National SDS
Collaboration

Connected Conversations

Learning Report from Outcome 2 Conversations

2025

Prepared by :

Karen Procek

in Control
Scotland

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 60 disabled adults and unpaid carers giving their thoughts and feelings in relation to 4 questions asked about Outcome 2 of the National SDS Improvement Plan.

Outcome 2 Questions:

These questions are about the staff involved in your support:

2.1 Do you think the person who helped you with your assessment or review knew enough about self-directed support?

2.2 Did the person explain all the options to you in a way you could understand?

2.3 Did you feel like the assessment or review was focused on you?

2.4 What do you think should change or what could help make your life better?

APPROACH

From March to June 2025, 60 participants responded through a range of methods:

- We received over 56 completed questionnaire results using a Microsoft teams form
- Several individual conversations took place with findings, then shared.

Findings will be presented at the National SDS Collaboration meeting on 2nd July 2025.

Feedback and any relevant action points from the National SDS Collaboration will then be shared with everyone who has asked to be kept updated of progress, as well as a copy of this report.

OUR LEARNING

All responses have been gathered and summarised into key themes.

Some people shared detailed thoughts; others gave brief agree/disagree responses. We're grateful to everyone who took part.

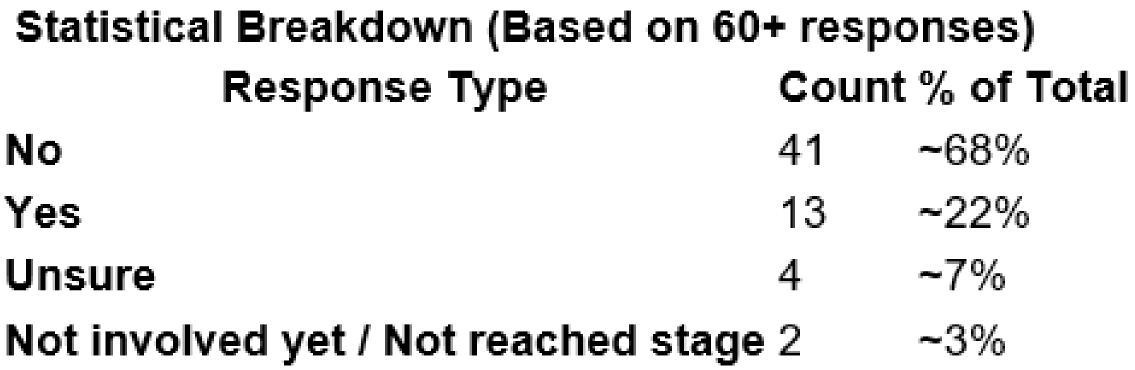
Findings, responses, and any actions will be shared with those who have requested feedback.

These conversations have generated a wealth of rich, often raw, data. For clarity, we've grouped the insights into key themes, which will be shared in the report.

QUESTION 1

2.1 Do you think the person who helped you with your assessment or review knew enough about self-directed support?

Summary of Key Themes and Statistical Breakdown in response to Q1:



Statistical Breakdown (Based on 60+ responses)

Response Type	Count	% of Total
No	41	~68%
Yes	13	~22%
Unsure	4	~7%
Not involved yet / Not reached stage	2	~3%

The findings from responses to the question *“Do you think the person who helped you with your assessment or review knew enough about self-directed support?”* overwhelmingly indicate a perceived lack of understanding, poor communication, and a need for reform in the delivery of SDS information and support.

While some positive experiences exist, they are found to be in the minority from the responses gathered and often framed as exceptions.

From the information we received, we have been able to identify key themes in the feedback:

Widespread Lack of SDS Knowledge Among Professionals

- The majority (68%) of participants reported that they felt the person assisting them did not know enough about SDS
- Multiple responses indicated professionals admitted their knowledge gaps, with several social workers admitting to knowing less than the disabled person. A common phrase that was used on multiple occasions was:

“She told me that it was likely that I knew more about SDS than she did”

QUESTION 1
(CONTINUED)

Poor communication and inadequate explanation of SDS options

- Many participants felt SDS options were not fully explained
- Discussions around support plans, outcomes, or flexibility were often missing or inadequate.
- Many users described poor or one-dimensional conversations focusing on only one aspect (e.g. hiring a PA via Option 1)

"At the time, I didn't know anything, so very much saw my social worker as being an expert. What I now realise is that although she was really nice as a person, she didn't give us a good conversation about SDS. There wasn't a full chat about the various options; she was just focused on the fact that we could employ a PA for my son, and nothing else was discussed. I don't feel she took the time to get to really explore what we wanted as a family and how SDS could help us. We didn't even devise a support plan or identify outcomes. When I later raised this point, I was told that outcomes weren't important"

- For many, there was little or no discussion around: All four SDS options, personal outcomes, flexibility of budgets, and legal rights

"There wasn't a full chat about the various options... nothing else was discussed."

