Connected Conversations

Learning Report from Outcome 4 Conversations

2025/26

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

Outcome 4 Questions:

These questions relate to local leaders listening to your voice.

4.1 Is there an opportunity for you to feed back your experiences, good or bad, locally to make change?

4.2 Are you on the option you wanted, and if not what is being done to rectify this?

4.3 Have you heard of the SDS Framework of Standards? If so, have you used them and how?

4.4 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 September to December 2025, 93 participants responded through a range of methods:

- We received over 28 completed questionnaire results using a Microsoft Teams form
- Several individual supported conversations took place
- 4 facilitated group conversations took place with findings received from members of the Coalition of Carers, In Control Scotland, SDS Borders Forum and a joint GCIL & LCIL group space.

Findings will be presented at the National SDS Collaboration meeting on 4th February 2026.

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 to share their story.

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

Is there an opportunity for you to feed back your experiences, good or bad, locally to make change?

Participants were asked whether they have opportunities to feed back their experiences locally and whether this leads to change. Their responses reveal not a lack of willingness to engage, but a system that makes safe and meaningful feedback extremely difficult.

Under the Social Care (Self Directed Support) (Scotland) Act 2013, accompanying statutory guidance, the National SDS Improvement Plan, and the SDS Framework of Standards, local authorities are required to:

- involve people meaningfully in decisions about their support
- learn from lived experience
- improve services based on feedback
- ensure transparency, dignity, and participation

Feedback is therefore not optional; it is integral to lawful, person-centred practice.

What people describe instead is a system where feedback often feels risky, ineffective, and disconnected from influence. Many experience consultations, reviews, or complaints processes as symbolic rather than transformative. A consistent theme that has been presented is the erosion of trust: people do not believe that speaking up leads to learning or change, and many fear it will actively make their situation worse.

Summary of key themes identified in response to Q1:

Theme 1: Impactful feedback

Participants described a wide range of formal mechanisms: reviews, consultations, forums, surveys, and complaints, but repeatedly questioned whether these had any impact. The gap between being *asked* for views and seeing *change* was striking.

Several participants described feedback processes as existing *"on paper"* but not in practice. One person stated plainly that while opportunities technically exist, ***"in reality, no one cares because there is absolutely no accountability."***

QUESTION 1

(CONTINUED)

Another reflected that families are asked at reviews how things are going, but ***"I don't think this information goes anywhere or constitutes feedback."***

This disconnect directly conflicts with statutory SDS guidance, which states that reviews and engagement should inform learning, service improvement, and outcomes. Feedback loops are intended to close, not stall.

Participants also described feedback fatigue, the sense that repeatedly sharing experiences without seeing change is draining and demoralising. Tokenistic consultations, inaccessible digital platforms, and poorly timed processes only deepen disengagement. As one person put it, consultation ***"only happens when the local authority wants it."***

What people want is simple and reasonable: feedback that is acknowledged, acted upon, and reported back on. Without this, trust collapses and engagement withers, undermining the purpose of participation set out in SDS policy.

Theme 2: Safe to speak

Fear runs through the feedback we received. Many participants described self-censoring or remaining silent because they believe speaking up could lead to cuts, increased scrutiny, or loss of essential support. This fear includes people who are otherwise managing well, who worry that visibility itself is dangerous.

One participant explained that ***"there is a massive fear that if you give feedback, your hours will be cut."*** Another noted that even people with positive experiences are ***"scared to draw attention to themselves."***

This indicates a deep power imbalance. Local authorities control access to support, assessments, and budgets, while people experiencing social care see themselves as having little leverage. In this context, feedback becomes a risk calculation rather than a right.

This directly contradicts the principles underpinning SDS legislation. A system in which people reasonably fear retaliation for honest feedback cannot be described as person-centred, rights-based, or compliant with statutory duties. The SDS Framework of Standards explicitly requires participation to be safe, respectful, and collaborative.

