

Connected Conversations

Learning Report from Outcome 1
Conversations

2025

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INTRODUCTION AND SCOPE

Conversations with disabled adults and unpaid carers have told us that they feel their thoughts and feelings are not adequately represented in national SDS discussions.

We know many feel frustrated and disillusioned by ongoing consultations that lack meaningful outcomes or change.

Disabled adults and unpaid carers want to be heard, but they also seek a safe and flexible space for participation.

We are optimistic that this newly designed model will help close the feedback loop more effectively, aiming to build trust and confidence among disabled individuals and unpaid carers, leading to meaningful change.

This is a report from engagement with 78 disabled adults and unpaid carers giving their thoughts and feelings in relation to 5 questions asked about Outcome 1 of the National SDS Improvement Plan.

Outcome 1 Questions:

These questions are about having choice and control over your support.

1.1 What's your experience of getting help, advice and advocacy when you needed it?

1.2 Were all 4 options available to you and did you get the one that you wanted?

1.3 Have you been able to find information about SDS that makes sense to you?

1.4 If you use a PA, do you feel they are supported?

1.5 What do you think needs to change/ what would it take to close the gap between your experience and living a good life?



APPROACH

From January to March 2025 78 participants responded through a range of methods:

- We received over 56 completed questionnaire results using a Microsoft teams form
- In Control Scotland hosted 2 conversation spaces and spoke to 8 individuals
- Several individual conversations took place within various organisations


All findings were gathered and collated into key themes. All responses are anonymous.

Findings will be presented at the National SDS Collaboration meeting on 2nd April 2025. Feedback from this meeting will then be shared with everyone who has asked to be kept updated of progress

A copy of this report and the action points discussed from the National SDS Collaboration meeting will be shared with all participants who have asked to be kept informed of progress and discussions.

OUR LEARNING

There has been a huge amount of rich and raw data gathered from these conversations, which for ease of interpretation has been described into key themes that we have noticed.



QUESTION 1

1.1 What's your experience of getting help, advice and advocacy when you needed it?

A range of responses was received in terms of ability to access help, advice and advocacy at the time the person needed it. The key themes that have been highlighted are:

Challenges Navigating the System

- The process is bureaucratic, confusing, and inconsistent
- Families often feel unsupported and left to figure things out on their own
- Social workers provide conflicting information, adding to frustration

One participant said, *"It felt like a struggle to get the help, advice and support we needed. Things have felt reactive and transactional rather than proactive and caring"*

Difficulties Accessing Support

- Long delays in securing budgets, especially during transitions. Transitions can often feel uncoordinated and extremely stressful
- Limited funding and high eligibility thresholds restrict access
- Overworked social workers lead to inconsistent service quality

A participant shared, *"It's been incredibly difficult; there is no dignity in the process. It's felt incredibly dehumanizing, and we can see the system is massively under-resourced"*

Lack of Clear Communication & Transparency

- Sense that social workers sometimes withhold or fail to provide essential information
- Families often rely on peer networks or charities for accurate guidance
- Different local authorities apply rules inconsistently
- Frustration that SDS is not being implemented as intended with a lack of accountability

QUESTION 1

(CONTINUED)

Emotional & Mental Strain on Families

- Stress, frustration, and uncertainty negatively impact well-being
- Fear of losing support leads to anxiety and mental health struggles
- People feel undervalued and exhausted from constantly advocating for their needs to be met

One participant shared, *"I would not be here without SDS, and now there is a threat of taking away people's support, it is clear disabled people are not respected anymore"*

Importance of Advocacy & Independent Support

- Advocacy services like Take Control, GCIL, and Crossreach were highly valued and praised for delivering clear information, advice, and support when people needed it
- Advocates play a key role in defending human rights and securing support
- However, not everyone knows about or has access to advocacy services

One GCIL member noted, *"We really have valued the support from the team; without them, we would have been at a loss to navigate through the magnitude of information"*