"We didn't even devise a support plan or identify outcomes"

Systemic Inflexibility

- Participants felt the system was more about control and gatekeeping than empowerment.
- There was a sense of repeatedly having to seek permission on how people can use their SDS budget

QUESTION 1
(CONTINUED)

“It feels as if the social work system is the one that holds all the power in terms of how I can live my life”

“ The system has made it so I’m not able to make those independent choices and decisions that many people take for granted in life. As a disabled adult, I have to constantly seek permission from the local authority on how I can spend my budget because a local authority process has been created in that way”

- Changing criteria and decisions without transparency left users frustrated:
  “The goal posts had been moved again... how am I meant to live my life?”

- Some felt social workers applied policies rigidly or interpreted SDS legislation selectively
  ”The system has made it that you are not able to make independent choices.”

Following on from the concerns about systemic inflexibility, people wanted to see greater flexibility and, in particular, more autonomy in how they use their budget, especially in crisis or for personal needs. Underspends and emergency needs were often denied without empathy or rationale.

“I just wanted to use my underspend to support my dad through a health crisis... I was told no. If she had said no, but I'm sorry, then that would have been easier to take, but there was absolutely no compassion or element of humanity”

QUESTION 1
(CONTINUED)

For some participants, this inflexibility within the system has led to a negative emotional impact. Multiple responses describe lasting mistrust, trauma, and stress for some and have created long-term disengagement from social services for others. Some participants felt invalidated, dismissed, or gaslighted by professionals.

> ***"I got gaslighted out of believing that SDS even existed, and the social worker even said she'd never heard of such a thing during the first visit."***

> ***"I am terrified of the repercussions, and I dread a future when my daughter requires adult services."***

> ***"I now don't meet with a social worker unless I have an advocate with me. I just want to live my life, but have to challenge so many of their decisions in order to do so"***

One participant shared that they feel labelled as "being difficult" for repeatedly challenging decisions, and believed that this perception invalidates their genuine concerns. The statutory principle of collaboration is absent, and opportunities for shared problem solving and trust building are missed.

We know that when the approach is person-centred, alternative perspectives are welcomed, creating understanding of the reasons behind the challenge and reframing "difficult" people as valuable allies for positive change.

There was a real desire for more co-production and for professionals to walk alongside individuals rather than direct them.

Positive Experiences

- While some positive experiences exist, they are found to be in the minority from the responses gathered and often framed as exceptions.
- A small number reported knowledgeable and supportive social workers who provided them with good support and appropriately signposted them to local SIRDS ie SDS Forth Valley and LCIL being mentioned.
- These experiences often included shared understanding, active listening, and creative problem-solving.

QUESTION 1
(CONTINUED)

“She was really good in helping me achieve my outcomes and my dreams from my plan as she was knowledgeable about the process and how we could make things happen within the “rules”

“Everyone has been very, very nice... I have always had good experiences with social workers”

These accounts highlight what effective, relationship-based support can look like; however, from the number of participants that engaged in this connected conversation, these positive experiences were outnumbered by poor experiences.

The feedback from this question highlights an overwhelming response that indicates a perceived systemic shortfall in knowledge, communication, and empathy in how SDS is being implemented.

Despite some positive experiences, most respondents describe significant barriers due to uninformed, inflexible, or disempowering practices by professionals. There’s a clear need for:

- Better training for social workers on SDS
- Improved communication and transparency
- Genuine partnership with service users
- A shift from gatekeeping to enabling

