The impact of Cuts to SDS Option 1 (direct payments) on disabled people and unpaid carers

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Background

This research was developed in direct response to concerns raised by Social Work Scotland's sector partners, including disabled people and unpaid carers, about cuts to Option 1 (direct payments). These concerns were first raised by an Independent Support Organisation, then at the Personal Assistant Programme Board and the National SDS Collaboration, which brings together Scotland's largest and most diverse network of people and organisations working to improve the implementation of Self-directed Support (SDS). The Social Work Scotland SDS project has stewarded this process, commissioning independent research to bring together this research report. We are indebted to those who shared their stories and to colleagues and partners from across the National SDS Collaboration and Independent Living Movement who have entrusted us with this undertaking.

While austerity has impacted on social care spending for fifteen years[1], stakeholders identified a worrying pattern: reductions in support increasingly concentrated on direct payments despite their central role in enabling independent living. In this paper, we refer to these reductions as cuts. **Cuts** is a term used to describe the process of reducing or entirely removing the money that disabled people and carers receive through direct payments to organise their own support. Cuts was the preferred term used by disabled people and unpaid carers in this work, and this paper aims to progress understanding of how people with lived experience these cuts.

The effectiveness of direct payments is a core interest of Social Work Scotland, following publication of SDS Standard 12[2], which focussed on access to budgets and flexibility of spend, and Standard 13[3], focused on the employment of Personal Assistants (PAs). Against this backdrop, this research seeks to document, understand, and respond to the experiences of those most directly affected. It aims to provide a clear, human-centred account of what these cuts look like in practice, why they matter, and how they shape the lives of people relying on direct payments for dignified, self-directed support. Initial findings from this research were shared across policy and practice networks, to sense-check results and ensure that disabled people and unpaid carers were engaged in the development and framing of this work. Initial themes were shared September – November 2025 in the following forums:

- The Personal Assistant Programme Board (PAPB)
- The National Care Service Advisory Board
- Standard 13 Action Group
- Standard 13 Peer Space
- The SDS Community of Practice
- The SDS National Collaboration
- The Social Work Scotland Adult Standing Committee Financial Challenge Workshop
- In a meeting with Self Directed Support Scotland (SDSS), the Scottish Government Fair Work Team and the Scottish Government SDS Unit
- A meeting with the Independent Living Fund for Scotland (ILFS)
- A meeting with Community Connections (Carrgom)

About Option 1 (direct payment)

Option 1 (direct payment) is one of the four options of support available through Self-directed Support legislation. The Social Care (Self-directed Support)(Scotland) Act 2013 (the Act) requires local authorities to offer people who are eligible for social care four choices to access support, taking account of the amount of choice and control the supported person wants over their social care arrangements. The four choices, or options, are:

Option 1: The making of a direct payment by the local authority to the supported person for the provision of support.

Option 2: The selection of support by the supported person and the making of arrangements for the provision of it by the local authority or an agreed third party (such as a support provider) on behalf of the supported person. Where the support is provided other than by the authority, the relevant amount in respect of the cost of that support is paid by the local authority.

Option 3: The selection of support for the supported person by the local authority, the making of arrangements for the provision of it by the authority and, where it is provided by someone other than the authority, the payment by the authority of the relevant amount in respect of the cost of that provision.

Option 4: The selection by the supported person of combinations of Options 1, 2 and 3 and, where it is provided by someone other than the authority, the payment by the local authority of the relevant amount in respect of the cost of the support.

However, it is important to note that direct payments pre-date Self-directed Support legislation, with roots in the Independent Living Movement and Disabled People's Movement. Driven forward by the advocacy and campaigning of disabled people, direct payments were introduced in 1997 and later expanded in the Community Care and Health (Scotland) Act 2002. Disability activist and scholar Jim Elder-Woodward notes that the legislating of independent living does not erase the history behind it:

> *As the state takes ownership of independent living, through Self-directed Support legislation and guidance, it should not be forgotten that such thinking and practice came from disabled people. Many had experienced the incarceration of residential care; and those who had not, had experienced the confinement and domination of community care. They had come together to fight for the right to live in the community as valued, participative citizens.* [4]

Option 1 (direct payments) are the only route for disabled people and families to employ personal assistants. However, they can also be used for other purposes, for example:

- To purchase a service from the Local Authority (or neighbouring local authorities)
- To purchase support from a private or voluntary sector organisation
- Products, equipment or items that help people to achieve their outcomes
- To purchase short breaks

In Scotland, disabled people are additionally enabled to live independently through the Independent Living Fund. This support is focused on those with more complex needs and generates significant social value[5]. The 2023 Programme for Government re-opened the Independent Living Fund for Scotland (ILFS), with a commitment of £9 million to support up to 1000 disabled people to live more independently in their communities. Many of the people in receipt of ILFS manage their support through direct payments, and the impact of cuts on the ILFS (both its intention and implementation) is explored in this paper.

Legislation, statutory guidance and the accompanying SDS standards of practice emphasise the importance of flexibility[6] in spending direct payments, balanced with adequate systems to help disabled people to manage the responsibilities and duties associated with holding a direct payment.

Why focus on direct payments?

While this work is focused on cuts to Option 1 (direct payments), it is possible that people accessing social care through Options 2, 3 and 4 will also be subject to cost-saving cuts. However, our focus is on Direct Payments because:

- Concerns raised by partners through the National SDS collaboration and other collaborative spaces have focused on cuts to direct payments
- In the last published dataset (from 2021/22), 10,035 people in Scotland were recorded as receiving a direct payment.
- Direct payments emerged from the Disabled People’s Movement and Independent Living Movement and so have both practical and symbolic significance[7].
- Direct payments represent the opportunity for to maximise independence, creativity and efficiency for disabled people.[8]
- Direct payments can deliver better value for money[9][10] than other approaches to organising social care[11].
- Direct payments are already subject to more monitoring and oversight, with a risk of disproportionate monitoring that dissuades people from taking full control of their support[12].
- Direct payments have greater uptake in rural areas of Scotland and amongst groups of people accessing social care[13] (with lower uptake from older people, for example), so there are likely equalities implications of cuts in this space.
- Direct payments currently the only means to employ Personal Assistants. This workforce is challenging to quantify (with over 5000 PAs on a database managed through SDSS), however PAs report poor terms and conditions, working for free to support their employers, and a lack of contractual clarity[14]. The most recent PA Workforce Survey (2025) states that “policymakers and commissioners are therefore cautioned that while PA work fosters autonomy and meaning, it is also at risk of unsustainable turnover if insecurity and instability are not actively addressed” Risks to direct payments present risks to Personal Assistant employment and destabilise efforts to drive recruitment and retention across this workforce.

Additionally, we should be interested in choice and control as these are fundamental values expressed in policy and public dialogue around social care. However, the most recent (2024/25) Health and Social Care Experience survey identified that while 64% of people agreed ‘I was supported to live as independently as possible’, only 53% agreed ‘I had a say in how my help, care or support was provided’[15]

Why talk about cuts?

