Self Directed
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Changes to Self-directed Support Direct Payments in Scotland

2026

Contents

Executive Summary

This research was undertaken by Self-directed Support Scotland (SDSS) to explore how Direct Payments (DPs) are currently being experienced and implemented across Scotland. Bringing together the perspectives of Independent Support Organisations (ISOs), disabled people and unpaid carers, the study sought to understand emerging challenges, identify their impacts and contribute evidence to ongoing discussions about the implementation of Self-directed Support (SDS), and to our knowledge is the first national Scottish study of this nature.

The research combined three sources of evidence: a national survey of 137 staff working within ISOs across Scotland; 5 focus groups involving 17 ISO staff; and 4 focus groups involving 17 disabled people and unpaid carers with experience of Direct Payments. The research was co-designed with people with lived expertise and ISOs.

Survey respondents and focus group participants described increasing reductions, restrictions and administrative barriers affecting DPs. Eighty-two per cent of survey respondents reported that changes to DP packages had become more frequent in their area of work. The most commonly reported changes included reductions following reviews or reassessments (74%), restrictions on how funds could be used (66%), delays in reviews or budget setting (61%), reclaiming unspent funds (61%) and changes to local eligibility criteria (61%).

The findings suggest that concerns relate not only to the level of support available, but also to how SDS is interpreted, implemented and experienced in practice. Participants described changes occurring across multiple stages of the SDS journey, including access to support, assessments, reviews, decision-making processes, budget allocation, flexibility of spend, recruitment of Personal Assistants (PAs) and the ongoing management of DPs.

Several themes emerged consistently across the research:

- Participants described a perceived shift towards higher eligibility thresholds, reduced access to preventative support and increasing focus on crisis intervention.
- Support was increasingly described as focused on essential care tasks, risk management and personal care, with less emphasis on participation, independence, community involvement and wider quality-of-life outcomes.
- Assessments and reviews were frequently described as difficult to navigate, slow to respond to changing circumstances and increasingly associated with anxiety, uncertainty and the possibility of support reductions.
- Participants raised concerns regarding transparency, consistency and accountability in decision-making, including significant variation between local authority areas.
- Many participants described increasing restrictions on how DPs could be used and reduced flexibility in achieving agreed outcomes.
- Recruitment and retention of PAs was identified as a major challenge, with some participants reporting situations where approved support could not be fully used because suitable staff could not be recruited.

- Disabled people, unpaid carers and ISOs described taking on increasing responsibility for navigating systems, maintaining support arrangements and responding to gaps elsewhere in the system.

Participants described impacts extending far beyond individual decisions about support packages. Disabled people described reduced independence, increased social isolation and fewer opportunities to participate in family, community, educational and employment activities. Unpaid carers described increasing caring responsibilities, loss of respite, impacts on employment and family life, and growing responsibility for managing DP arrangements and PAs. ISOs reported increasing workload, growing complexity of casework, emotional strain on staff and concerns regarding the long-term sustainability of current ways of working. Many described spending increasing amounts of time supporting people through reviews, reassessments, complaints, appeals and complex employment issues.

The findings should be understood within the wider context of workforce shortages, increasing demand and financial pressures affecting social care across Scotland. However, the evidence suggests that resource pressures alone do not account for many of the concerns raised. Recurring issues relating to communication, transparency, accountability, consistency, flexibility and partnership working point to implementation challenges that warrant attention alongside wider discussions regarding funding and capacity.

Taken together, the findings suggest that current concerns regarding DPs are not solely about the level of support available, but also about how SDS is being implemented and experienced in practice. The reported impacts on independence, participation, wellbeing, family life and support organisations indicate that these issues require careful consideration across policy and practice.

Summary of Recommendations

1. Strengthen flexible, informed and outcome-focused Direct Payment practice
2. Improve the quality, consistency, and transparency of policies and procedures
3. Strengthen availability and access to independent support, advocacy and brokerage
4. Improve evidence, monitoring and shared learning on Direct Payment implementation

Methodology

Research Aim and Questions

The overall aim of this research was to understand how changes to SDS Direct Payment (DP) (Option 1) packages are being implemented and experienced across Scotland from the perspective of Independent Support Organisations (ISOs), disabled people, unpaid carers and related services.

The research explored the following questions:

- What types of changes to DP packages are being observed across Scotland?
- How are these changes being implemented in practice?
- What impacts are being observed for disabled people, unpaid carers and families?
- Which groups appear to be most affected?
- How are these changes affecting ISO staff, teams and organisations?
- What examples of better practice, potential improvements or alternative approaches are identified by participants?
- How might evidence on DP implementation and experiences be gathered more effectively on an ongoing basis to inform policy and practice?

Research Design

This study used a mixed-methods design combining a national survey of Independent Support Organisations (ISOs) and related services with a programme of qualitative focus groups involving both ISO staff and people with lived experience of Direct Payments (DPs).

The ISO survey was co-designed with ISO staff members, the project reference group and the SDSS team. The focus group discussion guides were similarly developed through consultation with ISO staff and people with lived experience of DPs through a series of preparatory one-to-one discussions.

Survey Distribution and Participation

An anonymous online survey was open between 2 and 15 March 2026. Participation was open to staff working within ISOs, Disabled People’s Organisations (DPOs), brokerage organisations and related services across Scotland.

The survey was distributed through SDSS mailing lists, partner organisation networks, direct organisational contact, social media, sector communications, and conferences and events. Multiple responses from the same organisation were permitted to capture a range of frontline and managerial perspectives.

A total of 137 responses were received. Respondents included frontline advisers and support workers (75), managers and team leaders (34), senior managers (16), and office or operational staff (12). Responses were received from staff in 30 Health and Social Care Partnership (HSCP) areas across Scotland, including rural, urban and island communities. Respondents worked with a broad range of groups, including disabled adults, disabled children and young people, unpaid carers, people living with dementia, people in rural and remote communities, people facing digital barriers, and people who speak English as an additional language.

Focus Group Recruitment and Participation

Focus group participants were recruited through several routes. ISO survey respondents who had expressed interest in further research, via a separate form from anonymous survey responses, were contacted directly and participating organisations were invited to arrange focus groups involving multiple staff members. An additional open invitation for ISO staff was circulated through SDSS communications and networks.

To recruit people with lived experience, participating organisations were provided with information and booking links to share with disabled people, unpaid carers and other DP recipients within their networks. Participation was voluntary and based on self-selection.

A total of nine online focus groups were conducted via Microsoft Teams between 13 and 26 May 2026. Five groups involved ISO staff and four groups involved people with lived experience of DPs. Thirty-four participants took part across the nine groups, including 17 ISO staff and 17 people with lived experience.

The ISO participants included frontline advisers, support workers, managers and senior managers from organisations providing independent support and related services across Scotland.

The 17 lived experience participants comprised of 6 disabled people, 8 unpaid carers, and 3 disabled unpaid carers.

This enabled the research to capture perspectives from people receiving DPs directly, those providing unpaid support to those with a DP, and participants with experience of both roles.

Volunteer participants with lived experience received a £20 payment in recognition of their time and expertise.

Data Collection

The survey explored the types of changes to Direct Payment (DP) packages being observed across Scotland, how these changes were being implemented, their impacts on disabled people, unpaid carers and families, and their effects on ISO staff and organisations. Respondents were also invited to identify examples of better practice and potential improvements.

Each focus group session lasted approximately one hour and followed a semi-structured discussion guide informed by the research questions, survey findings and preparatory consultation discussions.

Discussions explored participants' experiences of DP changes, how these changes were being implemented in practice, their impacts on individuals, families and organisations, and examples of better practice or potential improvements. Additional questions were included within the ISO groups regarding impacts on staff, teams and organisations.

Participants were able to contribute verbally or through the meeting chat function. Advance information about the research, participation arrangements and payment was provided through recruitment materials and booking forms. Participants were also invited to identify any accessibility or support requirements before participation.

Data Analysis and Integration

Quantitative survey data were analysed descriptively using frequencies and percentages. Qualitative survey responses and focus group transcripts were analysed using reflexive thematic analysis informed by Braun and Clarke's methodology. The analysis combined deductive and inductive approaches. Deductive coding explored the research questions relating to DP changes, implementation mechanisms and impacts, while inductive coding enabled the identification of new issues, experiences and recommendations emerging from the data. Analysis was iterative and involved repeated engagement with survey responses, transcripts, codes and themes. Themes were reviewed and refined throughout the analytical process. Following separate analysis of the survey and focus group datasets, findings were compared and integrated through thematic synthesis.

Ethics, Data Protection and Reflexivity

Ethical considerations were embedded throughout the design, delivery and analysis of the research. Participation was voluntary and participants received information about the purpose of the research, how information would be used, confidentiality arrangements and payment arrangements before taking part. All focus group participants provided informed consent as part of the booking process.

Survey responses were anonymous. Focus group transcripts were pseudonymised during analysis and reporting. Identifying information relating to individuals, organisations and local circumstances was removed or generalised where necessary to reduce the risk of identification.

A Data Protection Impact Assessment (DPIA) was completed to support the use of digital and AI-assisted tools within the project. Data protection arrangements were reviewed through project governance processes, including discussion with the project reference group. Particular consideration was given to confidentiality, secure storage, data minimisation, retention periods and the handling of potentially identifiable qualitative information. The use of AI-assisted tools was considered as part of the DPIA process and associated risk mitigation measures.

Microsoft Teams was used for online meetings and recordings. Fellow was used to support transcription and meeting summaries. ChatGPT business was used to assist with transcript preparation, coding exploration, thematic development and synthesis. AI-generated outputs were treated as analytical support tools rather than findings. All analytical decisions, interpretation, theme development and reporting remained the responsibility of the researcher. AI-generated outputs were critically reviewed and refined throughout the analysis process and were subject to ongoing discussion and challenge through engagement with the project reference group and SDSS senior management team.

The research was informed by both professional and lived experience perspectives. Alongside their role within the SDS sector, the researcher has direct experience of DPs as an unpaid carer supporting an adult family member who employs a PA through a DP arrangement. This provided valuable contextual understanding of the issues explored throughout the study while reinforcing the importance of reflexive engagement during data collection, analysis and interpretation.