Variability in Experiences & Service Quality

- Some families had positive experiences with well-informed professionals
One person shared, *"My social worker was so supportive and fought to have my son's needs met"*
- Others found the system to be a *"nightmare"*. Many people spoke of long delays, restrictive eligibility criteria, difficulties in accessing a social worker and inconsistencies in service provision, which caused numerous challenges for people
- Organisations like FAIR Advice, GCIL, Take Control and VOCAL were all praised for providing better guidance and support

QUESTION 1

(CONTINUED)

Transition to Adult Services as a Major Struggle

- Transition from child to adult services is often uncoordinated and stressful
- Delays and lack of preparation leave families feeling unprepared
- Support packages are often inadequate, requiring families to fight for more

Concerns About Future Support & Policy

- Fear that funding cuts will further reduce already limited services
- Services focus on budget constraints rather than individual needs
- Concerns persist given funding issues and potential closure of services
- Reviews are causing additional stress for families with, many fearful of what support they will have access to in the future

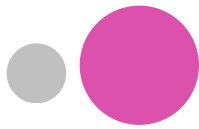
One participant shared *"With the real cuts to local authorities, I am anxious when budget talks are due. I have seen friends have their budgets cut, so I fear its only a matter of time"*

Accessing SDS is widely seen as frustrating, emotionally draining, and difficult to navigate, with families feeling they are often left to advocate for themselves due to a lack of professional support. While many individuals and families find the process of accessing support through SDS challenging and isolating, the role of Third Sector organisations has proven to be invaluable in providing guidance, support and clarity. Their assistance helps bridge the gap between individuals and the complex systems they must navigate.

"It felt like finances were dictating the support options provided, it was cheaper for my daughter to attend a social work group for disabled children rather than be given an SDS package of support where she can go out in the community with her friends"



QUESTION 2



1.2 Were all 4 options available to you and did you get the one that you wanted?

We heard varying experiences from people trying to navigate their preferred option of support. Key themes identified included:

Positive Experiences and Outcomes

- Some individuals successfully accessed their preferred option
- Good experience with social workers and positive referrals made to local services for additional support
- Good support was received from local SDS organisations for some people

One person stated, *"I've had conversations with agencies and social work regarding SDS and I've understood what it is so I haven't had to look for other information."*

Lack of Clear Explanation of Options

- Many individuals were not fully informed about all four SDS options
- Some were only presented with a single option rather than given a real choice
- Explanations were often unclear, requiring individuals to seek out information themselves

"I don't feel the options were explained well, or what the impact would be. I was just given a video to watch but no-one checked if I understood"

Limited Availability of Options

- Some options, particularly Option 2, were effectively unavailable in certain areas
- Local authorities often steered people toward Direct Payments (Option 1) due to limited commissioned services
- Even when an option was chosen, it was not always implemented as expected

QUESTION 2 (CONTINUED)

Bureaucratic Barriers and Delays in Accessing Support

- Long waiting times for assessments (sometimes years) and long waits for funding approvals
- Bureaucratic challenges, such as paperwork, no allocated social worker and banking requirements often complicated the process
- Individuals often felt forced into specific choices due to a lack of available services and options

One participant noted, *"We had difficulty in recruiting a PA, so I asked if the funds could be used for sensory equipment, activities, or to fund a short break but was told no; it was just there for PA recruitment"*

There was a lot of conversation about the pressures social workers are under, the bureaucratic barriers they face that keep them permanently in crisis mode. A desire for social workers to have more time to learn and share good practise was highlighted. One person said *"We really feel for social workers, they have such a high workload with such pressures at all times to save money with no investment in them"*

Challenges with Service Provision and Flexibility

- Even when funding was granted, it could not always be used in a way that suited individuals' needs
- Shortages of care providers, personal assistants (PAs), and local services limited real choice
- Some felt SDS was ineffective because there were no suitable services to use the funding on

"People get more information from other parents than they do from professionals. It's like there is so much secrecy within the professional world because there is such a lack of resources"

"One of the key words is choice, but it doesn't feel that we had a choice, we were pushed onto option 1"

QUESTION 2 (CONTINUED)