Social care is an investment in Scotland’s people and economy, with every £1 spent on social care, generating £1.98 in socioeconomic benefits[16]. For the last fifteen years, local authorities in Scotland have faced financial pressures. First, through austerity policies later compounded by inflation, COVID-19 and recovery efforts. Over this extended period of cost-saving, local authorities have been criticised for short-term thinking, cutting preventative and community-based supports[17] despite strong evidence that these supports deliver long-term value. We cannot deny that local authorities face significant financial pressures, projected to worsen[18] but must draw from the evidence when considering the rationale for, application of and impact of cuts.

This research builds on previous evidence[19][20] and ongoing work at Inclusion Scotland to understand the scale and experience of cuts to direct payments. This work also contributes to understanding on how we quantify unmet need nationally[21]. Evidence landscape for Self-directed Support is complex[22], unreliable and since 2023 there has no requirement to report on the uptake of SDS options at all. Data collection on eligibility criteria and wait times is currently paused[23], and we lack real-time understanding of how eligibility criteria is currently applied in practice. Post-legislative scrutiny of the Self-directed Support act found “very little data and information available in the public domain pertaining to the number of people accessing SDS, their experiences with the system and its processes, and importantly the level of unmet need[24].”

Methods

This research seeks to foreground the voices of disabled people and unpaid carers to understand how cuts to direct payments impact on all aspects of their lives.

In September 2025, Social Work Scotland, supported by partners across the SDS sector including Disabled People’s Organisations and Independent Support Organisations disseminated an open call for evidence (included in Annex 1 of this paper), inviting people with lived experience of social care to submit evidence about the impact of cuts to Option 1 (direct payments) on their lives. We welcomed contributions in different forms including:

- individual narratives submitted directly by disabled people and unpaid carers, primarily through email but with one Facebook message.
- semi-structured interviews with disabled people, unpaid carers and professionals.

We worked to remove as many barriers to participation as possible and be flexible about how people could contribute their stories. For example, some disabled people chose to be interviewed with a family member present for support, and one interview was undertaken by an Independent Support Organisation partner who knew the person well and was attuned to their communication needs. The call for evidence included reflection questions, intended to focus contribution rather than be over-prescriptive; it was important for disabled people and carers to be able to focus on what was important to them.

Independent Support Organisations (ISOs) and Disabled Peoples Organisations (DPO's) disseminated the call to action to disabled people and unpaid carers in their networks. These organisations also submitted their own evidence in the form of:

- case studies, gathered with consent from people accessing their support
- practice reflections from professionals with supporting roles in direct payments
- semi-structured interviews
- team meetings note

This report draws on diverse evidence, detailed in Table 1. It may be useful to note that the detail, background and length of submissions varied significantly across submissions. We were overwhelmed with the response from stakeholders and are grateful to all of those who were able to submit evidence over such a short time scale (September 2025 – end October 2025).

This research did not intend to represent a cross-section of people using direct payments. We did not have the time or resources to engage more systematically with diverse disabled communities. We note that our approach is likely to have missed disabled people and older people who are not engaged with Independent Support Organisations (ISOs), those facing digital barriers, and those who struggle with reading or writing or speak English as an additional language. Future work should seek to bridge these gaps, as disabled people and unpaid carers are a diverse group with intersectional experiences.

Some participants chose not to share their local authority in the evidence they submitted, so we do not have complete data on this. However, ten local authorities were named in submissions. Across the evidence we have representations from urban, rural, remote and island communities. Narratives discuss the experiences of children, young people, adults and older people.

Some case studies have been adapted for brevity and across all the quotes, case studies and examples in this paper names and identifying features have been changed.

Table 1: **Type of evidence**	**Number of submissions**
First person narratives from disabled people and unpaid carers	11
Interviews with disabled people, unpaid carers (and one social work professional)	8
Case studies submitted by Independent Support Organisations/Disabled People’s Organisations	44
Additional submissions from Independent Support Organisations/Disabled People’s Organisations (practice reflections, letters, meeting notes and one interview)	8
Total individual evidence submissions included in this work	71

Section 1: How cuts are made

This section outlines ways in which participants described cuts to Option 1 budgets. By exploring in depth how direct payments are being cut, we can both identify patterns in practice and better understand the experience and impact on people with lived experience. Some of the mechanisms in this section may not appear to be traditional ‘cuts’ understood as reduced budgets but describe the ways in which direct payments have been rendered unspendable for disabled people and unpaid carers, and costs have been passed on to people accessing support.

1. Delays in receiving a direct payment

The evidence submitted described significant delays in the assessment and award of direct payments. Case studies, interviews and individual accounts described waits of over a year. During these periods of delay, disabled people and unpaid carers have had to manage significant unmet need and uncertainty about the future. This aligns with wider social care trends, with the 2024-25 statistics from Public Health Scotland (focused on care at home) demonstrating a 30% increase from the estimated number of people waiting for social care assessments in the last year. Delays in assessment and award of direct payments are described as stressful and poorly managed. One case study detailed an eight-year delay in setting up appropriate support. In one interview, a disabled person shared their reticence to challenge the assessment process, because of fear it would be further delayed:

> *I could ask for another social worker. But that's not gonna help the urgency. That will just put it back even further if I request a new social worker, and I'm not … time is not on my side. (interview with disabled person)*

While delays in assessment are likely to reflect on a stretched social work workforce[25], it is important to note that delays were described in some case studies as a mechanism used to keep social work budgets in line with projected budget.

One Independent Support Organisation shared that the local authority they support put a hold on all “SDS assessments” pending the new annual local authority budget being agreed. This has caused significant pause in progressing any assessment of support needs and following assessment, there is no guarantee that the local authority will have the funding capacity to meet the assessed needs. It should be noted that there is no ‘SDS assessment’ as defined by current legislation, instead a legal duty to undertake an assessment of needs is part of the Social Work (Scotland) Act 1968[26]. The use of terminology such as ‘SDS assessment’ suggests that these assessments are optional or additional. This budget-first approach does not recognise the lived experience of people waiting for support.

Additionally, there are reports of delays in arranging support once an assessment has been completed and a direct payment budget is in place. These delays are significantly extended by ongoing issues recruiting Personal Assistants (PAs) which mean that even when budgets are in place, disabled people are still without support

2. Eligibility criteria

The evidence submitted described ways in which changing eligibility criteria (or changing application of eligibility criteria) impacted on direct payment budgets. Increasingly high eligibility thresholds mean that people who were previously eligible for social care are now having their budgets removed or significantly reduced. Eligibility criteria are described by disabled people, unpaid carers and professionals as unclear, with the frameworks used to identify moderate, substantial, or critical needs applied inconsistently. Some accounts noted that eligibility criteria is hard to challenge.