The development of research tools, interpretation of findings and ongoing project discussions were informed by input from ISO staff, people with lived experience, the project reference group and the SDSS team. As with all qualitative research, interpretation involved an element of researcher judgement. Reflexivity was supported through iterative reflection, engagement with multiple perspectives and critical review of emerging findings throughout the project.

Strengths and Limitations

The study combined national survey evidence with in-depth qualitative discussion, enabling exploration of both breadth and depth across a wide range of experiences and organisational contexts. The inclusion of both ISO staff and people with lived experience strengthened the research through triangulation of perspectives and comparison across different sources of evidence.

As with all voluntary participation research, the findings may reflect higher participation from individuals and organisations with particular experiences or concerns regarding current DP implementation, and should not be interpreted as statistically representative of practice across Scotland. Focus groups provide insight into participants’ experiences and perceptions but cannot establish prevalence. Similarly, survey findings reflect respondents’ observations and experiences rather than independently verified administrative data. Despite these limitations, the consistency of findings across participant groups, geographical areas and research methods provides strong evidence of recurring patterns and shared concerns across Scotland.

Extent and Nature of Reported Changes

Survey respondents described widespread concern regarding changes to Direct Payment (DP) packages across Scotland. The vast majority of 137 Independent Support Organisation (ISO) survey respondents (82%) reported that changes to DP packages had become more frequent in their area of work.

While respondents often described these experiences collectively as “changes” to DPs, the findings suggest several distinct but interconnected types of implementation change emerging across Scotland. These included:

- direct reductions in funded support, such as reduced budgets, hours or staffing;
- administrative and procedural barriers, including delays, reassessments, suspensions and lack of transparency;
- and narrowing interpretations of SDS in practice, particularly through reduced flexibility, restrictions on social support and more limited understandings of eligible need.

The most commonly reported changes included:

- reductions following reviews or reassessments – 102 respondents (74%)
- restrictions on how funds can be used – 90 respondents (66%)
- delays in reviews or budget setting – 84 respondents (61%)
- reclaiming unspent funds – 84 respondents (61%)
- changes to local eligibility criteria – 83 respondents (61%)
- reductions without review or reassessment – 64 respondents (47%)
- changes to charging policies – 38 respondents (28%)

Only 5 respondents reported observing no significant change.

The data also suggested that respondents perceived these changes as increasing over time. 48 respondents reported first noticing these changes more than a year ago, while many others described significant escalation during the previous 6–12 months.

Concern levels were high across the sample:

- 59 respondents described the situation as “urgent; requires immediate attention”

- 39 respondents described “significant concern; needs attention soon”

No respondents described the overall impact as positive.

Mechanisms of Reductions, Restrictions and Other Barriers Across the SDS Journey

The Social Care (Self-directed Support) (Scotland) Act 2013 and accompanying statutory guidance sets out processes intended to support involvement in decision-making, informed choice, flexibility and outcomes-focused support planning. Respondents, however, described increasing concern regarding reductions, restrictions and administrative barriers emerging across multiple stages of the SDS process. The findings below are organised broadly around stages of a typical SDS journey to examine how these developments were being implemented in practice.

Accessing Support: Eligibility

Free personal care in Scotland should be available to adults of any age who are assessed by their local authority as needing personal care, regardless of income, capital or condition. The Scottish Government describes personal care as support with tasks such as “personal hygiene”, support “at mealtimes”, “immobility problems”, “medication” and “general wellbeing” (Scottish Government, 2024). It also notes help with “housework, laundry or shopping” and services outside the home, such as day care centre costs, are not defined as personal care and may be chargeable following financial assessment, dependent on individual Local Authority (LA) policy (Scottish Government, 2024).

The Self-directed Support (SDS) Statutory Guidance says eligibility criteria should not operate only as a crisis threshold. LAs should target resources towards adults at “critical or substantial risk” while “not excluding consideration of the benefits of preventative support and less intensive care services for people at less risk”. For adults, the authority has a duty to conduct an assessment of needs for community care services. For carers, LAs must offer an adult carer support plan or young carer statement and must provide support where the carer’s identified needs meet local eligibility criteria. LAs also have power to provide support for needs that do not meet those criteria (Scottish Government, 2025).

Eligibility emerged as one of the strongest areas of convergence across the survey, Independent Support Organisation (ISO) focus groups and lived experience focus groups. While concerns about access to social care and SDS were not new, participants across all three datasets described what they perceived as a shift towards higher eligibility thresholds, narrower interpretations of need and increasing variation in how eligibility criteria were applied in practice. Taken together, the findings suggest that eligibility is not only determining who receives support in practice but increasingly shaping the types of need recognised as legitimate, the outcomes considered important, and the circumstances under which support becomes available.

Restrictive Eligibility Thresholds and the Erosion of Preventative Support

Across all three datasets, participants described a perceived shift towards higher eligibility thresholds and increasing reliance on crisis-based approaches to decision-making. Participants frequently contrasted current practice with the preventative principles underpinning SDS. Rather than support being used to maintain independence, wellbeing and participation, many described situations in which support was only considered once circumstances had significantly deteriorated. ISO participants described increasing difficulty securing support where needs had not yet reached crisis point, even where earlier intervention might have prevented escalation. Several described supporting people who, in their view, would previously have met local eligibility criteria or secured increases to existing support packages in the past, but who were now being assessed as ineligible or told that their circumstances did not meet local thresholds. Participants viewed these experiences as evidence of increasingly restrictive interpretations of eligibility and a growing focus on managing only the most acute levels of need. ISO participants explained:

> *"People are isolated, struggling mentally, families are at breaking point, but because they are surviving somehow, they are not considered critical."*

> *"Everything is about crisis now. If somebody is not at immediate risk, then they are often told they don't meet the threshold."*

> *"People have to become incredibly unwell before anything meaningful happens. It feels like preventative support has disappeared."*

Several ISO participants described situations in which concerns had been repeatedly raised with social work teams, requests for reassessment had been made, and evidence of deteriorating circumstances had been provided, but additional support was not agreed. One survey respondent reported having to raise Adult Support and Protection concerns where individuals appeared to be at risk because appropriate support was not in place. One ISO participant stated:

> *"I have had experience of a young adult with additional support needs and a history of poor mental health (including attempts to take their own life) applying for SDS funding only to be told they don't meet the critical criteria. This left the young person very low in mood and actively suicidal, it put increased pressure and stress on their mother as their unpaid carer but the decision was upheld."*

Narrowing Interpretations of Need and Outcomes

Alongside concerns about eligibility thresholds, participants described changes in what was recognised as a legitimate reason for support. Across the survey and focus groups, there was a perception that support was increasingly framed around personal care and risk management, while broader outcomes associated with independent living increasingly difficult to secure support for. ISO respondents commented:

> *"People without physical care needs are almost punished for asking for support to go out or take part in the community."*
>
> *"Support is increasingly about keeping people alive rather than helping them live. It's really sad because this isn't what Direct Payments were supposed to be."*

A small number of examples also suggested that visible participation or independence could sometimes be interpreted in ways that concerned participants. One ISO participant described the experience of a young disabled woman whose support package was reportedly reduced after social work viewed a video of her taking part in a fitness activity. Staff described the impact on her confidence and wellbeing and viewed the case as illustrating wider concerns about how participation and independence could be interpreted within decisions about support.

> *"She just feels vulnerable [and] feels that everybody's looking at her now and seeing that she's trying to cheat the system."*

Disproportionate Impacts of Current Eligibility Systems

Participants also raised concerns that current eligibility approaches have increased impacts on specific groups of people. While these concerns were not necessarily described as new, participants suggested that increasingly restrictive eligibility thresholds and narrower interpretations of support could have disproportionate consequences for some groups, including autistic people, people with learning disabilities, people experiencing mental ill health, older people, individuals experiencing social isolation and people with complex or intersecting support needs. This aligns with SDSS's wider evidence base in recent years on barriers to SDS for specific groups, including autistic people, people living with dementia, and those who use alcohol and other drugs (SDSS, 2025b; SDSS, 2025c), and with the Post-Legislative Scrutiny of SDS' findings on variation in SDS implementation between areas and care groups (Scottish Parliament, 2024).

Lived experience participants frequently described difficulties explaining the realities of daily life within assessment and eligibility processes. Participants highlighted particular challenges associated with fluctuating conditions, fatigue, emotional wellbeing and forms of need that were not always immediately visible. Participants did not suggest that these groups were excluded from support altogether. Rather, they described concerns that some forms of need fit less easily within eligibility system. Several felt that eligibility systems were often better equipped to recognise needs that were observable, measurable or closely linked to personal care. As one participant explained:

> *"A lot of the reality of daily life never seems to fit neatly into assessments."*

Growing Postcode Lottery in Access to Support

Across the ISO and lived experience focus groups, participants repeatedly described variation in how eligibility criteria and SDS principles were applied across Scotland. While local variation has long been recognised within social care systems, including within the Post-Legislative Scrutiny of SDS, many participants felt that differences between areas were becoming increasingly pronounced (Scottish Parliament, 2024).

Participants described examples where people with similar circumstances appeared to receive very different outcomes depending on which local authority was responsible for decision-making, how local eligibility criteria is interpreted, or which team or practitioner was involved. Several participants felt that outcomes could depend as much on local interpretation and organisational culture as on the circumstances being assessed. For participants who had experience of moving between local authority areas, these differences could involve reassessments, delays and different decisions about eligibility and support.

Participants also described variation in how SDS guidance was interpreted in practice. Some areas were perceived as working with individuals to identify solutions and maximise choice and control, while others were described as applying eligibility criteria more narrowly and acting primarily as gatekeepers to limited resources. One ISO participant summarised this contrast by stating:

> *"It's like two completely different systems depending on where you live. One area will actually work with people to try and make things happen, and the other feels like constant gatekeeping."*

Assessments and Reviews

Assessment processes under SDS are intended to be collaborative, person-centred and focused on identifying individual outcomes and support needs. The SDS statutory guidance states that, when carrying out an assessment, social workers should consider “the whole experience of the supported person” and “the needs and the outcomes of the person”, with risk managed “in an enabling and positive way”. Authorities must take reasonable steps to help the person “play a full part in their assessment”, understand the choices available, and decide how they want to arrange their support. Assessment should be based on an outcomes-focused approach that supports the person to take control, rather than as a passive recipient of services (Scottish Government, 2025).