The Role of External Support and Self-Advocacy

- Many only understood their options after attending training or seeking independent advice. Partners in Policymaking was mentioned as an excellent source of information. One participant shared, *"If I hadn't completed Partners in Policymaking, then I wouldn't have understood the options and what could be achieved. I led the conversation with social work because I had this additional learning"*
- Many people only understood their options after seeking independent advice or training, as many felt this information was given much more clearly from third sector organisations

"I had to go to a training event in an evening, ran by a charity to teach myself what the options were. Initially I was asked what I wanted, and when I asked what was available, I was told it doesn't work like that. I advised them I didn't know what I wanted as I had never navigated the system before and again I was asked "what did I want". I asked the social worker to leave. It took me 2 years to pluck up the courage and try again"

Frustration with Bureaucracy and certain Social Work Practices

- Families faced miscommunication and inconsistent social worker support. Social worker absence and lack of an allocated social worker were both highlighted as areas of concern
- Some attempts at creative solutions were rejected due to rigid policies
- Financial constraints and policy restrictions sometimes forced families to return unused funds

OPTION 1

SDS options often feel more theoretical than practical, with limited availability, poor communication, and systemic barriers preventing people from accessing truly personalised support.

OPTION 2

OPTION 3

Many families feel frustrated by the lack of genuine choice and flexibility, often having to fight for the support they need.

OPTION 4

The good examples were greatly overshadowed by negative experiences.

QUESTION 3

1.3 Have you been able to find information about SDS that makes sense to you?

People shared their experiences of trying to access information in a way that made sense to them. Again, feedback was varied.

Lack of Clear and Accessible Information

- Many individuals were not informed about independent advice, resources, or support
- Information on council websites was often outdated, and social workers provided inconsistent explanations

One participant described her regular struggle and frustration in trying to get easy-read documents from her local authority in order to discuss SDS processes with her daughter. Whilst, another carer shared she recently read an easy-read document that had been made available by her local authority on non-residential charging policy, yet she still couldn't understand the policy despite it being in an easy-read format. It was still incredibly complex and difficult to understand.

Confusing and Inconsistent Guidance

- Available information was often complex, unclear, or contradictory
- Different social workers gave different explanations, making it difficult to understand the full picture
- Some professionals lacked knowledge of SDS, leading to misinformation



“Even when you think you understand it, you speak to someone in social work and they seem to either over complicate things or tell you your options are more limited than advertised”

QUESTION 3 (CONTINUED)

Reliance on Self-Education and External Support

- Many had to educate themselves through online research, charities, and support organisations
- Independent bodies like In Control Scotland and Carers Trust were often more helpful than social services

“Although organisations like In Control Scotland offer depth and breadth of information about SDS, this is not usually matched by those allocating/administering support. Social work staff do not encourage people to use SDS to the full scope in my experience”

Lack of Transparency in Funding and Decision-Making

- Requests for budget breakdowns were often denied, with local authorities not following national guidance
- Some felt actively discouraged from exploring SDS and made to feel guilty asking for support
- Bureaucratic delays and unclear decision-making processes added stress to families

“I know of a Mum that was told she could use her budget to go to the carnival at the SEC but couldn’t use her budget to actually go on any of the rides when they were there, that just doesn’t make sense”

Empowerment Through Training and Peer Learning

- Programs like "Partners in Policymaking" helped families understand SDS and use budgets more effectively. One participant shared, *“Partners helped me to understand the language that was involved and gave me the confidence to ask about SDS once I knew about the possibilities”*
- Learning from other SDS users inspired individuals to explore creative solutions
- Access to proper training helped some challenge social workers and advocate for better support and change within local authorities

QUESTION 3 (CONTINUED)

Emotional and Practical Barriers

- Navigating SDS generally felt overwhelming, especially for people with disabilities and unpaid carers
- Paperwork and administrative requirements created significant burdens
- The process was described as undignified, exhausting, and frustrating

Challenges with Local Authority Systems and Flexibility

- Local authorities were often rigid and resistant to creative budgeting solutions
- Inconsistent decisions led to frustration
- Arbitrary restrictions, like limiting respite care options, made SDS less practical for some families