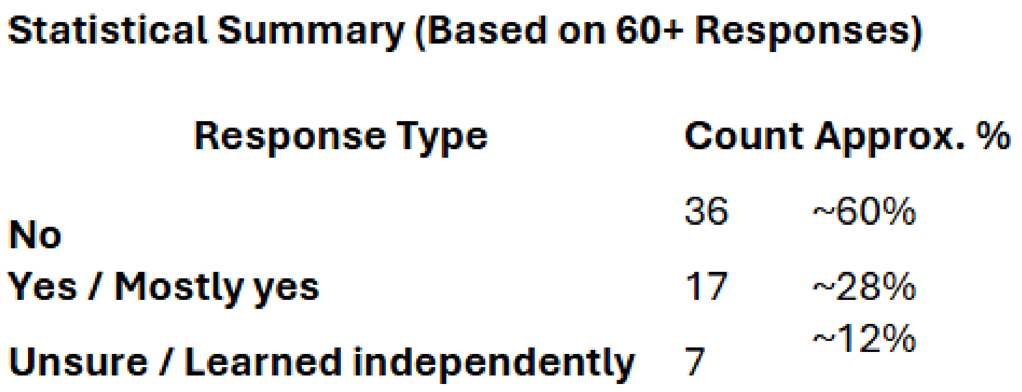
“I genuinely believe social workers don’t enter the profession to harm people or make people's lives difficult; they want to make a change for people, but some people have lost that skill because they're trying to navigate challenging systems and have forgotten the values of why they came into Social Work in the first place. The social has been lost in Social Work”

QUESTION 2

2.2 Did the person explain all the options to you in a way you could understand?

This question allowed us to review responses from participants reflecting on whether the person who supported them during their SDS assessment or review explained all four SDS options in an understandable way.

The findings reveal that the majority of participants did not feel the options were clearly explained, with many relying on self-research or external support organisations. This lack of clarity significantly impacts individuals' ability to make informed choices, reinforcing power imbalances and systemic barriers within SDS delivery.



Statistical Summary (Based on 60+ Responses)

Response Type	Count	Approx. %
No	36	~60%
Yes / Mostly yes	17	~28%
Unsure / Learned independently	7	~12%

- Over half of the participants said SDS options were not explained clearly.
- Just over a quarter felt the options were explained understandably.
- The rest relied on self-learning or external organisations.

This lack of clarity significantly impacts individuals' ability to make informed choices, reinforcing power imbalances and systemic barriers within SDS delivery.

QUESTION 2

(CONTINUED)

Key Themes Identified:

Incomplete Information

- Many participants felt that only one SDS option was presented, often Option 3 or Option 1, without a full explanation of the 4 options. A few participants responded, saying they felt they were *"told"* what option they would be on, rather than having a balanced conversation that meets the statutory duties that ensure informed choice.

- Some participants were told misleading or incorrect information: ***"They made up a new option that isn't even one of the four"***

- Participants reported a feeling of being steered toward a preferred option by professionals. ***"I was told 'just stick with what we give you,' that turned out to be Option 3."*** or another participant who shared: ***"No – it was first put into place at hospital discharge, and it was all very focused on option 3 care at home without anything else being discussed. Reviews haven't mentioned changing options, so it's all just stayed as it is"***

Reliance on Self-Research

- Several participants only came to understand SDS through:
- Independent online research and accessing community forums
- Community organisations (ie, SIRD Organisations such as LCIL and SDS Forth Valley were mentioned. We do know from some participants that Social Workers are signposting people appropriately to the relevant SIRD organisation which is really postive.
- Trial and error

"I had to research everything myself."

"LCIL have been great in helping me understand things"

QUESTION 2
(CONTINUED)

Emotional Toll and Lack of Support

- A number of individuals reported feeling ashamed or embarrassed about not understanding the options, leading to silence and withdrawal.
- Lack of clarity led to users feeling confused or unintelligent, which prevented them from asking for help, thus remaining "stuck" in the system

"I felt really stupid not being able to understand the 4 options. That made me afraid to ask"

- Some felt unsupported and forgotten, with no follow-up after initial discussions. One participant shared,

"I have had support from social work for over 20 years now as a disabled adult, and there has only ever been 1 social worker that I feel has really listened and advocated on my behalf for me"

Power Imbalance

- Participants expressed that professionals often controlled the narrative, leaving little room for questions or empowerment. There was little opportunity for good conversations or meaningful dialogue.

"I wasn't given options – I was just told what I was getting"

- Decisions were made without discussion and came across as a "take it or leave it" approach, especially during hospital discharges or reviews.

Positive Practice

- Some participants shared examples where professionals explained options clearly or directed them to the right supports.