Review processes within SDS are intended to ensure that support arrangements continue to reflect people’s needs and outcomes over time through ongoing involvement and collaborative discussion. The SDS Statutory Guidance states that changes to Direct Payments or budgets should be discussed with the person and grounded in assessed needs and outcomes. It also states that any budget change should have “a sound rationale” that is “clearly communicated” according to the person’s preferences, with “sufficient notice” unless there are exceptional circumstances (Scottish Government, 2025).

Assessments and reviews emerged as one of the most consistently discussed aspects of the SDS process across the survey, Independent Support Organisation (ISO) focus groups and lived experience focus groups. Participants described difficulties securing assessments, reviews and changes to support, alongside concerns about how decisions were reached and implemented. While challenges navigating assessment processes were not new, participants across all three datasets described increasing effort being required to secure, maintain or change support.

High Amount of Energy Required to Engage in Assessment and Review Processes

Across the survey and focus groups, participants described assessment and review processes that were often difficult to navigate, slow to respond to changing circumstances and heavily dependent on individual persistence. Many participants felt that securing changes to support frequently required repeated requests, sometimes over months or years, for reassessment and ongoing efforts to ensure concerns were acted upon.

A recurring theme across the lived experience groups was that access to support often depended on an individual's ability to “keep fighting”. Several felt persistence itself could influence outcomes, creating inequalities between those who had the confidence, knowledge or support to continue challenging decisions and those who did not. One participant described the effort required to secure a promised increase in support:

> *"It took three years to get the increase we had been promised. I repeatedly contacted the social work assistant and fought continuously to get the support increased."*

Need to Reassert Needs that Have Already Been Assessed or Communicated

Participants described repeatedly having to prove needs that had already been recognised. Across the lived experience and ISO groups, participants reported being asked to provide information multiple times, justify ongoing support, and revisit issues that they felt had already been established through previous assessments. Some described this as exhausting and demoralising, particularly where circumstances had not fundamentally changed. This was particularly difficult for those lifelong or progressive conditions. Disabled people stated:

> *"Social work had effectively signed me off and that I no longer had a named social worker. Now, whenever I need support or reassessment, I have to begin the process again through a new referral despite having a lifelong degenerative condition."*

> *"Every stage feels like starting again and having to prove everything from scratch."*

Reassessments or reviews not occuring responsively or proactively

Many participants felt assessment and review processes did not always respond well to changing and complex realities. Lived experience participants described circumstances where support had failed to adapt to changing needs, changing family circumstances, or increased caring responsibilities. Participants described lengthy delays between identifying a need for change and any action being taken.

Concerns about continuity and responsiveness were particularly evident during transitions to adult services. Participants described reassessment processes that created uncertainty, delays and disruption at a point when support needs were often changing significantly. Several described support arrangements failing to keep pace with changing circumstances, resulting in young people entering adulthood with packages that no longer reflected their needs. ISO participants explained:

> *"When [clients] move into adult services everything changes and families suddenly find themselves fighting all over again."*

> *"Transitions are traumatising for some families."*

> *"When children are transitioning into adult services they seem to be getting told that the support they have has to stop."*

A mother stated:

"He first started getting direct payments as an eight-year-old child and he's now 22, and we still have four hours a week. As my son has grown older, his needs have changed significantly; [his] outcomes [...] are completely redundant now but he has never been properly reassessed."

Reviews Increasingly Experienced as a Source of Risk, Rather Than Support

Alongside concerns about the practical challenges of assessment and review processes, participants described a significant shift in how reviews themselves were experienced. Rather than being viewed as opportunities to discuss changing circumstances and ensure support remained appropriate, reviews were increasingly described as exercises focused on reassessing existing support and identifying potential reductions. Participants repeatedly described a shift in the purpose and perceived function of reviews. One ISO participant stated:

> *"The whole tone around reassessment has changed."*

Lived experience participants provided some of the strongest examples of the emotional impact associated with reviews. Participants described severe anxiety before reassessments, loss of sleep, and persistent worry about what might happen to existing support arrangements. One participant described experiencing two weeks of night terrors while preparing for a review that required her to explain the worst possible consequences of losing support. Other lived experience participants explained:

> *"The last proper review we received was in 2017. Since the pandemic my daughter's needs have changed significantly, but I feel frightened about requesting a reassessment because [...] support could be reduced."*
>
> *"I avoid requesting any changes or reviews [...] in case raising concerns risks destabilising the support we already have."*
>
> *"Reviews feel like something you survive rather than something supportive."*

ISO participants had also observed avoidance of requesting reviews, contacting services, or reporting changes to circumstances because they feared the potential consequences. ISO participants explained:

> *"People are frightened to ask for reassessment because they think they'll lose what little they already have."*
>
> *"We've got clients [with] support plans [that] were a bit more flexible. And they have said to me, 'I don't want social work anywhere near us because they're just going to cut the package.'"*

Decision making and influencing changes

SDS Statutory Guidance states that supported people should “have enough information” to understand what is available and to make choices that are right for them, including information about independent support. The statutory guidance is clear that supported people should be actively involved in decisions about their support. It states that people should “have a say in planning what their support looks like” and have “as much involvement as they want in decisions about their support”. The guidance also defines involvement as the principle that the supported person “must have as much involvement as the person wishes” in both assessment and the provision of support. This is closely linked to informed choice and collaboration, with authorities expected to understand what outcomes matter most to the person and the level of choice and control they want. It also says people should have opportunities to “challenge and ask questions” about any aspect of their support, particularly when support is being stopped or changed (Scottish Government, 2025).

Across the research, participants described growing concerns about transparency, communication and accountability within Direct Payment (DP) systems. While the principles of Self-directed Support (SDS) emphasise informed choice, participation and the ability to challenge decisions, many participants reported difficulties understanding how decisions were made, influencing decision-making processes and securing effective responses when concerns were raised. These experiences were frequently linked to wider concerns about consistency, fairness and the practical accessibility of rights within the SDS system.

Opaque Procedures and Decision-Making Processes

Participants frequently distinguished between the principles of SDS and their experiences of how SDS was being implemented in practice. Across the datasets, concerns about communication, information, and decision-making were closely linked to wider questions regarding fairness, accountability, and consistency. Participants across the survey and focus groups also raised concerns about how decisions were made following assessments and reviews. A recurring theme was a perceived disconnect between assessment conversations, professional recommendations, and final decisions regarding support.

Indeed, participants described a growing emphasis on immediate safety, risk and crisis management, alongside a reduced focus on prevention. This was illustrated by examples of small support packages that enabled people to participate in their communities being removed because they were no longer considered essential.

ISO participants in particular described increasing use of panel processes and internal decision-making structures. Several felt that social workers were becoming less able to influence outcomes, even where they understood an individual's circumstances and supported requests for additional support. Participants described situations in which assessments appeared to identify needs, but decisions made later through internal processes did not reflect those recommendations. Some ISO participants felt that social workers themselves were frustrated by these arrangements. Staff described practitioners carrying out assessments and reviews but having limited influence over final decisions. This was viewed as contributing to delays, confusion and a growing disconnect between assessment discussions and eventual outcomes. ISO participants stated:

> *“The social workers are saying: ‘actually, we think that you need 10 hours worth of support, but we are going to put through 15 hours so that when they decline it, they’ll maybe decline it to 10’. They’re having to play the system.”*

> *“It’s not the individual social workers that are making the decisions, it’s the managers, that’s the panel.”*

> *“Everything has to go through a panel now. Your social worker does their support plan, and says: ‘this is what I think the person needs’. It gets picked to pieces by this panel.”*

Participants also raised concerns about transparency. Across the datasets, some felt it was becoming increasingly difficult to understand how decisions were reached, why recommendations were accepted or rejected, and what factors had influenced final outcomes. Several described decisions appearing disconnected from the assessment process itself. ISO participants also described significant changes in their relationships with local authorities. Several contrasted current experiences with earlier periods of partnership working, where ISOs had been able to work directly with social work teams and managers to resolve concerns and explore solutions. Participants described increasing difficulty discussing decisions with decision-makers, securing responses from managers, or resolving disagreements through established professional relationships.

Participants repeatedly suggested that the issue was not simply disagreement with decisions themselves, but difficulty understanding how those decisions had been reached. Several described situations where restrictive decisions were attributed to "policy" or "procedure" without clear explanations being provided. ISO participants reflected:

> *"Nobody really seems able to explain where some of these decisions are actually coming from. They don't have the policies to back up their decisions."*

> *"Very woolly boundaries that are not solid at all."*

Lack of Consistency in Decision-Making

Participants described variation not only between local authorities, but also between teams within the same authority and, in some cases, between departments applying different interpretations to similar circumstances. Several questioned why people with comparable situations appeared to receive different decisions depending on where they lived or who was involved in decision-making.

Examples included different decisions being made regarding the employment of family members as Personal Assistants (PAs) under apparently similar circumstances. Participants described these experiences as contributing to a perception that SDS decision-making could be difficult to predict and inconsistently applied. As one ISO and one lived experience participant observed, respectively:

> *"It depends massively on the culture of the area. In one area there's at least a conversation. In the other it's just shut down immediately."*

> *"It completely depends on who you get and what their interpretation is."*

Barriers to Challenging Decisions and Making Complaints

Across the datasets, participants repeatedly suggested that the ability to challenge decisions was not equally distributed. While formal routes for complaints, reviews and appeals existed, participants described outcomes often being shaped by confidence, persistence, knowledge and access to advocacy. ISO staff described many people accepting decisions they believed were unfair because they felt exhausted, intimidated by the process or fearful of potential repercussions.

A recurring concern was that people with similar levels of need could experience different outcomes depending on their ability to navigate complex systems over extended periods. ISO participants observed:

> *"Those who have the confidence and the self-efficacy to fight and challenge, they might get there and others won't."*

> *"If you are articulate and persistent, you are more likely to get somewhere."*

ISO Participants also highlighted the emotional consequences of challenging decisions. Some described people becoming reluctant to question decisions because they feared negative consequences or further instability.

> *"People are scared of rocking the boat."*

These concerns closely mirrored findings from the lived experience groups, where participants repeatedly described lengthy efforts to secure support, repeated reassessments and ongoing battles to obtain information or challenge decisions. Several questioned what happened to people who lacked the confidence, knowledge, time or emotional energy required to sustain these efforts. One person observed:

"Many families do not have the energy, confidence, or skills to keep fighting."