Systemic Issues Within Social Work and Local Authorities

- A sense that social workers faced high workloads, financial pressures, and crisis-driven systems
- A hope that opportunities exist for social workers to share best practices and learn from successful cases
- Many individuals did not know their assigned social worker, highlighting a lack of consistent support

The lack of clear, accessible, and transparent information has left many struggling to understand and access SDS effectively. Families often rely on external support, self-education, and advocacy to navigate a system that feels complex, inconsistent, and bureaucratic. Only 1 participant mentioned the SDS Handbook as a source of information. SIRD organisations and carers centres continue to foster a culture of sharing what's good and possible for many

“It feels like local authority structures in place just now keep social workers stuck in crisis mode, always thinking about budgetary constraints”

“We need more investment in social workers to learn about SDS so we can help them be creative and bold and share these lessons in teams and local authorities”

QUESTION 4

People shared a variety of issues and concerns that they feel are important to consider when thinking about Personal Assistants (PA's) being supported.

Some participants chose to share what option they employed their PAs through, whilst others did not disclose.

Key themes identified included:

Lack of Awareness & Information

- Many people are unsure if their PAs receive support or where they can go to find resources. One participant shared, *"I feel like I support them as much as I can, but they could do with more support, but I'm not sure where to signpost them to"*
- Many employers often provide informal support but lack guidance on external help
- Some people spoke about the need to create their own systems and procedures without external support, as nothing was provided to them

"I don't feel my PA is supported well but that's because I'm not supported well to support the PA"

"But lots of families don't know how to support their PAs, or know what good support even looks like"

Recruitment & Retention Challenges

- Difficulty in finding skilled PAs, particularly for specialised needs
- Low pay, poor working conditions, and lack of supervision contribute to high turnover. One participant shared *"I can't get a PA, been without one for over a year now"*

Lack of Training & Professional Development

- Many feel PAs receive minimal supervision, external support, or relevant training
- Employers struggle to secure funding for training. One participant noted *"I'm really struggling to get adequate training secured in the budget"*
- Some PAs might be resistant to training or find it irrelevant or too academic



QUESTION 4

(CONTINUED)

Employer Burden & Responsibilities

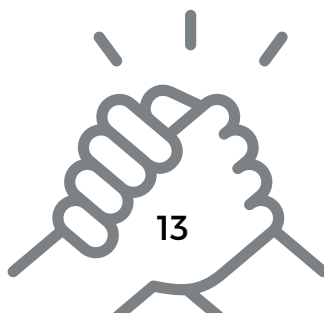
- Families/employers manage staff without sufficient external support
- Navigating employment issues, contracts, and disputes is stressful
- Many feel unsupported by social services, especially in crisis

One participant shared, *"I have PA staffing on top of all the other responsibilities, it's just so much and I feel I can't cope at times"* whilst another shared her recent stress, *"There was a time I thought I was going to have to pay off my PAs because social work took so long to transition us to adult services that we didn't have any idea what our package was going to be"*

Effective PA Relationships

- There was a strong emphasis on maintaining good working relationships through clear communication, fairness, and ensuring PAs have external support systems
- Efforts are made by people to ensure PAs feel supported through open communication, external advice, and networking opportunities. One participant shared, *"I know that for me to keep good staff, I need to invest in their support and training so that my son trusts them and they trust my son. I want our PAs to feel that there is a value to staying with us so that's why I invest heavily in their support and training"*
- Successful recruitment can have a transformative impact on the person, emphasising the importance of the right support

One participant shared, *"My PAs always compliment me on how I support them with any questions or issues they have. I always give time for communication and give space to PA's to express themselves. I don't like being the only voice for my PAs so I seek advice from other places to make sure they get fair advice"*



QUESTION 4

(CONTINUED)

Need for a Centralised Support System

- Calls for an organisation to provide guidance, training, and employment resources.
- Employers seek clear information on contracts, redundancy, and PA rights
- Independent advice services are appreciated at bridging this gap