> *She kept repeating during the interview that the criteria have changed. The criteria have changed. You know, it's just personal care. But afterwards, I researched what comprises personal care and found that, you know, what we were saying is personal care. (interview with disabled person who is also a carer for their partner)*

Submissions from Independent Support Organisations (ISOs) raised concerns about how eligibility criteria are applied, and issues with inequity. For example, one ISO describes “blanket rules” in place by local authorities that autistic people are not eligible support unless there is a co-occurring learning disability or physical disability. Another ISO noted that a person they supported had been told they did not meet eligibility criteria because they had sourced a provider for their own support independently. Another Independent Support organisation identified that eligibility for the disabled person often extended to the eligibility of their unpaid carer to access support:

> *In [local authority], almost all carers statutory support is 'rolled up' with that of the cared-for person, even when legislation is clear that support can be available for unpaid carers even if the cared-for person is not eligible for statutory support. (ISO account)*

Eligibility criteria are an area of national debate, with concerns that the approach stops preventative, person-centred approaches to social care[27][28]. The Scottish Government committed in 2022 to the "overhaul of the current mechanism of eligibility criteria to ensure an approach to adult social care support that is based on human rights and needs"[29], but this change has yet to be actualised.

Additional to formalised eligibility criteria, the evidence describes a patchwork of local rules, misunderstandings and decisions.

The below email from unpaid carer Sheena about her experience of assessment and cuts, and life supporting her husband Jude whilst also managing cancer, demonstrates the application of local rules of eligibility:

During the pandemic, Jude's condition deteriorated further, I took early retirement, and, following numerous hospital admissions more recently with sepsis, urinary tract infections, aspiration pneumonia etc, the hospital refused to discharge him without the addition of two staff visiting four times a day to provide personal care. Jude is almost completely paralysed, and the PA's role became replacement care by default. There was still no carer support plan.

When the four times a day visits began, the social work assistant had said that Self-directed support was ending. I pointed out that SDS is how social work is delivered in legislation. The senior [social work assistant] visited, and we were told that a review would be completed. There had been no review since 2018.

A year went by, with numerous hospital admissions, and the social work assistant allocated was apparently unable to complete the review as a result and was off work for an extended period.

In November last year, a Senior Practitioner was allocated to support [the social work assistant] and they visited us. Before any review had begun, they announced that Jude's direct payment was ending. The four half-hour visits a day are apparently the maximum which can be provided - if more is needed, they assess that residential care is required. The carers budget, still unspent with no plan, was to be cut, and could be used for either 2 hours a week replacement care or one week's respite.

3. Lack of choice

Despite policy ambitions, people are not always able to choose the Self-directed Support option that works for them. If there is no adequate Option 2 or Option 3 provision locally, people who need social care may have to take on a direct payment or choose to live without support. The SDS Act Statutory Guidance states that "there should be no assumption that the Scottish Government, local authorities or social workers consider any option as a preferred or default option, only that the supported person is empowered to choose the option that works best for them, in accordance with their preferred level of choice and control."[30] However, we know that all four options are not consistently available across Scotland[31]. This means that some people accessing direct payments have not chosen to direct their own support and may not be able or willing to manage the associated responsibilities.

Case studies illustrate known challenges with embedding Option 2 supports[32], and the limited availability of full choice and control across Scotland. However, some of the evidence suggested that a default to direct payments was a deliberate cost-cutting choice, as direct payments are often cheaper for a local authority, and can be 'capped'. One ISO described this practice when a disabled person sought out alternative Option 2 support when they no longer wanted to manage a direct payment:

> *Disabled person found a suitable option 2 provider with a higher hourly rate and were told rates were too high so not really given choice. Then told they could seek another provider under Option 1 or 3 - but would still need to cover the shortfall. (ISO account)*

In this case, restrictions to choice represent a cost saving for the local authority and sit in direct tension with the principles of choice and control.

Another example lack of choice is illustrated in the use of 'deflators 'in resource allocation systems when disabled people live in the same home as their carer. The 'deflator', which reduces the overall budget allocation significantly, is applied even if the carer is not willing or able to provide unpaid care. In one case study presented, this has led to the mother moving out of her home shared with her daughter, to enable an accurate assessment of support needs.

4. Lack of consistent review

Submissions described long periods between reviews of direct payments, which best practice guidelines suggest should be annual[33]. In one case study submitted, a direct payment was not reviewed for nine years. Without regular review, disabled people and unpaid carers cannot discuss changes in circumstances with social workers:

> *There's not been a review of Bea since she's hit adult services. She's now 22. She's had a physical accident. Her back's been broken, and it was missed at the time through the NHS. That's been ignored. Her mental health has completely dropped out. It's not even included in her assessment as it is just now. The fact that the social worker can come out and have such a strict remit [to impose cuts] and not have a system or something in place seems to me just... so ridiculous. (Interview with disabled person and unpaid carer)*

One narrative from an unpaid carer described her experiences of being investigated for misspent funds, despite having no review of her direct payment, or communication with social workers, for three years:

> *You can't be left with something for nearly three years and nobody oversee it and then be told anything is your fault when there's no guidance, no support around that…He says I couldn't spend the money then without phoning up, getting any permission. I've not touched the money for months. [On a short break] this weekend I paid for it separately because I don't even… It feels like dirty money. It just feels like dirty. (interview with an unpaid carer)*

5. Inflexible spend

Across the evidence, people describe increasing controls on how direct payments can be spent. Rules and policies on 'appropriate spend' were described as complex and changing. Disabled people and carers were often unclear of what decisions were within their control, and where they would need to seek approval from the local authority. Narrowing the 'acceptable' use of funds is a way of cutting budgets, as unspent funds can be reclaimed by the local authority (see cycle below).

> *In any meeting (which were [very] few), I have felt a veiled threat that the funds could go down as well as up, so don't rock the boat. Along with increasingly bizarre rules of how I was allowed to use those hours, which would just come out of her mouth round the kitchen table. (Email from unpaid carer)*

The experience was also described by disabled people and unpaid carers as disempowering, making them feel as if they needed 'permission' to exercise agency:

> *For example, one unpaid carer had been using their respite funding towards the cost of at-home massage appointments. This gave them the break from care and chance to relax that met their needs and also avoided the need for hard-to-find and expensive replacement care. However, at a recent review the unpaid carer was 'chastised' for using funding in this way and told the money could only be used for replacement care and/or an overnight break. (ISO account)*

Facing challenges in recruitment, some disabled people and unpaid carers wanted to use their budget more flexibly to improve rates of pay to attract Personal Assistants, which was possible in some local authorities, but not others. One case study submitted by an ISO describes how this limited flexibility left people without a path forwards – if they can't attract a PA to support them, what comes next?