However, some participants acknowledged that some people have 'no choice' but continue to challenge decisions being made. One participant noted:

"Some families fight constantly because they have no choice."

Participants also raised concerns about the practical accessibility and effectiveness of challenge mechanisms. While formal complaints procedures, reviews and legal routes existed, many questioned whether these provided meaningful opportunities for independent scrutiny in practice. ISO participants described complaints processes as lengthy, difficult to navigate and often ineffective. Several expressed concern that decisions were frequently reviewed by the same organisations that had originally made them, limiting confidence in the independence of the process. Others questioned whether formal challenge routes were realistic for disabled people and unpaid carers already managing significant pressures in their daily lives. One ISO participant noted:

"Judicial review timelines often run out before complaints processes are finished."

Participants also described situations where concerns had been raised formally through established channels but little appeared to change. One ISO participant described a local stakeholder group had produced a detailed paper outlining concerns regarding recruitment, flexibility and employment issues. Despite these concerns being raised collectively and formally, they reported that two years later no meaningful response had been received. Participants viewed examples such as this as contributing to a growing sense that raising concerns did not always lead to action.

Communication, Responsiveness, and Partnership Working Are Under Strain

Across the datasets, participants described increasing difficulty obtaining information, securing responses, and maintaining collaborative relationships within SDS systems. Many participants described feeling increasingly responsible for obtaining information themselves and ensuring that concerns remained visible. Participants described these experiences as creating uncertainty, frustration, and delays in resolving issues. Several suggested that obtaining information often depended on persistence rather than routine communication. Lived experience participants characterised their experience as:

"Emails, phone calls, repeated conversations, complaints, chasing people constantly."

"You are expected to just keep navigating the system yourself."

“There never seems to be any clarity about what is actually happening or when.”

“I did get properly shouted at by the lady from social work for challenging that [decision]. I’m not ever speaking to that lady again.”

ISO participants uniquely described a perceived weakening of partnership working between ISOs and statutory services. Several contrasted current experiences with earlier periods when they felt more actively involved in discussions regarding support arrangements and decision-making. ISO participants reflected:

"Historically I would say we were very much in the mix for decisions. But I do feel we're being more and more kept at arm's length."

"I've been trying to get a meeting with a senior manager since before Christmas and I'm still waiting."

ISO participants also expressed concern about the position of frontline social workers within increasingly constrained systems. Some felt that social workers were becoming less able to advocate for assessed need because they anticipated requests being reduced or rejected elsewhere in the process.

“Social workers have lost the will.”

“It becomes ‘what will I get through’ rather than ‘what does the person actually need?’”

Participants suggested that this contributed to frustration among practitioners and reduced opportunities for constructive problem-solving between professionals and support organisations. While participants frequently emphasised that many individual social workers remained committed and supportive, they also described systems that appeared increasingly fragmented, with fewer opportunities for collaborative problem-solving and constructive dialogue. Several participants contrasted current experiences with earlier periods when they felt their knowledge and expertise were more valued within local systems. One participant reflected:

“I do feel that our experience and our knowledge of the clients was always seen historically as a real benefit to the local authority. Whereas at the minute I’m just feeling we’re getting a bit of pushback.”

Budget Allocations and Rules on Spend

Once support needs and outcomes have been identified, Self-directed Support arrangements are intended to provide people with flexibility, choice and control in how support is arranged and used to meet agreed outcomes. The SDS Statutory Guidance provides a clear basis for understanding Direct Payments (DPs) as a flexible mechanism for meeting assessed needs and agreed outcomes. It states that a DP's purpose is to meet, "in a flexible way", the outcomes agreed in the support plan, and that the DP amount should be a fair and sufficient estimate of the cost of securing support to meet those outcomes. The guidance also states that local procedures should assist people to use the available resource "in a variety of ways" and "in any way" provided that it secures the agreed support and meets the outcomes in the support plan (Scottish Government, 2025).

Across the survey, Independent Support Organisation (ISO) focus groups and lived experience focus groups, participants described growing concerns about both the level of support being funded through Direct Payments and the increasing restrictions placed on how that support could be used. While challenges relating to funding and flexibility were not entirely new, many participants described what they saw as a significant shift in recent years, with support becoming more tightly constrained, more closely scrutinised and increasingly focused on essential tasks rather than broader outcomes.

Participants frequently contrasted these experiences with the principles of SDS, which emphasise choice, control, flexibility and support tailored to individual circumstances. Across the datasets, many felt that support was increasingly being shaped by budgets, limits and rules rather than by what people needed to live independently and participate in their communities.

Reductions, Caps and Limits on Support Packages

Across all three datasets, participants described support packages that were being reduced, capped or failing to keep pace with changing needs and circumstances. Survey respondents reported reductions in funded hours, staffing levels, respite support and opportunities for social and community participation. Many also described support being reduced following reviews and reassessments, while others reported reductions taking place without what they considered to be a full reassessment of need.

Participants described several ways in which support became smaller or less valuable over time. For some, reviews resulted in direct reductions to support packages. For others, support remained unchanged despite increasing needs, changing circumstances or rising costs. Several participants felt that support packages had become increasingly disconnected from the realities of their daily lives. One participant described their support package being reduced, alongside the loss of respite support. They explained that the reduction left them largely confined to their home and unable to continue many of the activities that had previously formed part of their daily life. They specified:

> *"The support was suddenly reduced from 50 hours to 14 hours."*

Participants also described situations where unused hours became a reason for reducing future support. Several argued that this failed to recognise the reasons those hours had gone unused, including difficulties recruiting suitable Personal Assistants (PAs) or arranging support in practice.

Alongside reductions and stagnation, participants described various forms of caps and limits being applied to support. These included restrictions on respite, limits affecting support available to unpaid carers and assumptions about the amount of care families could reasonably provide themselves.

Charging policies and financial contributions were also raised as a concern. Participants described disputes regarding assessed contributions, prolonged disagreements with local authorities and increasing anxiety about the affordability of support. One participant described a lengthy dispute over charging arrangements that had a significant impact on their mental health and eventually led them to seek support from their GP.

Across the datasets, participants repeatedly linked reductions and limits on funded support to increasing reliance on unpaid care. Families described stepping in to provide support that had previously been funded, taking on additional caring responsibilities and filling gaps left by reduced packages.

Overall, participants described support packages becoming increasingly constrained through a combination of reductions, limits, charging arrangements and failures to adapt to changing circumstances. Many felt that support was becoming less responsive to need and increasingly shaped by financial pressures and local restrictions.

Direct Payments Becoming Less Flexible and More Closely Controlled

Alongside concerns about the overall level of support available, participants repeatedly described growing restrictions on how DP funding could be used in practice. While participants acknowledged that accountability requirements and spending rules had always existed, survey respondents highlighted increased scrutiny of spending, tighter expenditure controls, clawback arrangements, and reduced flexibility regarding how funding could be used.

ISO participants described situations where funding technically existed within a package but could not be used in ways that would address unmet needs or achieve agreed outcomes. Participants also provided concrete examples of restrictions affecting everyday life. One participant described being unable to take a holiday abroad with the support of their PA because funding could not be used to cover the PA's associated travel expenses. As a result, they remained dependent on family support rather than being able to travel independently using their DP. Others described restrictions relating to transport, shopping support, respite arrangements and alternative forms of support that they believed would previously have been considered reasonable and proportionate. Several viewed this as a growing contradiction within the system, as explained in these cases:

> *"[The client] was told he couldn’t use the accumulated funds to increase PA wages even though he couldn’t recruit anyone."*

> *"I was trying to work with my social worker to arrange respite care that would allow me to visit family because I cannot access adapted accommodation in the area where they live. We explored care homes where I could stay temporarily with my own carers, but we could not identify a suitable arrangement. I had enough money within my allocated budget to pay for alternatives, but because flexibility was refused, I ultimately had to return money through clawback."*

> *“The package literally said the money could be used to make life more comfortable, but they still wouldn’t allow taxi costs for hospital appointments.”*

One participant described feeling treated with suspicion when trying to explain spending decisions.

> *"I requested permission to use the accumulated hours more flexibly over the summer [...], but I was accused of potentially defrauding the council!"*

Others described spending considerable time attempting to justify arrangements they believed were fully consistent with SDS guidance.

> *“I repeatedly referred the council to Scottish Government guidance around flexibility and creative use of direct payments to achieve positive outcomes, but I was met with an absolute brick wall.”*

ISO participants frequently described a reduced willingness to approve person-centred solutions. One participant reflected:

> *"There’s much less willingness now to look at creative or flexible uses of Direct Payments."*

Support Defined Through Tasks, Hours, and Rules Rather Than Outcomes

Across the survey and focus groups, participants described a perceived shift away from support focused on outcomes, independence and quality of life towards approaches increasingly defined by tasks, hours, rules and measurable activities. Several participants explained:

> *“If you read the support plans, it’s all stipulated how they can use that Direct Payment. So there’s no real flexibility in it.”*

> *"Outcomes are really just tasks. Everything is like timetables of care and being very prescriptive into what they can use their budgets for."*

> *"Every single second is being justified."*

Participants frequently linked this change to wider developments in assessment and review processes. Several felt that discussions increasingly focused on what could be measured, counted or justified rather than on what support enabled people to do. For many, this represented more than a different way of organising support. It represented a change in the purpose and character of SDS itself.

Direct Payments in Practice: Choice, Management, and Support

Across the survey and focus groups, participants described challenges that arose after a Direct Payment (DP) had been agreed. Participants also described increasing difficulties accessing support, managing employer responsibilities and maintaining support arrangements over time. Much of the discussion focused not on the funding itself, but on what is required to make a Direct Payment work in practice.