Staff Wellbeing & Stability

- Training opportunities and networking improve job satisfaction and retention
- A stable team structure fosters trust, reduces anxiety, and ensures continuity of care
- Some families invest in PAs' development more as they feel this leads to better outcomes

Lack of Formal Support for PAs

- A feeling that PAs lack official guidance, support and protection
- A sense that PA roles are often undervalued, leading to poor retention
- It was suggested that some families don't fully invest in supporting their PAs, either due to lack of knowledge or seeing the role as just a few hours of work, leading to high turnover and poor PA retention

Desire for Better Information & Guidance

- Families struggle with legal and employment matters due to a lack of accessible resources
- Social work is often seen as unhelpful or inconsistent in providing support
- Employers want clearer, more centralised information to ease their responsibilities

"I want them to feel this is more than "just a job", so they stay with us and don't go to another family who might pay 50p more per hour"



QUESTION 4 (CONTINUED)

Appreciation for Independent Advice:

- Many families expressed gratitude for receiving helpful advice from independent organisations, such as SIRD organisations, especially when social work is unaware of critical issues like redundancy or employment law
- One participant noted, *“Our SIRD organisation gave me advice about the potential redundancy of staff. Social work didn’t know anything about it, so I was grateful that the independent SDS local organisation gave me the right information so I didn’t break employment law.”*

Overall, the findings highlight systemic gaps in PA support, training, and retention, placing significant strain on employers and PAs alike. There was a clear demand for a centralised support system that could help bridge these gaps, ensuring better working conditions and improved care quality.

What was insightful was the lack of awareness of the PA Network Scotland (<https://panetworkscotland.org.uk>) and the PA Employer Handbook (<https://handbook.scot/the-pa-employer-handbook>) that currently exists.

“Nobody gave me any advice or support on how I was meant to be supporting my PA”

“This kind of information would be so helpful if it was stored centrally so that as soon as you become a PA employer you just know where to go for everything”

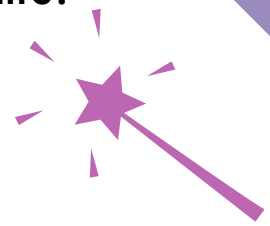




QUESTION 5

What do you think needs to change/ what would it take to close the gap between your experience and living a good life?

Participants were asked to consider if they had a magic wand, what would they do to improve things?



Simplify and Improve Access to Support – SDS must be easier to navigate, with clearer guidance, transparent processes, and flexible funding to meet individual needs

Address PA Recruitment & Retention Challenges – Better pay, working conditions, and structured recruitment support are needed to attract and retain skilled Personal Assistants (PAs)

Enhance Training & Professional Development – Social workers, PAs, and families all require better education on SDS processes, employment rights, and person-centered care approaches

Increase Accountability & Transparency – Clearer complaint processes, independent oversight, and reduced bureaucratic blame-shifting are all essential for a fairer system

Boost Funding & Resources – Greater investment in SDS budgets, PA wages, and alternative care services is needed to close service gaps and improve support options

Ensure Person-Centered & Flexible Support – SDS should empower individuals by prioritising choice, reducing barriers, and allowing support tailored to their unique needs. One participant shared “*Things have always felt service-focused; we have to slot into what’s available, rather than person-led.*”



QUESTION 5 (CONTINUED)

Reduce Employer Burden & Strengthen PA Support – Families managing PAs need centralised resources for employment matters, and PAs require structured guidance and protections

Standardise SDS Across Local Authorities – A fair, nationwide approach is needed to prevent regional disparities and ensure equal access to SDS support

“The Scottish government need to sit down with every local authority and tell them they are all doing it differently and its incredibly stressful for families, we need consistent approaches to SDS”