QUESTION 1
(CONTINUED)

What people want is protection: reassurance that raising concerns will not be penalised, and that honesty will be met with support rather than punishment. Without that, choice and control cannot exist in any meaningful sense.

Theme 3: Dialogue, not defence

Participants consistently described feedback being reclassified as formal complaints, even when they had not intended to complain. This shift was experienced as silencing rather than supportive.

Several people described sending feedback only to be told their ***"complaint had been received,"*** despite explicitly not making one. Once relabelled, feedback entered adversarial processes with long timescales, internal investigations and little perceived independence.

One participant summed this up: ***"They investigate themselves, so nothing changes."***

This defensive posture undermines the learning culture explicitly promoted within SDS statutory guidance.

Informal feedback and early concerns are intended to support reflective practice and service improvement. When every issue is escalated through formal processes, nuance is lost, and trust erodes.

People want proportionate responses: clear distinctions between feedback, concerns, and formal complaints, and opportunities for early resolution. These are principles of good public administration and are fully aligned with existing SDS standards, not additional demands.

Theme 4: Collective voice

Across the data, participants expressed greater trust in third sector and peer-led spaces than in statutory systems. Organisations such as GCIL, LCIL, SDS Borders forum and the Coalition of Carers were described as safer places to be heard.

One participant noted that ***"a collective voice is listened to more than my individual one."*** Others said they could *"only give feedback in groups like this,"* or that if they wanted change, they turned to voluntary organisations because statutory routes felt unsafe.

QUESTION 1
(CONTINUED)

This highlights the essential role of independent advocacy, a role explicitly recognised within the SDS Framework of Standards. The reliance on the third sector to make feedback safe indicates uneven delivery of statutory responsibilities by local authorities.

One person shared, ***"local authorities need to stop seeing a collective voice being a perceived threat and do more to support the coming together of people locally"***

People want sustained, properly funded independent advocacy and participation infrastructure so that voices do not disappear when individual capacity runs out. This is not a discretionary extra; it is integral to equitable participation.

Theme 5: Capacity to engage

Many participants described living in constant crisis. They are juggling caring, work, health, poverty, and bureaucracy. In this context, feedback processes, particularly slow, written or formal ones, are inaccessible.

As one participant explained: ***"When you're barely surviving, you don't have the energy to give feedback."*** Another said bluntly: ***"This is my life. I need answers now, not in 28 days."***

The SDS Framework of Standards emphasises responsiveness to individual circumstances. Feedback systems that assume people have time, stability and emotional capacity fail to meet this expectation.

People want feedback routes that work during crisis, not only when life is calm.

Given current eligibility thresholds, it is primarily people with critical needs who are receiving support, meaning inaccessible feedback systems exclude the very group SDS is designed to serve.

Theme 6: Accountability and transparency

Finally, participants repeatedly asked: who is accountable? Who monitors local authority practice, investigates concerns independently, or ensures SDS law is applied consistently?

QUESTION 1
(CONTINUED)

People described opaque decision-making, ignored FOIs, unclear budget criteria, and consultations they believed were ethically flawed or manipulative.

One participant asked directly: ***"Who investigates local authority poor practice?"*** Another stated plainly, ***"There is absolutely no accountability."***

Another participant noted ***"People have been polite to politicians and leaders for so long and things never change, people have had enough. Enough telling our stories, there needs to be action."***

Transparency and accountability are explicit requirements within SDS standards and broader public law duties. Where people cannot see how decisions are made or challenged, those standards are not being delivered.

The emotional impact of this absence is severe. Participants described despair, abandonment and dehumanisation. ***"Leaders don't care that I'm barely surviving and existing either locally or nationally; if they did, they would fix things".***

Some expressed fear for their safety and wellbeing as unpaid carers and disabled people. One participant shared, ***"The system is more upsetting and difficult than it is to look after my medically complex granddaughter. My life has stopped."***

What people want is oversight that is visible, independent and trustworthy so that fairness does not depend on resilience, legal knowledge or personal sacrifice.