> *Despite a DP having been in place for some time, the carer has been told that they can no longer pay their son's PAs a higher hourly rate for his care and take on some of the care themself ("over Xmas , holidays etc") to free up some of the budget to be able to pay the higher rate. So now what? (ISO case study)*

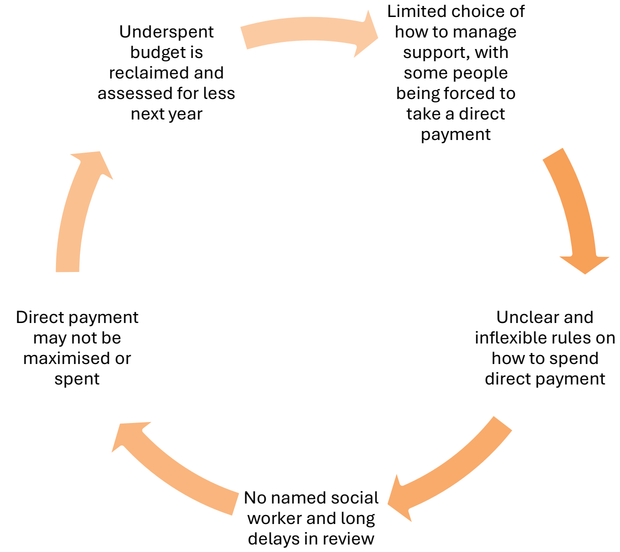
Additionally, cuts to short breaks (often referred to as respite by people with lived experience) was a common theme across submissions, with unpaid carers taking fewer opportunity to care for themselves. One ISO noted a trend in respite allocation being 'capped', without prior information or policy information, meaning that there are maximum days a carer can access overnight respite. Again, suggesting a lack of person-centred planning and flexibility for families to choose how they should best use their direct payment to meet outcomes.

6. Reclaiming of unspent funds

Across the submissions, evidence was submitted detailing the practice of local authorities in reclaiming unspent funds from direct payments, often without appropriate discussion about why underspends are happening (e.g. hospital stays, PA recruitment delays), what needs to change and how the funds could be otherwise spent to meet outcomes. Underspends are sometimes framed as evidence that the disabled person can 'cope without' in cuts to budgets. There are some accounts that the use of pre-paid cards allows finance teams to reclaim funds without permission from the disabled person.

> *Feels like money is being brought back that local authorities have paid out (interview with a disabled person)*

At this point in the paper, it is useful to unpack more on how lack of choice and inflexibility of spend leads to underspend and further cuts. This cycle, which was widely reported in the evidence submitted, has been visualised below (see Figure 1 below)



It is important to be attentive to this cycle in action, as it is unique to the application of direct payments, and would not play out across any other SDS option. The case study below was submitted by an unpaid carer, and summarised for readability, and demonstrates this cycle in action

Jessica was awarded Direct Payment in June 2024 for £3000 to support her son Dan who is autistic. The family struggled to recruit a PA because of low pay rates set by the Local Authority. They did eventually find a PA candidate who knew the young man and was experienced in working with autistic people. He could not accept the standard pay level, but mum decided that it was worth having the right person for fewer hours than continuing on without any PA support. In their annual review, they were then told by their social worker that they cannot pay the enhanced hourly rate even though the budget remains the same. This meant the PA could no longer work for them.

The review has been significantly delayed, and a new budget has not been signed off. Dan has been without any paid support since the assessment in June 2025.

Jessica has complex intersecting health needs and she is significantly impacted by her caring role. She asked Dan's social worker about a carers assessment. She was told she could not access a carers budget because her son already has a budget and "its either one or the other as they are cutting back".

7. Static budgets are cut budgets

Self-directed Support Statutory Guidance states: "a direct payment is not a benefit or a gift. Its ultimate purpose is to meet, in a flexible way, the outcomes of the disabled person as agreed in the support plan. The direct payment amount should therefore be what the local authority considers to be a fair and sufficient estimate of the cost of securing provision of support for the person to enable them to meet their outcomes. This should reflect the market rates that authorities recognise in their own commissioning activity".[34]

The evidence describes significant increases in costs of care (for short breaks, residential support, and provider support). When direct payments stay static and do not rise with inflation, they lose their spending power, and result in cuts to hours of support.

In the cases where direct payments were used to employ Personal Assistants, concern was raised over the suitability of pay rates set by Local Authorities. Some local authorities allowed direct payment holders to set their own rate of pay to attract PAs but did not raise overall Direct Payment rates to align with these higher pay rates. Some local authorities did not allow the pay rates to go beyond capped rates, which was challenging for some people: An unpaid carer, Agnes expressed concerns about the financial limitations of the care package, which restricts the hourly rate they can pay PAs to £12.60. In her interview, she noted that this rate is insufficient given the specialised and complex nature of the support required, which sometimes involves two-to-one care. While she is allowed to set her own rates for PA by the local authority, the overall budget will not increase. Which means she will have to cope with fewer hours of support.

One case study demonstrated how a budget was 'frozen' during transition from children's to adult services, in order to manage discrepancies in funding between children's social care and adult social care:

> *After many months, many meetings, inaccurate adult assessment, assessment delays, and complaints the family were at breaking point as Adult social work would not honour the previous hourly rate [for PAs] and ultimately froze the budget until it came into line with living +wage. They worded it in such a way that it was a favour as the budget should have been cut in their opinion…. The impact of not having sufficient monies to pay staff, give then yearly cost of living wage rises, has meant a reduction in staff numbers/ hours/ retention etc. (Case study submitted by ISO with consent from the family)*

This example demonstrates the bind faced by disabled people and unpaid carers who use direct payments – they are responsible for being good employers, and recognise that they must make the PA role attractive to recruit and retain good quality PAs. The most recent Scottish PA workforce survey identifies that PA employers are not consistently supported to ensure they meet their legal obligations in paying the National Minimum Wage.[35] Beyond retention and recognition, there are significant legal liabilities involved with not aligning direct payments with legal requirements.

8. Interactions with the Independent Living Fund for Scotland

Some people in receipt of direct payments can access the Independent Living Fund in Scotland[36]. However, concerns have been raised through the evidence submitted that cuts to direct payments may bring ILFS recipients below the qualifying budget thresholds, meaning they also lose their ILFS funding. There is one case documented by ILFS to date, which has had a significant impact on the disabled person and their carer:

> *In May 2025 we were notified by [unpaid carer] that the LA were significantly reducing her care package from 58 hours per week to 14 hours per week. The budget was reduced to £439.16 per week which meant she was no longer eligible for her ILF funding. [Unpaid carer] was devastated by this news. (ILFS case study)*

In one interview, an unpaid carer described the practice in her local authority of accounting for ILFS funding when calculating direct payment budgets, despite the policy intention for ILFS to provide additionality for disabled people:

> *They'll, you know, they'll say, oh, you get that from ILF, we don't need to give you that. We'll just give you this package. So they calculate it in a way that my ILF is not an addition to [my budget]. (interview with unpaid carer)*

9. Passing on costs

Some cuts to budgets were made by passing on costs to disabled people, representing an overall cost saving for local authorities with disabled people and unpaid carers 'picking up the slack'. Charging was described in the evidence submitted as a barrier to accessing social care, making care unaffordable for disabled people. This aligns with wider evidence that "charging policies across Scotland are inconsistent, mask unmet need and are causing significant financial hardship." [37] One ISO in an interview noted that some people are foregoing essential expenditures, such as food and heating, to afford their care. Others are unable to sustain payments, putting them at risk of losing their entire support package. Another ISO case study identified a disabled person in significant arrears for their charges, and described the associated stress and anxiety this has caused. Charging is particularly difficult when used to pay for support that was insufficient and not the person's choice:

> *Put simply, life has now become little more than an existence and never ending battle just to get through the day. Causing some very dark and intrusive thoughts about life and living. To add insult to injury, we still have to hand over £155.20 of Lizzie's ADP every month just for the privilege. (Email from disabled person who is also an unpaid carer)*
>
> *The person being cared for is now contributing £93.84 a week toward their care, while the local authority pays only £5.04. No one helped them understand what this meant or gave time to adjust. The carer remembers being asked about household income, but says it wasn't properly explained. Later, someone even suggested they should've said less. that being less honest might have helped get more support. They said, "I'm not a liar. I just told the truth. I don't know what difference it would've made." (ISO case study)*

There is very little publicly available data on who is affected by non-residential social care charges, and no national dataset provides this level of detail.