Choice of SDS option is not always genuine or fully informed

Across the ISO focus groups, staff repeatedly described situations where people accepted DPs because there was no realistic alternative available. Participants emphasised that this was not their experience in every area and should not be viewed as a Scotland-wide picture. However, in some local contexts, shortages of provider-based services and limited availability of social work-managed support meant that DPs were often the only practical way to access care and support. Several ISO participants explained:

> *"People are being pushed into Direct Payments. People are not making the choice to take them on, they're being pushed into it because there's a lack of providers, a lack of care through social work. I think it's just completely changed how Direct Payments are operating. It's really sad."*

> *"They don't want the responsibilities of being an employer, paying staff, finding people, getting holiday cover, sickness cover for their PAs, checking PVGs."*

> *"A lot of the people would prefer social work managed. They just want social work to find them a provider and get their care coming into them."*

> *"We are seeing people who are absolutely stressed to the hilt. They wouldn't have chosen a Direct Payment, whether it be family members or the individuals themselves. They just want care. And they're being steered towards a Direct Payment, not really comprehending the responsibilities they have as being an employer."*

These findings suggest that, in some local areas, the practical choice facing people was not between different SDS options but between accepting a DP or going without support. Participants viewed this as difficult to reconcile with SDS principles of informed choice and control.

Lack of Support to Manage the Complex Responsibilities of Being a PA Employer

Across focus groups, participants described the practical realities of managing a Direct Payment as substantial and often underestimated. Participants acknowledged that DPs have always involved responsibilities such as recruiting staff, managing payroll, organising rotas, and dealing with employment matters, but increasingly felt left to deal with these responsibilities on their own once a DP had been agreed. Participants described having less contact with social work services, fewer opportunities to access practical support when problems arose, and greater reliance on ISOs, unpaid carers and their own efforts to keep support arrangements functioning. Lived experience participants noted:

> *“I am supposed to be receiving support from a payroll and support organisation, but my mum and I still feel like we are trying to navigate employment law and recruitment completely on our own. It feels like a minefield.”*

> *"That includes payroll, rotas, recruitment, training, disciplinary procedures, arranging cover when staff are unavailable, and all of the wider responsibilities that come with being an employer. It is effectively a full-time management role. "*

> *"I had to give up my own employment in order to manage my adult daugher’s support package and coordinate staffing. I rarely get proper breaks or holidays because there is always some issue requiring attention."*

Across the ISO groups, participants repeatedly described increasing involvement in helping people manage the ongoing realities of DPs. Several felt that their role had expanded significantly beyond providing information and advice and increasingly involved helping people sustain support arrangements that might otherwise fail. Several ISO participants described supporting people through complex employment situations involving grievances, disciplinary procedures and disputes with staff. Participants also described support needs becoming broader and more complex over time, with ISOs increasingly assisting people with issues relating to benefits, housing, healthcare navigation, safeguarding concerns and crisis situations. ISO staff members noted:

> *"As soon as [clients are] allocated a Direct Payment, that's it, the social workers are gone. We get all the questions that you might have for your social worker. "*

> *"Without us being here, the people who are in receipt of Direct Payments would not be able to manage the responsibilities of being an employer […]. If we weren't here, […] they wouldn't have any care."*

PA Recruitment and Workforce Challenges

Across the survey and focus groups, participants described increasing difficulties recruiting and retaining Personal Assistants (PAs). While recruitment challenges are not new, many felt they had become more pronounced in recent years. Participants repeatedly described situations where support had been approved and funded but could not be fully used because suitable staff could not be found or retained.

Recruiting PAs is increasingly difficult

Across all three datasets, participants described recruitment and retention as one of the most significant challenges facing Direct Payments. Survey respondents frequently highlighted workforce shortages, while ISO staff and lived experience participants described increasing difficulties finding suitable PAs. Participants acknowledged that recruitment challenges have existed for many years. However, many felt that finding and retaining suitable staff had become increasingly difficult, particularly where support required specialist skills, specific experience or an understanding of complex support needs. ISO participants noted:

> *“Recruitment has become one of the biggest ongoing stresses.”*

> *“The package exists on paper, but there is nobody actually available to provide the support. The hours sit there unused because there’s nobody to recruit. Then the argument becomes, ‘well you’re not using the hours anyway.”*

Lived experience participants described spending months advertising vacancies, interviewing candidates and attempting to maintain support arrangements despite ongoing staffing shortages. Participants described a range of factors that could make recruitment difficult. These included rural and remote locations, small support packages, split shifts and limited hours. Two participants reflected:

> *"Everything depends on whether you can actually find the right people, and often you can’t."*

> *“Even when the funding exists, it does not mean the support is actually available in reality.”*

Several participants questioned how attractive some PA roles appeared compared with other employment opportunities, particularly where hours were limited or future funding arrangements felt uncertain. One lived experience participant noted:

> *“Why would somebody commit ten years of their life to working for an individual employer when they could go somewhere with proper protections?”*

Participants also raised concerns about inconsistent approaches to family members acting as Personal Assistants. Several felt that restrictions in this area could make recruitment more difficult in situations where suitable alternatives were unavailable. As one ISO participant explained:

> *"They're trying to eliminate family from being able to be the PA. The choice straight away is taken away because they're not getting the autonomy to decide who they employ."*

Across both the ISO and lived experience focus groups, participants described recruitment difficulties as having direct consequences for disabled people and families, including reduced independence, missed opportunities, disrupted routines and social isolation.

Retaining PAs is increasingly difficult

Participants also identified features of the Direct Payment employment model that could make recruitment and retention more challenging. This included uncertainty following package reviews, concerns about redundancy liabilities, fragmented working hours and lack of budgets for training and professional development. An ISO participant stated:

> *“Clients are legally employers but they don’t have the money to pay redundancy.”*

Across both datasets, participants also described unpaid carers stepping in to fill gaps when support could not be recruited or retained. ISO staff described families taking on additional caring responsibilities and attempting to maintain support arrangements that could no longer be sustained through paid support alone. Participants reflected:

> *"Families feel abandoned with all the responsibility."*

> *"Carers are doing everything."*

> *"A lot of unpaid care is just being assumed."*

Impact on Daily Life, Wellbeing and Independent Support Organisations

Across the survey and focus groups, participants described impacts extending far beyond individual decisions about support. Disabled people, unpaid carers and Independent Support Organisation (ISO) staff described the cumulative effects of support reductions, increasingly restrictive approaches, workforce shortages and ongoing uncertainty about future support arrangements. Participants repeatedly linked these experiences to reduced independence, declining wellbeing, increasing pressure on families and growing concern about the future.

Impact on Independence, Participation and Life Opportunities

Across the lived experience and ISO focus groups, participants described changes to support affecting their ability to live independently, maintain relationships, participate in their communities and pursue opportunities that had previously been possible through Self-directed Support.

Several participants contrasted their current circumstances with earlier periods when support arrangements had enabled them to participate more fully in education, family life, employment and community activities. While participants acknowledged that barriers and challenges had always existed, many felt that opportunities which had previously been achievable were becoming increasingly difficult to sustain.

Participants also described impacts on family relationships. One participant explained that she had been unable to visit family members for two years because suitable respite arrangements could not be agreed:

"I have not seen my family for two years."

Several participants described impacts on education and future opportunities. ISO staff discussed the case of a young blind woman whose support was reduced during her transition to adult services and following an unannounced review. Staff explained the resulting disruption contributed to her giving up a university place because she could no longer reliably access the transport support she required.

Across the datasets, participants repeatedly linked changes in support to increasing social isolation. Participants also described situations where support disruptions reversed progress that had taken years to build. One young autistic adult experienced a prolonged gap in support following a move between local authority areas. During this period, he became increasingly isolated and lost confidence to participate in activities and groups that had previously supported his independence and wellbeing:

"This is socially isolating not only for me but also for my parents because they are constantly caring for me."

Living with Fear, Uncertainty and Exhaustion

Alongside impacts on daily life and participation, participants described significant emotional and psychological consequences associated with living with increasingly uncertain support arrangements.

Across the survey and focus groups, fear, uncertainty and exhaustion emerged as some of the most commonly described impacts. While participants acknowledged that reviews and reassessments have always formed part of Self-directed Support (SDS), many felt that support arrangements had become less secure and less predictable over time. ISO participants explained:

"There is always this fear that support arrangements could suddenly collapse."

Participants described living with uncertainty about future reviews, reassessments and support arrangements. Several spoke about feeling unable to plan for the future or feeling that support could change at any point. The emotional impact of these experiences was described in a range of ways, including anxiety, exhaustion, loss of confidence and declining mental wellbeing. Lived experience participants explained:

"My mental health deteriorated significantly and I ended up needing support from my GP. It feels like constant paperwork, administration, and fighting."

"You are constantly holding everything together."

"There's a level of exhaustion that never really goes away."

Across the datasets, participants frequently linked these experiences to declining trust and confidence in systems that were intended to support them.

"People lose trust in the system completely."

Increasing Pressure on Unpaid Carers and Families

One of the most consistent findings across the survey and focus groups was the extent to which unpaid carers and families were absorbing the consequences of wider pressures within the system. Participants described increasing caring responsibilities, loss of respite, financial pressures and significant impacts on family life. Several contrasted their current experiences with earlier periods when more support had been available and families felt less responsible for filling gaps in provision. An ISO participant described:

> *"Unpaid carers are crying and anxious because they feel they are being blocked, not heard and very tired."*

Across the focus groups, participants frequently described family members taking on additional caring responsibilities when support arrangements changed or became unavailable. Several felt that responsibilities previously shared across services were increasingly being absorbed by families themselves. Participants also described the impact of these pressures on their own wellbeing and on family life more broadly. One unpaid carer expressed:

> *"The emotional toll is enormous. My entire family is exhausted. I'm constantly running on empty."*

For some, the consequences extended beyond caring responsibilities themselves and affected employment, finances, relationships and opportunities for family life. One participant explained that after her support package was substantially reduced, her husband left his job and became her full-time unpaid carer. The family subsequently relied on Universal Credit for the first time. Others described the impact on wider family relationships. One parent explained that repeated disputes with social work regarding support arrangements contributed to severe emotional strain within the household, difficulties within her marriage, and anxiety affecting her child.

