Awards based on age appear to undermine the principles of a human-rights-based approach. While breaking Disability Assistance into three age groups – children, working-age adults and older people – makes some sense on the basis that everybody's needs change across various life stages, it raises some important questions.

For example, what is the human-rights-based justification for treating a person who has reached state pension age differently to a disabled person just two years younger. While the former might face lifelong poverty and increased social isolation, the latter can retain any mobility component awarded under the terms of the Adult Disability Payment lifelong.

It is not currently proposed to offer a mobility component to disabled people who will qualify for the Pension Age Disability Payment which is replacing Attendance Allowance in Scotland from 2021. In its February 2020 position paper, the Scottish Government made clear that this was mainly on the grounds of cost. It calculated that the additional costs of so doing would be in the region of £580 million annually which, as it was not a feature of the UK system, would have to be afforded from the block grant (Scottish Government, (B) 2020). We already know that continuing to work after state pension age is not just a right but a financial necessity for many people, and that social isolation and loneliness contributes to worsening health and wellbeing. The current policy appears to be at odds with others designed to address those challenges.

There are also anomalies when it comes to young people. Extending the upper age of qualifying children and young people from 16 to 18 is welcomed, but it is a potentially difficult transition to force onto a young person and their family while many young people will also be navigating other major changes in their lives. Meanwhile policies related to the Children and Young People (Scotland) Act 2014 have extended the upper age for additional and transitional support arrangements up to the age of 26.

As one disabled person put it:

“I feel very strongly about the transition period being looked at in more detail and I think it should be 16 to 24.”

#### **4.4.2 Parents and carers of young adults**

There is a delicate balance to be struck between enabling young disabled people to choose to make the transition to adult-style independent living, and assisting their parents and carers to cope with the impact of that change on their finances. If families are not living in poverty before a disabled child decides to leave home or manage their own finances as well as social care if it is needed, they might well be afterwards. As one disabled person said, it is ridiculous to assume that a parent who has spent years caring for a disabled child can walk out the door and get a decent, well-paid job straight away.

#### **4.4.3 Transitions into and out of paid work**

In addition to the parents mentioned above, many disabled people who want paid work and who can find jobs are made anxious by the sharp edges of a social security system that still feels hard to get into and therefore risky to leave. Scotland’s new social security system will have to co-exist with the UK system and it is at this intersection with, for example, Universal Credit and also the tax and VAT system that those sharp edges are felt most keenly.

One specific concern is that the real cost of moving into work should be more adequately recognised and provided for. That includes the basic requirement, temporarily alleviated by the pandemic for many, of increased travel costs above and beyond those faced by non-disabled commuters. It can also be the costs of specialist equipment, such as lighter or more manoeuvrable mobility aids. One particular bugbear is that the rules currently preclude VAT relief on many useful aids that were not primarily designed for use by disabled people, which covers a lot of useful digital hardware.

#### **4.5 Passported benefits**

“I didn’t know how to apply for the winter fuel payment. Nobody tells you about these benefits.”

Disabled person

Many people find the complexity of a system littered with add-ons and extras confusing, exhausting and inefficient. However, there is support for tackling poverty by offering certain additional benefits. For example, automatically extending the Scottish Child Payment to all families with a disabled person, adult or child, living with them. Stories about missing out on key ingredients in the social security mix abound. The biggest complaint is of not being told clearly what is available and the onus being placed on individuals to both find out about them and then repeat details of their condition, diagnosis and/or general financial and personal status multiple times to multiple people in order to access entitlements.

The second complaint is that some additional forms of assistance, in particular the National Entitlement Card for free bus travel, are of little real benefit to many. For example, its use is limited in areas poorly served by public transport or by people who struggle to navigate streets and vehicles not well-adapted to their needs. The COVID-19 pandemic, which has prevented many disabled people from using public transport at all, highlighted the cost of taxi travel for those who cannot or do not drive a car. Most people would like to see the unavoidable (in the current non-disabled person friendly environment) additional costs of travel better recognised in core benefits entitlements.