In addition to charging policies, people who hold direct payments reported that they were expected to cover costs associated with their direct payment, for example PVG costs (£59 for a Confirmation of PVG scheme membership (Join) or £18 for a Confirmation of PVG scheme membership (Existing) associated with hiring Personal Assistants. This is more likely to have a significant impact for employers with multiple PAs, or those with high PA turnover. One Independent Support Organisation shared that PA employers are being asked to independently fund training for PAs, offering the example below:

> *The request to use self-directed support funds for training was refused. X was advised that, as he receives the highest complex rate of direct payment, it was expected that any new personal assistant would already have the appropriate training before starting their role. X was further informed that if he wished for his personal assistants to undertake training, he would need to fund this from his personal independence payment or adult disability payment. (ISO interview)*

Additionally, some disabled people and unpaid carers wanted more recognition for how their contribution to managing a team of Personal Assistants saved the local authority significant costs: one unpaid carer likened her role as PA employer as like running a business, with responsibilities including recruitment, training, and supervision of PAs, as well as handling administrative responsibilities.

10. Erosion of community supports

The Feeley Review highlights the need to strengthen preventative activity across the social care system. Fifteen years of austerity has led to erosion of community supports like community regeneration, community learning[38] and development as well as grants to third sector organisations[39]. Across the evidence submitted on the impact of cuts, people describe a landscape where cuts to direct payments form part of a wider picture in which voluntary sector, and community supports are also facing pressures. The Glasgow Disability Alliance's 'Definitely, maybe, sometimes, never'[40] paper on prevention in social care describes these community supports as 'foundational prevention' that "nurtures strong communities and relationships". The erosion of community supports, when coupled with cuts to paid support, meant that disabled people felt increasingly confined to their homes:

> *I feel if organisations are closing, then it will go back to 2020 when everything shut down (Interview with disabled person)*

We cannot present this evidence without explicitly noting the lasting impact[41] of COVID-19 on the wellbeing and connectedness[42][43] of disabled people and unpaid carers. The lasting impact of the pandemic is woven into the evidence submitted for this work, an important part of the context in which people experience cuts.

11. Complaints

It should be noted that across a significant proportion of the evidence submitted, disabled people and unpaid carers reported that they had taken action to challenge cuts. Actions included:

- Individual complaints, sometimes escalating to the Scottish Public Services Ombudsman[44]
- Requests for re-assessments, that were sometimes upheld
- Collective action, addressing shared concerns with peers and at forums, often with support from Independent Support Organisations
- Seeking support from advocacy services
- Seeking legal advice

However, these were rarely successful, often demoralising and difficult to progress when people were faced with addressing the immediate challenge of losing social care. Some participants involved in this project shared that they did not know how to raise complaints, which reflects known challenges in complaints across social work and social care[45]. In the Independent Review of Adult Social Care[46], Feeley heard repeatedly that simpler and more accessible arrangements to challenge decisions need to be established.

In the evidence submitted, there were some reports of people being dissuaded from complaining by social workers.

One ISO account noted that cuts were implemented so quickly (with only four weeks' notice) that families could not process the information, impact or make alternative arrangements. Many accounts demonstrate the exhaustion felt by disabled people and unpaid carer, who are "*so worn down and broken by the process"* (ISO case study)

At a national level, there are reports of increases in complaints (for example trends in fitness to practice referrals[47]) However, the evidence submitted suggests that many people affected simply do not have the emotional energy or the information to pursue complaints:

> *Unpaid carers are on their knees. Covering carers annual leave, sickness, welfare, employment issues, training etc. Chasing extra funding. On call 24/7. I didn't go to my brother's funeral, because I was too exhausted. (email from unpaid carer)*

The impact of cuts on disabled people and unpaid carers

People who hold direct payments are not a homogenous group. Their individual circumstances, personal outcomes and informal support arrangements differ significantly. However, emerging from the 71 points of evidence is a shared pattern of harm that arise when direct payments are cut. The evidence submitted presents a distressing picture.

One disabled person highlighted the importance of assessing impact on different groups, suggesting that local authorities should undertake impact assessments to understand which groups may be disproportionally affected. A reminder to us to consider that disabled people and unpaid carers will not all be impacted in the same ways.

A note: This paper focuses on the experiences of disabled people and unpaid carers, although professionals were in the process. However, it is important for social workers and other practitioners involved in cuts to have the opportunity to reflect on their experiences. A survey was distributed to social workers to accompany this work, and findings are available here. Both reports are discussed in an overarching paper, The State and Future of Social Work and Social Care Funding in Scotland, Social Work Scotland, available here.

1. The breach of trust

Disabled people and carers describe an erosion of trust with social workers and social work professionals involved in assessments, reviews or resource decisions. A lack of clear policies and guidance, and a lack of transparency in decision-making made disabled people and carers feel distrust towards professionals. Transparency was viewed within a frame of power dynamics, shifting away from a collaborative assessment:

> *She was one of the most senior social workers. So I thought, you know, might be a really good conversation. But it wasn't a good conversation. I felt under attack the whole time.* (interview with disabled person)

In some cases, people with lived experience expressed compassion for social workers who they felt were in a difficult position. However, most disabled people and unpaid carers who submitted evidence expressed intense dissatisfaction with the practice they were met with in the process of having their direct payment cut. Having no named social worker was a common challenge shared by disabled people and unpaid carers in this work. One carer reflected that without a named social worker, it is difficult to form relationships and that social workers were increasingly perceived as adversaries.