Impact on Independent Support Organisations and Staff

The findings also highlighted substantial impacts on ISOs and their staff. Across both the survey and ISO focus groups, participants described increasing workload, growing complexity of casework, emotional strain and concerns about the sustainability of current ways of working. Participants repeatedly described the emotional impact of this work:

> *"As staff we are stressed and emotionally burnt out."*

> *"It's difficult not to be impacted when you have to sit with them in tears, knowing that you also cannot change things for them."*

> *"It's become really quite frustrating for ourselves and quite upsetting."*

At the same time, participants were careful to distinguish between wider system pressures and individual practitioners. Several highlighted examples of committed and supportive social workers and stressed that many of the challenges discussed reflected broader pressures across the system rather than the actions of individual staff members. One participant summarised the situation as follows:

> *"People are trying to do good work inside systems that are becoming impossible."*

Ongoing Evidence Gathering, Learning and Accountability

Across both the ISO and lived experience focus groups, participants emphasised the importance of continuing to gather evidence about how Self-directed Support is implemented in practice. Discussions focused on the value of documenting experiences, identifying emerging issues, sharing learning and ensuring that evidence contributes to meaningful change. Participants also reflected on the practical realities of participation, including accessibility, consultation fatigue and the emotional impact of repeatedly discussing difficult experiences.

Ongoing Evidence Gathering Remains Important

Participants consistently emphasised the importance of continuing to document people's experiences of Self-directed Support.

ISO staff described seeing changes in local approaches, reassessment practices and restrictions over time and felt that ongoing evidence gathering was necessary to understand how these developments were affecting disabled people, unpaid carers and families in practice. Participants suggested that evidence collected at one point in time could not provide a complete picture of implementation as systems and practices continued to change.

Several participants reflected on the value of bringing together experiences from different organisations and local authority areas. They suggested that comparing experiences often helped identify common issues and patterns that were less visible when viewed through individual cases alone. Participants from both focus group types said:

> *"We need ongoing evidence because the situation is changing constantly."*

> *"These conversations are important because people realise the problems are systemic."*

> *"There needs to be a way for experiences to be gathered continuously rather than only occasionally."*

Participants also highlighted the contribution that disabled people, unpaid carers and families can make to understanding how SDS operates in practice.

> *"There's a huge amount of knowledge sitting within families and disabled people themselves."*

Evidence Gathering Should Contribute to Accountability and Change

Alongside support for continued evidence gathering, participants expressed frustration that many of the issues discussed within the focus groups had been raised repeatedly over a number of years. ISO staff described revisiting similar concerns through consultations, engagement exercises and organisational feedback while seeing limited improvement in practice. Participants therefore emphasised the importance of ensuring that evidence gathering is linked to action and accountability. One ISO staff member noted:

> *"We keep saying the same things over and over. There needs to be much more accountability around what's actually happening locally."*

Some participants questioned whether existing systems were sufficiently able to respond when concerns were identified and suggested that future evidence-gathering should be accompanied by clearer routes for influencing change. Lived experience participants expressed similar frustrations.

> *"People keep sharing the same problems but nothing seems to change."*

One participant went further to suggest:

> *"There needs to be some kind of national organisation with actual authority and accountability powers."*

Evidence Gathering Can Also Support Learning, Connection and Shared Understanding

Participants discussed a range of possible approaches for gathering experiences and sharing knowledge, including peer-support group meetings, online reporting systems, case-study databases, searchable knowledge resources, WhatsApp groups, and discussion forums. Several participants highlighted that different approaches could serve different purposes. Some were seen as useful for collecting evidence and identifying patterns, while others were valued because they enabled people to exchange practical advice and learn from one another's experiences. Participant suggestions included:

> *"I think there should almost be a searchable knowledge base or flowchart system where people can input their situation and then access examples, case studies, and solutions from others who have experienced similar issues."*

> *"Potentially AI could even help organise those experiences and identify patterns."*

Participants repeatedly described learning from other disabled people, unpaid carers and families who had experienced similar challenges.

“Often the best support comes from other people who actually understand the reality of it.”

“Families and disabled people often end up helping one another informally because formal systems are insufficient.”

ISO participants similarly highlighted the value of bringing organisations together to compare experiences and share learning.

“There’s huge value in bringing organisations together to compare what’s happening.”

“People need spaces where they can actually talk honestly.”

Participants reflected on the emotional impact of participation in peer-group meetings. Several noted that many disabled people, unpaid carers and practitioners were already dealing with significant pressures and could find it difficult to repeatedly discuss challenging experiences:

“People are exhausted by constantly having to explain the same problems over and over again.”

“Sometimes support groups can actually feel overwhelming because everybody attending is already struggling themselves.”

“It’s quite depressing just listening to everybody having such a hard time.”

Participants therefore emphasised the importance of ensuring that future evidence-gathering activities are accessible, proportionate and realistic, recognising the pressures already experienced by disabled people, unpaid carers and practitioners.

Conclusion

This research combined evidence from a national survey of Independent Support Organisation (ISO) staff, five ISO focus groups and four lived experience focus groups involving disabled people and unpaid carers. Across all three datasets, a high degree of convergence was observed. Participants consistently described concerns regarding increasing restrictions, administrative barriers and uncertainty affecting access to, management of and experiences of Direct Payments across Scotland.

The findings do not suggest a loss of support for the principles underpinning Self-directed Support (SDS). Rather, they point to growing concern regarding the extent to which those principles are being realised in practice. Across the evidence base, participants repeatedly described what they perceived as a shift towards higher eligibility thresholds, reduced access to preventative support, narrower interpretations of need, increasing restrictions on flexibility, greater emphasis on tasks and risk management, and growing difficulties navigating assessments, reviews and decision-making processes. Participants frequently distinguished between the principles of SDS and their experience of local implementation.

The findings also indicate that the consequences extend beyond individual decisions about budgets or services. Participants described support arrangements becoming less responsive to changing circumstances, increasing anxiety surrounding reviews and reassessments, and growing uncertainty regarding future support. Across the datasets, participants linked these experiences to reduced independence, social isolation, loss of opportunities for participation, disruption to education and employment, declining wellbeing, and increasing pressure on family life. Unpaid carers frequently described taking on additional caring, coordination and employer responsibilities, while Independent Support Organisations (ISOs) reported growing involvement in advocacy, crisis support and navigating increasingly complex systems.

A notable finding was the extent to which participants described pressures being transferred elsewhere within the system. Support needs did not disappear when support was reduced, delayed, or restricted. Instead, participants frequently described those pressures being absorbed by disabled people, unpaid carers, families and third-sector organisations. Many of these consequences, including emotional strain, unpaid care, advocacy demands and the effort required to sustain support arrangements, are unlikely to be fully visible within routine performance data despite their significance for individuals and communities.

These findings must be understood within the wider context of workforce shortages, increasing demand and financial pressures affecting social care across Scotland. However, the evidence suggests that resource pressures alone do not account for many of the concerns raised. Recurring issues relating to communication, transparency, accountability, consistency, flexibility and partnership working point to implementation challenges that warrant attention alongside wider discussions regarding funding and capacity. The findings also indicate opportunities for improvement in areas that are not solely dependent on additional resources.

The research additionally highlights the importance of drawing upon multiple forms of evidence when evaluating SDS implementation. Disabled people, unpaid carers, ISOs and Disabled People's Organisations (DPOs) contribute distinct forms of lived and practice-based expertise that are not readily captured through administrative data alone. The consistency of findings across all three datasets demonstrates the value of these perspectives in identifying emerging issues, understanding implementation in practice, and informing improvement activity.

In conclusion, the findings suggest that current concerns regarding Direct Payments (DPs) are not solely about the level of support available, but about how SDS is being implemented and experienced in practice. Ongoing monitoring, meaningful accountability, stronger partnership working and continued engagement with lived and practice-based expertise will be essential to ensuring that the principles of choice, control, flexibility, participation and Independent Living remain evident not only within legislation and guidance, but within the everyday experiences of the people SDS is intended to support.

Recommendations

The findings from this research suggest that action is required at both national and local level to ensure that Direct Payments continue to reflect the principles of Self-directed Support (SDS), including choice, control, flexibility, participation and Independent Living. Although there is a recognition that social care requires further financial investment to support better social care provision, these recommendations focus on what cross-sector stakeholders can begin to take action now, irrespective of public funding pressures (COSLA, 2026). These recommendations align with various pieces of SDS improvement work, with specific examples noted alongside each recommendation.

Strengthen flexible, informed and outcome-focused Direct Payment practice

This recommendation reflects the report's findings that Direct Payments (DPs) are being experienced as less flexible in practice, including through restrictions on spend, reduced packages, increased scrutiny and review processes that can be experienced as primarily cost-focused, with impacts noted on Personal Assistant (PA) employers in their ability to fulfill their role effectively. It aligns with calls in other work, such as My Support My Choice, the Post-Legislative Scrutiny of SDS, and the SDS Framework of Standards, for greater consistency, transparency and flexibility in SDS implementation (Health and Social Care Alliance Scotland and SDSS, 2020, Scottish Parliament, 2024, Social Work Scotland, 2024). This aligns with Standard 13's emphasis on DP agreements, sufficient budgets, employment responsibilities and reducing unnecessary bureaucracy for PA employers, while ensuring that people should receive information and advice about all four SDS options before deciding to use a DP to employ PAs (Social Work Scotland, 2025). It also aligns with calls made in the Scottish Personal Assistant Workforce Survey 2025 to improve DP agreements, employment conditions, communications, wellbeing and data relating to the PA workforce (SDSS, 2025a).

- Local authorities and Health and Social Care Partnerships should review DP policies, procedures and monitoring arrangements to ensure that they support flexible, outcome-focused practice.
- Local rules and practice should not unnecessarily restrict how a DP can be used where the proposed use is lawful, proportionate and connected to the person's assessed needs and agreed outcomes.
- Commissioners should work to identify where gaps exist locally, that mean people are not freely choosing to take on a DP, and work to fill these gaps, using creative and flexible solutions.
- Information about DPs should explain both the flexibility and control they can offer and the responsibilities that may come with managing a budget or employing Personal Assistants.
- Where underspend is identified, reviews should consider whether the DP could be used differently or more creatively to meet outcomes, rather than being treated primarily as an opportunity to reduce or recover funds.
- Where DPs are used to employ PAs, local areas should ensure that assessment, budget-setting and review processes take account of the person's role as a PA employer, including the length of time it may take to recruit a PA in practice.
- DP budgets should be sufficient to meet agreed outcomes and enable PA employers to fulfil legal and employment responsibilities, including payroll, insurance, pensions, sickness, holiday, redundancy, recruitment, PVG-related costs, training and other necessary employer costs.
- Reviews or reductions to DP should explicitly consider the potential impact on PA employment arrangements, continuity of support, the supported person's independent living outcomes, and the working conditions of PAs.