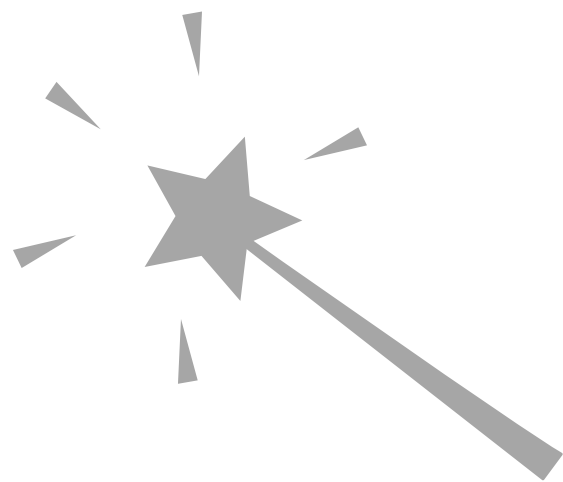
Improve Communication & Information Sharing – SDS policies, processes, and entitlements must be clearly communicated with better documentation and proactive engagement

Prioritise Dignity, Rights & Fair Pay – Social care must focus on empowerment, ensuring fair wages (£15/hr minimum) and recognition for PAs and unpaid carers

A well-funded, transparent, and person-centered SDS system is essential for individuals to live with dignity, independence, and the support they need.

“There is so much information that we need to try and keep on top of then we get comments like “don’t you know that already exists,” like we are at fault for not knowing!

It needs to be easier!”





CONCLUSION

The experiences shared from disabled people and unpaid carers highlight the need for a fairer, more transparent, and person-centered approach to Self-Directed Support in Scotland.

These findings are not new. What we need to consider is why, so long after implementation of The Social Care (Self-directed Support) (Scotland) Act 2013 are people still highlighting the same issues?

Many individuals and families face significant barriers in accessing support and navigating the system, with the good news stories feeling like the exception rather than the norm in terms of experiences with local authorities. In order to close the gap between current experiences and a system that truly enables a good life, the disabled adults and unpaid carers we have heard from tell us what they feel the priority areas for concern are:

Simplify Access & Improve Communication

- o SDS processes must be easier to navigate with clear, accessible information
- o Local authorities should ensure consistent guidance, reduce bureaucracy, and engage proactively with individuals and families

Strengthen PA Workforce & Employer Support

- o Increase PA wages to a minimum of £15/hr to improve recruitment and retention
- o Establish a centralised support system for PA employers, covering contracts, legal rights, and employment guidance





CONCLUSION

(CONTINUED)

Increase Accountability & Standardisation

- o Ensure fair decision-making and prevent inconsistencies across local authorities and uphold individuals' rights

Improve Funding, Flexibility & Person-Centred Support

- o Enhance SDS budgets to ensure sustainable, flexible care options that meet individual needs.
- o Prioritise person-centred planning, reduce unnecessary restrictions and enable genuine choice

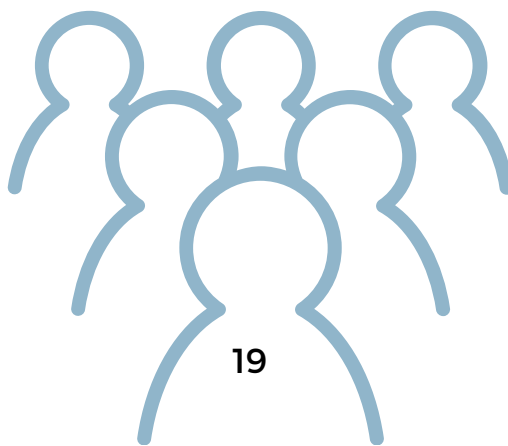
Expand Training & Advocacy Support

- o Provide better training for social workers, PAs, and families to ensure informed decision-making and rights-based care
- o Strengthen access to independent advocacy services to empower individuals and families in navigating SDS

Connected Conversation was established as a means of amplifying the voices of those with lived and loved experience in this National Collaborative Space.

Those voices are telling us that there is a real need for a fairer and more accessible approach to SDS.

Thank you to everyone that shared their thoughts and feelings with us. We appreciate the emotional investment you have taken to have this conversation with us. Your thoughts and feelings will be shared with the National SDS Collaboration and feedback will be provided to those who have asked for further information.



*We would like to thank everyone
that took the time to participate
in this conversation*



*Working for a fairer and more
inclusive system of social care*

www.in-controlscotland.org