"Yes, the woman who supported me in my assessment and review knew what she was talking about. It was a really nice experience"

- However, even some "Yes" responses noted that the process was overwhelming, especially for newcomers to the system of health and social care.

"Yes, however, there's a lot of information, and for 'newbies' to the social care sphere, this is daunting and confusing"

QUESTION 2
(CONTINUED)

Responses to question 2 indicate that the majority of participants did not receive a clear, understandable explanation of the SDS options, despite us knowing that it is a statutory duty to explain the options in a meaningful way.

Many were either misinformed, partially informed, or directed to self-educate.

This has led to some people having mistrust in the system, not using SDS, increased emotional stress or facing barriers to exercising informed choice.

The failure to explain SDS options clearly:

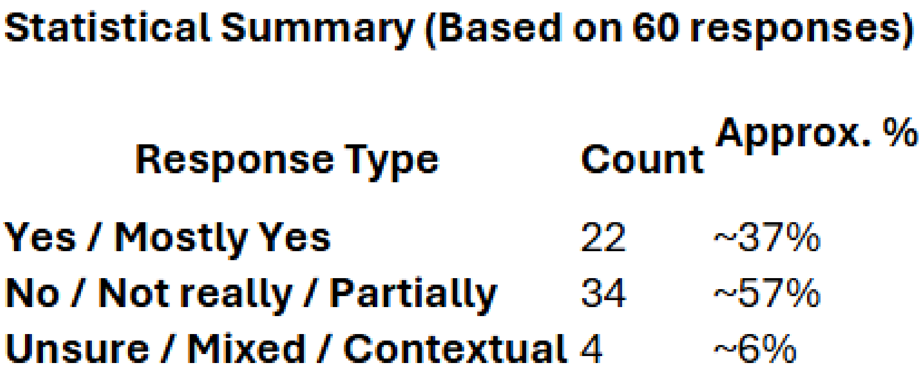
- Undermines informed choice and control
- Leaves individuals vulnerable to options that are not suitable for them or their family
- Contributes to mistrust in services
- Places the burden of learning on already-stressed individuals or families
- Reinforces a power imbalance between professionals and service users.

This feedback clearly indicates a systemic gap in how SDS options are communicated. By improving explanation practices, we can significantly enhance people's ability to access and shape the support they need, in line with the founding principles of Self-Directed Support: choice, control, and dignity.

QUESTION 3

2.3 Did you feel like the assessment or review was focused on you?

This question summarises 60 responses to the question: *"Did you feel like the assessment or review was focused on you?"* A common concern was the lack of personal focus—particularly for carers—who often felt sidelined or judged. Many described assessments as funding-driven or administrative, rather than centred on real needs. Some expressed fear and mistrust due to perceived budget pressures and a lack of transparent communication. Positive experiences were less common but highlighted the value of supportive, communicative social workers and good preparation. These interactions felt more person-centred and inclusive.



Statistical Summary (Based on 60 responses)

Response Type	Count	Approx. %
Yes / Mostly Yes	22	~37%
No / Not really / Partially	34	~57%
Unsure / Mixed / Contextual	4	~6%

- Just over 1 in 3 respondents felt the process was genuinely focused on them.
- More than half said it was not focused on them or their real needs.
- Some responses described mixed experiences.

Key themes that have been identified from participant feedback include;

Lack of Personal Focus (particular focus on carers)
A lack of personal focus during conversations was the most common response from 57% of participants with many highlighting key concerns for carers.

- Some felt assessments were funding-driven rather than needs-based

“It was about cutting costs as much as possible.”

QUESTION 3

(CONTINUED)

- Several mentioned reviews feeling more like an administrative process rather than a meaningful interaction

"The reviews now are just tick box exercises and alternatives are not mentioned"

- Reviews and assessments were centered on the cared-for person, not including the carer or wider family. This left many carers feeling uninformed about choices (e.g., how funding could be used)

“It felt everything then centred around this throwaway comment I had made… I didn’t realise I could spend the funds differently”

“The social worker was lovely, but the conversation could have gone a lot better”

- Carers highlighted key issues such as finding Adult Carer Support Plans hard to access or them not being seen as a priority, or that their role as a carer is rarely recognised or reviewed within the review process. It was noted that some carers felt overlooked or minimised within assessments. Some carers even felt they had been unfairly judged when trying to access support for their family.

- Others described hostile or judgmental attitudes (e.g., parent blame and defamation) which contribute to a sense of fear, judgment and mistrust in the system of support. Some reported having been mischaracterised or even blamed within assessments.