Improve the quality, consistency, and transparency of policies and procedures

This recommendation aligns with concerns raised about inconsistent review processes, unclear decision-making, reduced involvement of supported people and carers, and difficulty understanding or challenging changes to DPs, and the impact this has on disabled people and unpaid carers. The SDS Framework of Standards sets out what good practice looks like in relation to transparency, meaningful recording, accountability, consistency of practice, and strengths-based assessment, planning and review (Social Work Scotland, 2024). It also aligns with the Post-Legislative Scrutiny of the Social Care (Self-directed Support) (Scotland) Act 2013 call for local processes to be evaluated to ensure they are consistent with SDS principles and that complaints processes are consistent across HSCPs and are clear, transparent and properly publicised (Scottish Parliament, 2024). Recommendation 16 and 25 within the Independent Review of Scrutiny and Regulation of Social Care also suggests scrutiny systems should take account of people's experience of service delivery and their wider care journey, and a call for clearer public information about how to raise concerns and use complaints systems, including routes of escalation and outcomes that may include redress (Scottish Government, 2023).

- Ensure supported people and unpaid carers should have access to clear, accessible, publicly available, and balanced information about all aspects of SDS, including policies, procedures (including complaints), and information about the four SDS options.
- Policies and procedures should be fair, consistent, accessible, and rights-based.
- Reviews of DPs should be carried out with the full involvement of the supported person and, where appropriate, unpaid carers, independent supporters, advocates or brokers, and review outcomes recorded consistently.
- Adapt local planning processes/procedures to account for known needs for reviews/reassessments, e.g. transitions.
- Carer assessments, Adult Carer Support Plans and Young Carer Statements should be used consistently to identify carers' own needs and outcomes and be suitably funded.
- Particular attention should be given to situations where changes to a DP may affect PA employment arrangements, family caring responsibilities, unpaid carers' wellbeing, or the person's ability to sustain independent living.
- Complaints and challenge processes should be timely and capable of informing learning and improvement.
- Particular attention should be given to situations where people feel unable to challenge reductions or restrictions because of power imbalances, lack of independent support, fear of losing support, or lack of accessible information.
- Local authorities and Health and Social Care Partnerships should review administrative and monitoring requirements attached to Direct Payments to ensure they are accessible and rights-based. This should include consideration of audit processes, repayment requests, payment card systems, budget monitoring and communication with DP recipients.
- Administrative processes should support accountability without creating unnecessary stress, delay or risk for DP recipients, unpaid carers, or PA employers.
- Equality Impact Assessments should be used actively to identify, monitor and address the impact of local Direct Payment policies and practices on different groups. This should occur with meaningful co-production from disabled people, unpaid carers, and wider communities.

Strengthen availability and access to independent support, advocacy and brokerage

The report highlights the growing role of ISOs, Disabled People's Organisations (DPOs), advocacy services and brokerage organisations in helping people navigate reductions, restrictions, reviews, disputes and increasingly complex systems. This aligns with Standard 1 of the SDS Framework of Standards on independent support, community brokerage and advocacy (Social Work Scotland, 2024) and with the Independent Review of Scrutiny and Regulation of Social Care's emphasis on access to independent advocacy to help people exercise their rights and navigate complaints or escalation processes where needed (Scottish Government, 2023).

- ISOs, DPOs, advocacy services and brokerage organisations should be recognised as key partners in effective SDS and Direct Payment implementation.
- Embed brokerage approaches locally to support preventative approaches in supporting people to live independently and in accessing holistic forms of support, e.g. mental health and wellbeing support.
- Referral routes should be clear and should include social work teams, health professionals, carers' organisations, transition services and other community-based services where relevant and occur as early as possible in the SDS process, including pre-assessment.

Improve evidence, monitoring and shared learning on Direct Payment implementation

The report identifies a need for stronger evidence about how DPs are being implemented and experienced, including reductions, restrictions, flexibility, administrative processes, impacts on PA employers and unpaid carers, and the role of independent support. This aligns with the PA Workforce Survey 2025's calls to improve data on the PA workforce (SDSS, 2025a), the Post-Legislative Scrutiny of the Social Care (Self-directed Support) (Scotland) Act 2013 call for a comprehensive monitoring and evaluation plan for SDS (Scottish Parliament, 2024), and the Independent Review of Scrutiny and Regulation of Social Care's call for the purpose and use of data to be reviewed so that it supports performance management and service improvement (Scottish Government, 2023).

- Ensure case recording systems are utilised effectively to ensure people do not have to repeat information several times.
- Establish consistent collection and sharing of evidence on DP implementation locally and nationally. This should include information on reductions, restrictions, delays, charging, complaints, appeals, unmet need, access to independent support, flexibility of spend, PA employer arrangements, and outcomes for supported people and unpaid carers.
- Data should be disaggregated where possible to identify unequal impacts across different groups and local areas.
- Lived expertise and practice-based evidence from disabled people, unpaid carers, PAs, PA employers, ISOs, DPOs, advocacy services and brokerage organisations should be used alongside quantitative data.
- Monitoring should include whether people are receiving information about SDS, whether they are being offered all four options, whether decisions are being communicated accessibly, and whether review processes are having unequal impacts.

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Appendices

Appendix 1 – Survey and Focus Groups’ Questions

Appendix 2 – Reflections and Ethical Considerations

Appendix 3 – SDSS National Voice Conference Workshop Reflection Notes

Appendix 1 – Survey and Focus Groups' Questions

ISO Survey Questions

Section 1: About you and your work

- What best describes your role?
- Frontline adviser/support worker
- Manager / Team Lead
- Senior Manager
- Office staff (payroll, finance, etc.)
- Prefer not to say
- Other

Which Health and Social Care Partnership area(s) do you primarily work in?

- Aberdeen City
- Aberdeenshire
- Angus
- Argyll and Bute
- Clackmannanshire and Stirling
- Dumfries and Galloway
- Dundee City
- East Ayrshire
- East Dunbartonshire
- East Lothian
- East Renfrewshire
- Edinburgh City
- Falkirk
- Fife
- Glasgow City
- Highland
- Inverclyde
- Midlothian
- Moray
- North Ayrshire
- North Lanarkshire
- Orkney
- Perth & Kinross
- Renfrewshire
- Scottish Borders
- Shetland
- South Ayrshire
- South Lanarkshire
- West Dunbartonshire
- West Lothian
- Western Isles
- Scotland wide
- UK wide
- Other

Does your organisation/service primarily support any of the following groups (tick all that apply)?

- Disabled adults
- Disabled children and young people
- Unpaid carers
- People living with dementia
- People in rural, remote or island communities
- People facing digital barriers
- People who speak English as an additional language
- Other

Section 2: Changes to Direct Payments

In the past year:

Have you observed changes to Direct Payment packages in your area(s) of work? *

- Changes are less frequent
- No change
- Changes are more frequent
- Not sure / prefer not to say

If yes, which types of changes have you observed? (tick all that apply)

- Reductions following reviews or reassessments
- Reductions without review or reassessment
- Delays in reviews or budget setting
- Change to local eligibility criteria
- Interim or temporary budgets becoming long-term
- Changes to charging policies
- Restrictions on how funds can be used
- Reclaiming unspent funds
- Other

When did you first notice this change?

- 0 - 3 months
- 3 - 6 months
- 6 - 12 Months
- More than a year
- Not sure
- Other

How concerned are you about this change?

- Not concerned
- Monitoring, but not urgent
- Some concern — may need action
- Significant concern — needs attention soon
- Urgent — requires immediate attention
- Other

Please describe any recent anonymised example(s) of a change to a Direct Payment package and how it was implemented.

Section 3: Impact on individuals and unpaid carers

Based on your experience, what impacts (if any) have these changes had? (tick all that apply)

- Reduced hours or support
- Disruption to care arrangement
- Reduced flexibility or choice
- Increased reliance on unpaid care
- Increased stress or uncertainty
- No significant impact observed
- Don't know
- N/A
- Other

Please describe any patterns you have observed in terms of who is most affected (e.g. geography, age group, rurality, types of support needed) and in what way (impact on independence, flexibility, wellbeing, unpaid carers, etc.)

Section 4: Impact on staff and organisations

Some questions in this section relate to professional and emotional impact. You may respond from your professional experience, and if relevant you may also draw on personal experience, or select “Prefer not to say”.

Have changes to Direct Payment packages affected your team or organisation?

- Me
- My team / service
- My organisation
- No impact
- Don't know
- Prefer not to say
- Other

If yes, how?

	Significantly worse	**Somewhat worse**	**No change**	**Somewhat better**	**Much better**	**Don’t know**
Workload or nature of casework						
Emotional burden						
Team morale						
Capacity						

Internal tension or complaints						
Staff retention						
Organisation’s finances						
Organisation's activities or strategy						
Other impact (please specify in the next question)						

Please describe in more detail how Direct Payment changes have affected you, your team or organisation (if relevant). Please avoid identifying information.

Please share any comments, suggestions for other organisations or Local authorities, or examples of better SDS practice.

ISO Focus Groups Prompts

- What changes or issues to Direct Payment packages are you seeing, and what are the consequences for people?
    - What impact are these changes having on the people you support?
    - Who seems to be most affected?
    - What consequences are you most concerned about?
- What is the impact on staff and support organisations?
    - What impact is this having on your organisation or staff team?
    - How has your role changed because of these issues?
    - What pressures are increasing?
- Do you have examples of good practice or ideas about what Good Practice looks like, or what is needed to improve SDS DP implementation?
- Let’s talk about how we can improve policy and practice through collecting evidence on an on-going basis to inform decision makers about what is happening on the ground.
    - How can we improve the collection of national evidence? Thinking about a systems or infrastructure:
        - For ISO to gather evidence and share stories or ideas
        - For people with LE
    - Should this national data be centralised (collected, analysed and passed on to advisory boards or policy makers) by a specific agency or in other ways?
- Is there anything important that hasn’t been said yet?

Lived Experience Focus Groups Prompts

- What changes or issues to Direct Payment packages have you experienced or witnessed, and what was the impact on you, and people around you?
  - => Did you get help from ISO?
- Do you have positive examples related to SDS (needs assessment, resolved an issue, package, communication with Social Work)
- If there was a way for people with experience of SDS to share their stories and ideas on an on-going basis, what could it be? Online platform, regular interviews, surveys...
- Is there anything important that hasn’t been said yet?