Some disabled people and unpaid carers expressed more serious concerns that their social worker has no regard for their wellbeing and some reflected that their needs were deliberately misrepresented through assessment. In some cases, this has led to complete disengagement with social work. One unpaid carer shared their experience of assessment, noting serious concerns about the content of the assessment, as well as attempts to exclude them from the assessment process:

> *We tried to see [the completed assessment] before it was passed by social work but it was not allowed. Even got the local counsellor involved, resulting in the area manager phoning, he said about not wanting a delay, so still didn't see it. We asked 2 lawyers and they said we had a right to see it… I then asked to see it after it had been signed off. We got a copy to see. I know if I didn't ask for a copy of it my social worker was going to bring it out expecting me to look at it during the meeting.*
>
> *There is some wrong information in it and some bits not up to date and query the care hours they have put for my Mum in the evenings. My circumstances are about to change due to my Mum's health (shes waiting for an operation) but nothing about that in my assessment.*
>
> *I feel they are pushing me to sign the [direct payment] agreement.*
> (interview with an unpaid carer)

Some people reported being told upfront that their support was being reviewed to save money. One ISO reports:

> *Families are being told verbally that their budget is being cut and will be reviewed this month. There is very little notice, and this is being advised verbally with no written confirmation and no indication of what to expect or how they are reassessing budgets in regard to making cuts and changes (ISO account)*

But for other participants, cuts were an unexpected outcome of what they thought was a routine review, and not a reflection of changed needs (with support needs or complexity often increasing), and even with social workers assessment. Assessment didn't feel like an exchange or collaboration, but a 'doing to'.

> *The cut came quickly. No one explained why it was happening, and the carer was told they didn't need to sign the new support plan because it was going to happen either way. (ISO account)*

It is important to be attentive to how people with lived experience talk about the speed of cuts, or the timing of cuts. For example, one family was particularly affected by a cut that was made on Christmas eve. Another unpaid carer noted that they missed a meeting as they were in A&E supporting their family member and were then informed that they had to pay back £800 in funds that they were told were inappropriately spent.

Concerns were raised about cuts leading to PA redundancies, particularly due to legal requirements on timelines surrounding redundancy. There is a particular power imbalance to this practice given the earlier theme on delays – assessments and reviews are delayed, often by months or years, but cuts are made quickly. This contributes to the distress experienced by people with lived experience, and their ability to respond to cuts.

2. Immediate risk of physical harm

The practical impact of cuts outlined in the evidence showed clear examples of risks associated with unmet needs. These included clear, practical accounts of how cuts to direct payments had increased the risk of infection, choking, dehydration, muscular atrophy and unsafe contact in the community. Simple tasks that brought joy to disabled people (like dog walks, spending time with family or attending creative groups) have been stripped away, and some people have no way to leave the home anymore.

It is important to frame the below evidence in the knowledge that people who need care may downplay their support needs—because of costs or not knowing what's available—which creates a paradox: by under-reporting, they may end up with more unmet needs[48].

3. Immediate risk of emotional harm

Cuts (and the processes taken to make the cuts) had a profoundly negative emotional impact on disabled people and carers involved in this work.

> *Yeah. It's our lives literally in the hands of other people… And it's in other people's hands that don't know me. Yeah. Don't have a clue about my life. Don't know what I do. (interview with disabled person)*

Loneliness and isolation are strong themes emerging from the evidence. Loneliness was sometimes a result of being denied the opportunity to connect with other people or participate in community life, hobbies or interests. One disabled person shared how community erosion and cuts to her direct payment impacted on her anxiety:

> *My impact is being able to attend youth group at the [centre] which is being shut down due to cuts I'm not sure of the impact on my anxiety that's going to have but also the filming group i attended got shut down due to council cuts which has been very difficult*

> *to adjust to but the cuts to my support staff is even worse it's had a very big impact on my anxiety and it's also impacted my mum… (Email from a disabled person)*

For some people who did not see anyone other than Personal Assistants or support workers, cuts made their home feel lonelier:

> *The support worker (who no longer works with the family) provided not just care, but also company, someone to talk to in a quiet house. That connection is now gone. No one comes anymore. (ISO account)*

Many participants expressed a strong sense of injustice, and a disregard for statutory duties and policy promises. One disabled person described the unfairness of rolling back entitlements to support:

> *I feel that they have put services in place, but now they want to cut them; that's going to really affect people from getting out and living a normal life (interview with a disabled person)*

Disabled people and unpaid carers felt that they needed to justify their support needs and make a case for why they *deserved* support. The process of justifying why support needed to be in place was demoralising and humiliating for disabled people and carers:

> *The lack of support has already taken a visible toll on his behaviour and wellbeing, and this cut will only make matters worse. I love my son with all my heart. My children are my world and everything I have done in my adult life has been for them. My son is the Earth Moon and Stars to us all and to be in a situation where I need to beg for support does not come easily to me. But the fact remains that he deserves a full and enriched life. (Email from an unpaid carer)*

Hopelessness was another theme emerging from the evidence. Disabled people and unpaid carers could not plan for their future or explore their own personal aspirations. Three case studies specifically mention suicidal ideation, and the risks of self-harm. Readers may find the next case study distressing.

Shazad is a 40 year old man who has had all paid supports removed. Consequently, he has experienced suicidal ideation, including a distressing incident where he tried to end his life in public. He has since turned to alcohol, isolates himself, and lives in deteriorating conditions, relying solely on ready meals (case study from an ISO)

Evidence presented in this research demonstrated the systemic devaluation of disabled people - their communities, relationships, contribution and potential. In an interview, one disabled person reflected:

> *Feels like people don't want disabled people around, going back to the days of asylums.*

The breach of trust in relationships with professionals involved in cuts had a lasting impact, causing fear of future interactions or complete disengagement with social work. Some people with lived experience described a fear of being seen to do well, or to become independent as this could lead to a further cut to support. This sits in fundamental tension with independent living.

> *Usually, I've been able to see light and everything… This time, I'm not so sure. Yeah. And that that is scary. (Interview with a disabled person)*

4. Risk to dignity and independence

In addition to the risk of physical and emotional harm was the lack of dignity afforded to disabled people affected by cuts. A disabled person explained in an interview the impact of losing their personal assistant on their home:

> *We're both immunocompromised. I've got leukaemia, and he's sort of got advanced cancer, although it is me who picks up most of well, more bugs than him.,, there's an awful lot of infectious fluids in our house… We need enhanced infection control. [The washing is] sort of just building up in a huge pile because neither of us, like, well, you can't walk, and I can't really manage the washing machine. So, you know, it's just like it's just absurd. (Interview with a disabled person who is also an unpaid carer)*

Some accounts describe how cuts were justified, sometimes suggesting alternatives to paid support that were not fit for purpose. For example, one disabled person had previously employed a Personal Assistant (PA) support to prepare and cook meals is now unable to maintain a healthy diet. She was advised to have food shopping delivered; however, there is no support to put the shopping away, leaving items on the floor which makes it difficult for her to move around her home. This is one of several examples reported in the evidence that frame assessments as ‘problems to be solved’, rather than a holistic view that builds on people’s capabilities.

One case study from an Independent Support Organisation demonstrated how cuts impacted on both disabled people and unpaid carers, resulting in a disabled person living most of his life in bed, and strain on the caring relationship:

Gentleman with advanced MS, he only has limited use of one arm, needs assistance to eat, drink all personal care, medication, finances etc has had his care package reduced so only has a personal assistant 9am till 2pm, from 2pm till 9am the next morning his wife is the sole carer.

But she has been diagnosed with heart failure has been told by her medical team not to carry out moving and handling for her husband due to the risk to her health, this means he is put into bed as hoisted by carers prior to them leaving at 2pm.