“It was implied that I had Munchausen’s by Proxy (Fabricated or Induced Illness), and this has followed me everywhere since, cropping up in reports from schools and educational psychology services”

QUESTION 3
(CONTINUED)

Positive Experiences – When the Process Worked

The second most common theme from 38% of participants, was to highlight a positive response, feeling that the assessment or review was focused on them.

Strengths that were identified included:

- Feeling listened to, included in the planning process

"Yes, we were asked as a family what was best for my son"

"Every review has always been focused on me"

- Some social workers were described as being understanding and supportive:

"It felt focused on me because they would go over different things and ask if I understood or if I was sure about what we had discussed"

"I do feel there is a change in social workers, and they are keen to learn more and learn more from people like me"

- Though some successful interventions were often linked to the disabled adult or carer being well prepared in advance of the meeting:

"Yes – I did my homework... taking responsibility for my family's situation."

"I had a bit of understanding of what I would be asked and sketched out my answers"

Funding Pressure Over Personal Needs

Funding-driven decisions over needs-based support were a recurring theme among participants as a real focus of concern and dissatisfaction.

- Participants described an overwhelming sense that decisions were led by budget restrictions, not care planning:

"Fear that my support will be taken away... budget cuts expected"

QUESTION 3

(CONTINUED)

- Multiple participants described fear or suspicion that funding constraints heavily influenced decisions. Social workers are seen as constrained or non-committal due to pressures from “money people” behind the scenes

“She understood... but until she gets senior management approval, she is always non-committal”

“It certainly partially focussed on trying to improve things for my son, but whether the objectives discussed were the most that could be achieved, I am not sure that they were”

- Some observed that social workers were empathetic but constrained by senior management or budget approvals.

“The money people are behind closed doors, never seen but have a huge impact on people's lives; they are the ones putting the social workers in uncomfortable positions”

This emotional toll was highlighted by one participant who shared

“I just know they will want to cut my budget even though my needs haven’t changed. I'm scared and I'm not sleeping”

As mentioned previously, fear, distrust and emotional strain placed on participants meant several described needing advocates present due to stressful or hostile interactions with social work. While some individuals reported positive experiences where they felt heard and involved, the majority of respondents (57%) indicated that their assessment or review was not focused on them personally. The strongest negative themes centre around lack of personal engagement, budget-driven decisions, and carer marginalisation.

Trust in the assessment process appears fragile for many, with several carers citing experiences of fear, judgment, or systemic constraints. Where the experience was positive, it often depended on the social worker’s attitude, communication skills, and the individual’s prior knowledge.

From the feedback received, it's clear there is a need from people to have

- Assessments that are co-produced and centred on the person and their individual needs and outcomes rather than service availability and tokenism
- A whole family approach is priortised
- Good conversations that are trauma informed

QUESTION 4

“What do you think should change or what could help make your life better?”

Within connected conversations discussions, it's important to allow people space to share what they feel would help to make things better. We have summarised the key feedback that was received:

Better Training and Understanding of SDS Among Social Workers

This was the most frequent suggestion that was made from 22 participants. Many people feel that social workers don’t fully understand SDS or how to apply it effectively.

"There are good social workers out there, but I just get the sense that they don’t know as much about SDS as they need to"

"Better trained Social Workers. Many of them don't appreciate the difficulties of being a carer supporting their family member"

"Local social services actually knowing about SDS and not actively discouraging or delaying access to it would be a good start"

People want to see skilled, knowledgeable, and compassionate social workers, who are often described as well-meaning but undertrained on SDS specifics and disability rights.

“They need to understand what SDS is actually for”

“More training, especially in complex disabilities and SDS flexibility”

“The ‘social’ is missing from social work”

QUESTION 4
(CONTINUED)

Flexibility, Personalisation, and Fair Access to Budgets
The next most common theme suggested was the need for flexibility, personalisation, and fair access to budgets with 20 people highlighting this issue. People want to make meaningful, creative, and needs-based use of SDS, for budgets to be flexible and based on individual needs and not be restricted to by rigid or resource-led systems.