Appendix 2- Reflections and Ethical Considerations

In relation to the ISO Focus Groups

Practice-based evidence as a distinct form of knowledge

One of the clearest reflections arising from the ISO focus groups was the distinctive contribution of practice-based evidence. Unlike individual lived experience accounts, participants were able to draw on experiences across multiple cases, families, local authorities and time periods. This enabled them to identify recurring implementation patterns, emerging trends and common mechanisms through which SDS policy is translated into practice.

The discussions highlighted the unique position occupied by ISOs between disabled people, unpaid carers and statutory systems. This perspective allowed participants to connect individual experiences to wider system-level issues and provided valuable insight into how policy intentions are experienced in everyday life. The findings reinforce the value of incorporating practice-based expertise alongside lived expertise, quantitative data and policy analysis when seeking to understand SDS implementation.

Learning from good practice

Although the focus groups primarily explored barriers, restrictions and changing implementation practices, participants repeatedly highlighted examples of good practice throughout the discussions. These included knowledgeable practitioners, flexible interpretation of guidance, collaborative problem-solving and approaches that remained focused on SDS principles and personal outcomes.

A recurring reflection was that future research and improvement work should not focus exclusively on problems. Participants suggested there would be significant value in systematically identifying, analysing and sharing examples of effective practice, particularly where local teams, organisations or practitioners had found ways to deliver more flexible, person-led and collaborative approaches.

This highlights an important opportunity for future research and knowledge exchange. Alongside documenting barriers and challenges, there may be value in collecting and disseminating good practice case studies that help demonstrate what effective SDS implementation looks like in practice and support learning across local areas.

Lived expertise within the workforce

A particularly important reflection emerging from the focus groups was that many ISO staff occupied dual roles as both professionals and people with lived expertise. Participants frequently described experiences as disabled people, unpaid carers, family members or members of the same communities as those they supported.

This appeared to strengthen empathy, trust and understanding, while also providing insight into issues that might not be visible through professional knowledge alone. At the same time, the discussions highlighted the importance of recognising the blurred boundaries that can exist between professional, advocacy and lived experience roles.

These reflections parallel wider discussions around peer support, peer advocacy and lived expertise within research and practice. They suggest that lived expertise can be a significant asset within support organisations while also requiring ongoing reflexivity and recognition of the unique pressures associated with these overlapping roles.

From evidence gathering to accountability and change

Participants consistently supported the collection of evidence about SDS implementation and highlighted the importance of documenting both challenges and examples of effective practice. However, discussions repeatedly returned to the question of what happens after evidence is gathered.

Participants emphasised the importance of ensuring that evidence contributes to learning, accountability and practical improvement rather than becoming an end in itself. Several also reflected on the need for reporting systems and research processes to be proportionate, accessible and capable of identifying meaningful patterns without creating unnecessary administrative burden.

The discussions additionally highlighted the potential role of technology and AI within evidence gathering and qualitative analysis. Participants were generally supportive of AI-assisted approaches but emphasised the importance of transparency, human oversight, contextual understanding and ethical governance.

Taken together, the focus groups suggest that evidence gathering is most valuable when it supports accountability, shared learning and positive change. Participants repeatedly emphasised the importance of ensuring that the expertise and experiences contributed through research are translated into improvements for disabled people, unpaid carers and the organisations that support them.

<u>In relation to the Lived Experience Focus Groups</u>

Lived expertise, co-production and peer research

One of the strongest reflections arising from this project concerns the value of lived expertise throughout the research process. Across the focus groups, participants demonstrated substantial knowledge of SDS systems, reviews, recruitment, employment responsibilities, advocacy and local authority processes. Their contributions frequently extended beyond personal testimony and reflected highly developed operational and policy expertise acquired through lived necessity over many years.

This reinforces the importance of viewing disabled people and unpaid carers not simply as people with lived experience, but as people with lived expertise whose knowledge can contribute meaningfully to all stages of research.

The project was developed using a co-produced approach, with people with lived expertise and independent support organisations helping to shape the research focus, design and delivery. The focus groups further demonstrated the value of involving people with lived expertise not only as participants but also as partners in generating, interpreting and applying knowledge.

The research also raises reflections regarding the role of peer research. Researchers with relevant lived experience may bring important contextual understanding, shared language and insight into issues that might otherwise be overlooked. Shared experience can help establish trust, reduce perceived power imbalances and create environments where participants feel understood and able to speak openly about sensitive or complex experiences.

At the same time, peer research requires ongoing reflexivity. Shared experience can create assumptions of understanding, increase the risk of over-identification with participants and blur the boundaries between research, advocacy and personal experience. These tensions highlight the importance of transparency, critical reflection and collaborative analysis throughout the research process.

The findings suggest that people with lived expertise should be involved throughout the research cycle, including the interpretation, refinement and dissemination of findings.

Participation, emotional labour and trauma-informed research

Across all four groups, participants described years of advocacy, complaints, reviews, reassessments, evidence gathering and repeated consultation. Many expressed frustration that concerns had been raised repeatedly without resulting in visible improvements.

The focus groups highlighted the emotional labour involved in participation itself. Contributing to research often required participants to revisit experiences of uncertainty, support reductions, isolation, conflict with systems and caring pressures that remained ongoing rather than historical.

This raises important ethical questions regarding consultation fatigue and the responsibilities involved in repeatedly asking people to recount distressing experiences.

The discussions also highlighted the importance of trauma-informed approaches to research. Many participants described experiences involving prolonged uncertainty, institutional mistrust, discrimination, social isolation, financial insecurity and cumulative emotional strain. While experiences varied, the focus groups reinforced the importance of creating research environments that prioritise safety, choice, transparency, collaboration and participant control.

Future research should consider not only how information is gathered, but how participation is experienced by those contributing, including opportunities to minimise unnecessary repetition, provide support where needed and recognise emotional fatigue.

Focus groups as spaces of peer support and mutual aid

One of the most notable observations across the focus groups was the extent to which discussions became spaces of mutual support, learning and collective problem-solving.

Participants frequently exchanged practical advice, shared resources, validated one another's experiences and discussed solutions to common challenges. Several participants appeared to gain reassurance from hearing that others were facing similar difficulties, while some expressed interest in remaining connected beyond the sessions themselves.

This highlighted the potential value of focus groups beyond data collection alone. In a context where many participants described feeling isolated or unsupported, group discussions created opportunities for peer learning, solidarity and mutual recognition that would not necessarily have emerged through individual interviews.

At the same time, participants also reflected on the complexity of peer-support spaces. While often validating and supportive, they could also become emotionally demanding when participants were already carrying significant responsibilities and pressures themselves.

The focus groups therefore highlighted both the supportive potential and the emotional intensity of collective research methods. This is particularly relevant given the limited use of group-based approaches within existing SDS research and suggests that focus groups may offer benefits extending beyond evidence generation alone.

Reaching people who are less visible and less heard

The focus groups also raised important questions about whose experiences are represented within research and participation activities.

Many participants were highly knowledgeable, articulate and experienced advocates. However, discussions repeatedly highlighted inequalities in access to information, confidence, advocacy support, time and energy. Participants frequently reflected on the difficulties faced by people who lacked the knowledge, resources or confidence required to challenge decisions, navigate complex systems or participate in consultations and research.

This raises important considerations for future research. Individuals who are less connected to support organisations, less confident in group settings, experiencing greater levels of crisis or fatigue, facing communication barriers or lacking informal support may be less likely to participate despite potentially experiencing some of the greatest challenges.

Future research should therefore consider proactive and flexible approaches to participation, including multiple ways of contributing, accessible communication methods and targeted efforts to reach people whose voices may otherwise remain underrepresented.

From evidence gathering to meaningful change

Perhaps the most significant ethical reflection arising from the focus groups concerns the relationship between participation and change.

Participants repeatedly expressed willingness to share experiences and contribute evidence. However, many also described frustration that concerns appeared to be raised repeatedly through consultations, engagement exercises and research activities without resulting in visible improvements.

This raises important questions about the responsibilities of researchers, policy makers and public bodies when gathering lived expertise. While research cannot guarantee change, the discussions highlighted the importance of transparency regarding how evidence will be used, communicating findings back to participants and creating clear pathways through which lived expertise can inform policy and practice.

The focus groups suggested that participants were not simply seeking opportunities to tell their stories. They were seeking evidence that their expertise could contribute to improving systems, influencing decisions and making life better for others facing similar challenges in the future.

Taken together, these reflections suggest that ethical lived expertise research extends beyond data collection alone. It requires meaningful partnership, trauma-informed practice, accessible participation, ongoing reflexivity and a commitment to ensuring that the knowledge shared by participants has the greatest possible opportunity to contribute to positive change.

Appendix 3 – SDSS National Voice Conference Research Workshops Reflection Notes

Question 1. Solutions and strategies to ensure SDS flexibility in practice	**Question 2. How can ISO and LA work together towards positive change?**	**Question 3. How to improve data collection on an on-going basis to inform policy and practice?**
Training for Social Workers: basics of SDS (options and outcomes), from senior management to front-line.	Proximity and personal relationships: knowing who you're emailing reduces conflict, e.g. picking up the phone.	Make research more personal: put a face to the researcher's name, more personal contact, build trust
Getting management on board on creativity - sometimes the smallest budget meets better outcomes and saves money (e.g. garden slabs to access garden and relax outdoors)	Building good communication, forming alliances	Research, data collection funded through SiRD, like attending the Roadshows.
A clearer roadmap for people from start to finish (who to contact, etc.)	Understanding each other's processes: accurate information, agreed timelines, better for support people	Feedback loop: demonstrate the impact so that participants feel they have agency
Being honest with people, e.g. record unmet needs in a view to meeting them in the future ; needs accountability	HSCPs need to learn from third sector	Resourcing the support to fill out the surveys, boosting lived experience participation
Better communication between ISOs and Social Work	Clearer accountability at LA level	
Recognise that people's needs are individual. ISOs get referrals of people whose package is not suitable.	More consistent application of rights and standards by HSCPs and individual teams across Scotland	
Good conversations and relationships by movng away from bureaucracy and targets		
Long term sickness / loss of Social Workers increase delays and loss of contact		
Lived experience should inform the way originations and professionals work		

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