His wife still works part time at weekends with adjustments to her job, when she challenged social work regarding cuts she was told she could give up work. Under Carers Act she is entitled to continue to work. This has had a big impact on both her mental health and on his, he feels that he is even more of a burden on her and her health.

5. Financial and legal risks

The working lives of disabled people and unpaid carers were also put at risk because of cuts. Disabled people face increasing barriers to securing adequate funding through Access to Work[49]

One interview explored one person's experience of losing their Access to Work through reassessment and asking to use their direct payment underspend temporarily to support them to continue to work during a process of review of Access to Work funding. This request aligned with the individual's outcomes around employment. The individual frames the importance of work in their lives:

> *It would also put me back in the benefits that I haven't claimed for such a long time. … I'm going month to month at the minute, and that's not good for anybody to work on that regard. (Disabled person, in interview)*

Throughout the evidence, unpaid carers raised concerns that they would be forced out of work because of their caring role[50], as illustrated in the below case study:

Rory is a young man with profound and multiple learning disabilities who lives at home with his mum and siblings. He has very complex needs, but his mum Eva has been proactive in finding him opportunities to be part of the community. The family have been through a difficult time after a period of close bereavement and significant housing insecurity. The transition from children's to adults services has been difficult, disorganized and had an impact on the continuity of support they have received.

Their previous SDS budget only offered support during Eva's working hours (9-5 Mon-Fri 39 weeks per year) Noting her son's distress at transition, and her own health deteriorating, she asked for this to be increased. But in her last review she was given a cut to the budget for Rory.

The impact of this cut has been significant. Rory, who expresses his feelings through behaviour, has been having more aggressive outbursts, unsafe behaviours, running away from home, running in front of cars and has regressed in his confidence. He is anxious and distressed. Eva's mental health is deteriorating, and she is considering leaving work to manage, but worries about how this will impact on her family financially as a single mother of 4.

(Direct account submitted by an unpaid carer)

One case study raised significant concerns about Personal Assistants being made redundant. Arrangements to pay for associated redundancy costs and support to follow proper processes were unclear in this case, demonstrating the significant legal risk associated with terminating employment.

Another legal and financial risk raised was the liability for PA employers who did not have the sufficient budget to send carers on formal training. Some parts of the PA role are extremely specialist, and PAs are reported across case studies as supporting people with complex, changing needs. One ISO questioned whether insurance would be invalidated if insurers became aware that PAs were completing complex tasks without appropriate training.

6. Dependence on unpaid care

The evidence presented suggests an underpinning assumption that carers will 'pick up the slack'. Carers describe a universally poor experience, with a negative impact on their mental and physical wellbeing. Carers report being expected to put their lives on hold, leave work and adjust to significant reductions in support. There are reports of carers being refused access to carers assessments, or having their assessment ignored.

Parent-carers reflected on the impact cuts had on their children's independence. Children, moving into adulthood, wanted to be supported by people other than their parents. But parent-carers felt they could not support transitions into adulthood when there was no alternative support available. One parent reflected that her daughter would never be able to save for a home, or a car, like her siblings, because savings were taken into consideration in social care charging. Another mother reflected on her journey to support her son into independent living, only to be expected to continue the same level of support in his new tenancy:

> *So I just think, why is the expectation back on the carer, the unpaid carer, to provide that support when it actually states in the Carers Act whether you're willing and able.* (Interview with an unpaid carer)

Another carer noted that people who hold direct payments take on significant administrative, training and management duties, without pay, often in addition to direct unpaid care:

> *You're doing all the recruitment. You're doing well, you know, everything that's involved in it. You're doing all the recruitment. You're doing all the inductions. You're doing all the different, you know, supervision, the training, all the different things. You're doing all of that.* (Interview with an unpaid carer)

Disabled people raised concern about the pressure on carers, and the pressure cuts had on the sustainability and of the caring relationship. One disabled person, who lost all access to respite reflected on what this meant for the caring relationship:

> *He has his own struggles as he's autistic and has been diagnosed with high blood pressure due to the stress of the level of care he provides me. Losing access to respite which was vital means he will have added pressure without the option for a break.* (Email from a disabled person)

Most of the carers involved in this study were experiencing significant impacts on their health, wellbeing, independence, finances and relationships.

> *I mean, literally, I have no time for myself whatsoever. Health, I've not been able to work. We've got financial issues. You know, there's a whole a whole host of stuff that's unattended to on the back of me doing everything, and I and I simply can't do it.* (Unpaid carer voice - interview with unpaid carer and supported person)

Unpaid carers are already under increasing financial strain, disproportionately affected by the cost-of-living crisis. The 2024-25 Audit Scotland paper on the *Integration Joint Boards' Finance and performance*[51] identifies the dependence on unpaid carers (Theme 5) as a particular risk for local authorities, stating "*This reliance on unpaid carers is increasing as the social care paid workforce is under increased pressure. This is unsustainable."*

7. Whole system pressures

Some of the evidence submitted described how direct payments, when well supported, could enable effective self-management of long-term conditions. When these are cut, there was a risk of added pressure across the health and social care system:

> *But also since having SDS I've been in hospital 5 times in 5 years compared to at least a few times a month… I'm now going to much higher risk of things such as pressure sores as I will be mostly in the house in bed as I cannot spend all day in my wheelchair due to chronic pain in my hips and spine and a spinal instability* (Email from a disabled person)
>
> *Now last year, we had a very dire situation with him where he was, you know, on the verge of having to be hospitalized. Right? And we're talking like [mental health facility]… So we were on the verge of that happening. But see, because I've got a really, good team round about him. He was really very paranoid, just a whole heap of things going on. But we all stuck together, supported each other, and got him through that. And that then didn't mean that he had to go into hospital. Now if he was in hospital, he would never have come out the same. Never ever. In fact, actually, I doubt if he ever would have came out.* (interview with unpaid carer)

Policy landscape and the levers of influence

The financial struggles facing local authorities are well documented, and present a challenging context in which we can address cuts. However, the focus of this work is the rights of disabled people and unpaid carers as encoded in policy in Scotland. The evidence demonstrates an implementation gap – where the aspirations of policy and strategy across Scotland are not being upheld. In this section we propose a different, rights-based narrative.

Both nationally and locally, human rights-informed approaches to budgeting can guide decision-making by recognising that "budgetary decisions can have materially different outcomes for different groups."[52] This approach requires resource decisions to be assessed for their impact on rights, rather than their cost-saving potential. Within this framing, spending on direct payments can be justified as rights enabling expenditure, while disinvestment may represent a retrogressive measure that requires strong justification under human rights principles. The UN Committee on the Rights of Persons with Disabilities has strongly criticised the UK and Scottish governments over failures to uphold disabled people's rights[53], and the harm described in this paper outlines how this impacts on disabled people and unpaid carer

The table below, outlines existing policy levers and implementation drivers to address cuts to direct payments, intended as a reminder of how direct payments are talked about in legislation, national plans and frameworks. A stark contrast to the evidence presented in this paper, but an opportunity to influence change.