"We were told our SDS budget was for a PA only and there was no wiggle room"

"Needs far more flexibility and more information on what is available locally that could be useful"

"It's a postcode lottery and depends on how hard the assessor pushes your case"

"Let us use unspent budget on positive outcomes instead of being blocked"

Improved Communication, Transparency, and Accountability
18 participants called for more honest and proactive communication, with clearer guidance. Participants are frustrated with bureaucracy, lack of updates, and no recourse when things go wrong. People shared their experiences of a postcode lottery or feelings that decisions are made arbitrarily, without clarity or fairness.

"The person doing my assessment not being constrained by lack of money or services"

"Too many systems and processes that just get in the way"

"I never received an apology, acknowledgement of errors, or accountability. This needs to change"

"The system feels secretive—there's no transparency"

"Different families using SDS in the same way are treated differently"

Repeated frustrations around delays, excessive paperwork, and repeated reassessments were raised as an issue that needs to be addressed.

"It takes too long to go from assessment to plan to funding"

"In early days of SDS there was less red tape and it worked better"

QUESTION 4
(CONTINUED)

A desire for regular check-ins, consistent workers, and responsive communication came through strongly from participants:

“It’s hard when you don’t know who to contact or what’s allowed”

“We need continuity—not a different worker every time”

Availability and Suitability of Services
Even when SDS is in place, it’s not helpful if appropriate services aren’t available or suitable, especially for people with complex needs, so there is a real desire from participants to have better availability and sustainability of services.

"The issue isn’t just about knowledge of SDS but about the local authorities commissioning the right services in their communities"

"We were left 6 months with no support because the service didn’t exist"

"Support services being available – something to spend the money on"

“There’s no point in choice if the services don’t exist”

“Our bespoke support failed because it wasn’t set up officially”

Recognition and Support for Unpaid Carers
Unpaid carers feel overlooked and undervalued, often struggling without proper financial or emotional support.

"Carers want their own needs recognised and supported"

"More help and support is needed for our young people, especially for parents who work"

Carers want to be recognised as equal partners in care, not left out or overlooked.

QUESTION 4
(CONTINUED)

Ending financial barriers to support
Several participants expressed strong concerns about the financial burden of accessing support through SDS, with five people explicitly calling for an end to care charges**.**

One participant stated, ***"To stop the care charge which is causing poverty,"*** while another urged, ***"Stop taking money from them, they shouldn't have to pay for support at all, it's all wrong."***

Another highlighted how ***"contributions are leaving disabled people with limited money to survive,"*** and that the system should enable ***"a good life without worrying about costs."*** Delays due to financial processes were also raised, with one participant noting, "***Lost so many workers due to finance not going through."***

These comments point to a clear demand for a more equitable, needs-led system that does not penalise disabled people or their families financially.

CONCLUSION

The voices gathered through these questions paint a clear and urgent picture: Self-Directed Support is not being delivered in a way that aligns with its core principles of choice, control, and dignity.

Through conversation, people shared experiences of confusion, poor communication, lack of clarity, and systemic inflexibility. Only a minority described positive, empowering interactions, highlighting what's possible when SDS is delivered well but also underscoring just how rare those experiences are.

A recurring theme is the power imbalance between professionals and those seeking support. Many respondents described being told what option they would receive, not being offered the full range of choices, or being left to educate themselves. Carers in particular felt invisible in the process—overlooked, unsupported, and, in some cases, actively judged.

Assessments too often felt like a tick-box exercise, driven by budgets, not needs. Where assessments did feel personal and compassionate, it was often thanks to the dedication of individual workers rather than a consistently supportive system.

Participants called clearly for change: better training for social workers, clearer and more honest communication, greater flexibility and personalisation, and an end to financial barriers that punish those who need support most. People want professionals who will walk alongside them, not gatekeep. They want to be seen, heard, and involved as equal partners.

Some of what has been reported indicates a failure in statutory duties, where practitioners have not offered and meaningfully explained the 4 options. Other reports indicate practice that falls below the level indicated by the SDS Framework of Standards, which has been accepted nationally to be what good looks like. Though we did hear of person centred assessments and effective collaboration on support planning.

CONCLUSION
(CONTINUED)

None of the suggested improvements are unreasonable; they are the foundation of rights-based, person-led social care that has already been agreed in the Self-Directed Support Framework of Standards.

It’s time to shift from tokenism to genuine partnership. From rigid systems to relational ones. From compliance to co-production.

Because at its heart, SDS should not be about navigating a system—it should be about living a good life.

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

in Control® Scotland

Working for a fairer and more inclusive system of social care

www.in-controlscotland.org