However, for as long as passported additional forms of assistance exist, disabled people would like to see them triggered automatically rather than remaining hidden or just signposted. The fact that Social Security Scotland's Our Charter commits to telling people 'if we think you might be entitled to benefits not delivered by Social Security Scotland' was not reassuring to people who have already experienced systems failure when it comes to being alerted to entitlements.

## Conclusions

Scottish Government has taken a pragmatic approach to the immediate business of rolling out devolved Disability Assistance payments, which is considered understandable by some DPOs, but is still contrary to advice it has actively sought from disabled people.

There will be very few substantive changes to important matters such as the levels, and therefore the adequacy, of entitlements or to eligibility criteria. Disabled people who were living in poverty before the new benefits become available will not have their standards of living transformed by the levels of benefits offered in the new system.

However, in setting out to create a social security system based on human-rights-based principles, in particular dignity and respect, there is a possibility that the Scottish Government will succeed in reducing poverty in some households by bringing those who were previously fearful of claiming their entitlements into the system.

There is a risk that budgets and budgeting processes will undermine this intention to deliver a human-rights-based social security system. Without additional legislation which incorporates economic and social rights in Scottish law, the commitments made are vulnerable to being undermined or weakened, and claimants do not have the widest possible means of redress.

There is not just concern about the impacts of budgeting on the adequacy of benefit levels and the eligibility criteria, but also about the ongoing investment needed to grow and maintain a high-skilled, supportive and non-discriminatory workforce at Social Security Scotland, to transform public attitudes and behaviours and to work effectively on increasing uptake. While benefits entitlements are important, the wider issue of equality, including tackling prejudice and discrimination that, for example, reduces access to paid employment as a route out of poverty, is front of mind for many disabled people.

The new system's potential to alleviate poverty is also limited for as long as passported or 'add-on' entitlements continue to be difficult to find out about, and laborious and sometimes distressing to apply for. There is a call for improved automatic triggering mechanisms which do not depend on individuals having to find out what they are entitled to, but also strong demand for improved access to specialist advice and advocacy services to ensure no disabled person misses out. If this advice and advocacy work is to be sustained adequately by the Third Sector this will require a much improved and more consistent funding system.



Retaining an age-banded system is also of concern. Refusing a mobility component of Disability Assistance to people who apply after State Pension age is at odds with the wider system that does not allow employers to discriminate against older employed people by enforcing a standard retirement age. Many older people work beyond retirement age to prevent poverty, not just for their general wellbeing. The additional costs of living for disabled people do not end at state pension age. Transitions, at life stages, and in and out of work, also look set to be served poorly by the way Disability Assistance will work.

The lack of any ongoing provision for meaningful scrutiny of the system by disabled people is at odds with the extensive efforts made to engage with disabled people, and disabled people's organisations, in the development of the proposed regulations and guidance on Disability Assistance. The proposed independent review of the system is scheduled too far in the future for people to be confident that any significant recommended changes to disabled people's wellbeing will come soon enough.

There is a great deal of hope and optimism that this engagement together with the human rights principles, which the Scottish Government described as underpinning the new system, will make a positive difference to the quality of life for disabled people. We can and must make that the reality.

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## Methodology

Shelagh Young was commissioned by the Joseph Rowntree Foundation to work with disabled people and disabled people's organisations in Scotland, to explore the poverty reducing impact of Disability Assistance payments in Scotland for working age people.

She heard from over 40 people in two on-line focus groups, and eight 1:1 semi-structured interviews, organised with the help of Glasgow Disability Alliance, Faith in Community Dundee, and Inclusion Scotland.

A big thank you to all the disabled people who shared their accounts of often difficult experiences, and their ideas for better ways forward and to John Beaton, Danielle Hinton, Brian Scott and Bill Scott who made these conversations possible.

## About the Joseph Rowntree Foundation

The Joseph Rowntree Foundation is an independent social change organisation working to solve UK poverty. Through research, policy, collaboration and practical solutions, we aim to inspire action and change that will create a prosperous UK without poverty.

We are working with private, public and voluntary sectors, and people with lived experience of poverty, to build on the recommendations in our comprehensive strategy - [We can solve poverty in the UK](#) - and loosen poverty's grip on people who are struggling to get by. It contains analysis and recommendations aimed at the four UK governments.

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