> *Disabled people's rights are not being taken into account. Rights are being stripped, which will only lead to negative outcomes (disabled person in interview)*

Legislation / Framework	What this means in relation to SDS Option 1 (direct payments)
UN Convention on the Rights of Persons with Disabilities (CRPD), Article 19	Article 19 establishes a clear right to independent living and community inclusion. SDS Option 1 is a key mechanism for realising this right by enabling disabled people to choose how support is arranged, who provides it, and how it fits their lives. Restricting or removing Option 1 risks undermining Scotland's compliance with Article 19.
Human Rights Act 1998 (incorporating ECHR)	The act protects rights such as respect for private and family life (Article 8). SDS Option 1 supports these rights by enabling personalised support arrangements that respect autonomy, dignity, relationships and home life. Inflexible or imposed care models may interfere with these rights, particularly as they relate to the role of unpaid carers.
Equality Act 2010	The act requires public bodies to advance equality and make reasonable adjustments to prevent discrimination and ensure equal access and treatment in services like social care, health, and education. Removing or limiting Option 1 may disproportionately disadvantage some disabled people and unpaid carers.
Social Care (Self-directed Support) (Scotland) Act 2013 and accompanying Statutory Guidance	This legislation and accompanying statutory guidance places a legal duty on local authorities to offer all four SDS options, including Option 1. The Act embeds principles of choice, control, involvement and collaboration. Option 1 is the most direct expression of these principles, particularly for people who want maximum flexibility and autonomy.

Legislation / Framework	What this means in relation to SDS Option 1 (direct payments)
Health and Social Care Standards (2018)	These standards state that people should experience care that is person-centred, respectful, and responsive to what matters to them. SDS Option 1 enables compliance with these standards by allowing individuals to directly shape their support and outcomes. Reduced access to Option 1 risks more task based, less responsive care. Additionally, the methods used to cut direct payments sit in tension with the principles in the standards.
Health and Social Care Services Renewal Framework	This framework focuses on prevention, early intervention and community-based support. SDS Option 1 aligns with this by enabling flexible, preventative support that sustains independence and reduces reliance on crisis or institutional care. Cuts are a threat to these approaches, particularly when justified through an eligibility lens.
Disability Equality Plan 2025	Developed in collaboration with three Disabled People's Organisations, this plan commits to removing structural barriers and advancing disabled people's freedom, dignity, choice, and control over their lives. Cuts to Option 1 risk contradicting stated equality objectives.
National Care Service (Scotland) Bill	While direct payments are not explicitly mentioned in this bill, the legislation aims to ensure that social care is delivered with human rights at the centre, respecting dignity and improving wellbeing. The legislation puts forward a plan to co-design a Charter of Rights and Responsibilities for social care and a robust complaints and redress system for people who rely on care and support.

Recommendations

The evidence presented in this report reveals a stark gap between Scotland's policy commitments and the lived experiences of disabled people and unpaid carers. Cuts to direct payments are stripping away the very principles Scotland's social care system was built on—choice, control, and independent living. The evidence in this report shows that these cuts are causing real harm: disabled people and unpaid carers are losing essential support, facing increased isolation, and being pushed into poverty. This is not just a policy failure; it is a human rights issue. Scotland has committed to a rights-based approach to social care, yet current practice falls far short. The recommendations call for immediate action to stop harmful cuts, reinstate support, and ensure that Self-directed Support delivers on its promise of dignity, autonomy, and fairness for all.

1. Improve the use of data across the Self-directed Support system in line with Recommendation 4.2[54] of the Self-directed Support Improvement plan focusing on information, choice and quality of options.
2. Recognise the harm being caused to disabled people and unpaid carers and stop cuts to direct payments immediately.
3. Where cuts have been made without appropriate assessment of potential harm, or the involvement of disabled people and unpaid carers, reinstate these direct payments immediately.
4. Undertake equality impact assessments of cuts to date, to understand the impact of cuts across specific groups of people accessing direct payments, including those whose voices may not have been represented in this research.
5. Prioritise the reform of eligibility criteria nationally, in line with commitment laid out in the COSLA and Scottish Government Joint Statement of Intent.[55]
6. Prioritise the reform of complaints procedures, prioritising a fair, effective and consistent approach to complaints and redress with appropriate and timely access to advocacy[56].
7. Stop non-residential social care charging nationally and locally to ensure that disabled people are not excluded from accessing social care, and pushed further into poverty.
8. Re-align practice around direct payments to existing statutory duty and best practice guidance, focusing on enabling flexibility in the use of direct payments and increasing transparency and accountability as per SDS Standards.
9. Invest in a rights-based approach to budgets, recognising the multiple marginalisation of disabled people and unpaid carers.

This is a collective responsibility. By working together, we can close the gap between policy and practice, restore confidence in Self-directed Support, and deliver on the promise of a fair, inclusive, and rights-driven social care system for Scotland by:

- Championing a rights-based approach to social care, ensuring that every decision respects the dignity and autonomy of disabled people and unpaid carers.
- Working collaboratively across sector, including local authorities, government, independent support organisations, disabled people's organisations and the Independent Living Movement, to implement the recommendations in this report.
- Stewarding systemic change, moving beyond short-term fixes to embed sustainable, person-centred solutions that uphold Scotland's policy commitments and human rights obligations.
- Ensuring accountability and transparency, creating clear pathways for participation, feedback, and redress for those affected by cuts.
- Investing in trust and relationships, recognising that meaningful change depends on listening to and acting alongside people with lived experience.

Acknowledgements

This work was undertaken over a period of three months in order to action change as quickly as possible. We are grateful for the trust placed in us by disabled people, unpaid carers, independent support organisation and sector partners.

Appendix 1

The impacts of cuts to Self-directed Support direct payments.

Evidence from people with lived and loved experience

The Self-directed Support Team at Social Work Scotland are hearing reports that in some areas, people who get their support through self-directed support option 1 (Direct Payments) are having their support budgets reviewed and reduced. This has an impact on disabled people, families, employers of personal assistants, personal assistants and unpaid carers who need the support and budgets to support independent living.

We want to have evidence of this impact for a short research paper which will be put together by our trusted independent researcher Rhiann McLean. The paper will help inform a 'call for action' which we will take to leadership in Scotland.

We are working together with the National Care Service Advisory Board and the Self-directed Support National Collaboration who are also collecting evidence on the impacts of cuts to the budgets of people with lived and loved experience.

We are very grateful for your help in gathering this evidence and acknowledge that it isn't easy to tell difficult, personal stories.

All the data will be treated with respect and in confidence and names and areas will be removed to support anonymity.

We need all evidence by Friday 17th October and we include a template to help you to think about your experience.

Thank you

Please return to

Donna.murray@socialworkscotland.org or Rhiann@threesistersconsultancy.org

You can write about your experience in any way that you like. You might want to think about the following questions:

- What has happened?
- What is your biggest concern about what has happened?
- What immediate impact will it have for you?
- What longer term impact do you think it will have for you?
- How do you feel about what has happened?
- What do you want to happen now?

Write about you experience here

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