Final Reflection:

Taken together, this evidence shows that people want to engage and influence change, and that difficulties with feedback arise from structural and cultural barriers rather than apathy or unrealistic expectations. People are describing environments that actively block participation, silence concern, and erode trust.

Crucially, many of the issues raised relate to things local authorities are already required to provide, including:

QUESTION 1
(CONTINUED)

- safe and meaningful participation
- regular and effective reviews
- transparency in decision-making
- access to independent advocacy
- learning from lived experience

These are not aspirational goals; they are embedded in SDS legislation, the National SDS Improvement Plan, and the SDS Framework of Standards.

People are telling us that when feedback feels unsafe, futile or exhausting, SDS cannot function as intended.

Fixing feedback, therefore, requires more than procedural tweaks. It requires a cultural shift, from defensiveness to learning, from control to trust, and from symbolic engagement to shared responsibility.

If leaders are serious about choice, control and person-centred support, they must create systems where people can speak honestly without fear, see the impact of their voice, and trust that accountability is real. Until then, feedback will remain a risk, and the promise of choice and control will remain unfulfilled.

QUESTION 2

Are you on the option you wanted, and if not what is being done to rectify this?

Participants were asked whether they are on the Self-Directed Support option they wanted and, where they are not, what action is being taken to address this. Responses show a complex and uneven picture.

While a number of people are on their preferred option and report positive outcomes, many others describe a system in which choice is heavily shaped by local service availability, workforce shortages, and the degree to which individuals are able, or able to continue, to push for what they need.

What emerges most strongly is that SDS can work well, but not consistently.

Outcomes vary significantly depending on local service models, commissioning decisions, and access to skilled support. In areas where these elements align, people report positive and sustainable experiences. In others, choice is limited, support is inconsistent, and control exists more in theory than in everyday practice.

As a result, people's experiences are shaped less by their needs and choices and more by postcode, provider availability, and the capacity to persist within the system. This sits in direct tension with the core values of SDS: choice, control, dignity, and equality.

Summary of key themes identified in response to Q2:

Theme 1: Choice constrained by availability

Many participants described being unable to access their preferred SDS option, not because it was unsuitable, but because alternatives were not realistically available.

Option 2 and Option 3 were frequently described as underdeveloped or absent locally, particularly in children and families' services and in rural or semi-rural areas. One participant shared ***"I wanted to explore Option 2, only to discover there are absolutely no services locally for children and young people, it's been 5 years now and still none exist"***

As a result, people were often presented with a binary choice: take on Option 1 and the responsibilities of being an employer or go without support altogether.

QUESTION 2
(CONTINUED)

Several participants explained that while Option 1 can work well, it only does so when recruitment is successful and sufficient support is in place. Without this, it becomes extremely difficult to sustain.

One person reflected that although Option 1 can be ***"great when you employ the right person,"*** when recruitment fails **"you just accept you had no option but to be an Option 1 employer."**

Others were explicit that the role was imposed rather than chosen, describing being told they *had to be the employers,* with ***"no conversation about any alternative because there just wasn't one available."***

Under SDS legislation, local authorities have a statutory duty to offer all four options and to support informed choice between them. Participants' accounts suggest that where only one option is practically available, this duty is not being met. People spoke about being channelled into Option 1 due to service gaps, provider refusal linked to complexity or risk, or budgets too low to attract commissioned services. In these circumstances, choice becomes procedural rather than meaningful.

Several participants described being forced into arrangements they had actively said they did not want or did not feel able to manage. One participant shared, ***"There is absolutely no way to challenge, and I can't afford a solicitor. That's what local authorities rely on, not being challenged because we can't afford lawyers' fees and can't manage the emotional trauma it would cause.***

In some cases, these arrangements led to financial strain, stress, and deterioration in health. As one participant stated, ***"Option 2 and 3 are unavailable... Option 1 is the only option open to me realistically, however I do not want a direct payment."***

This reflects a system where choice is shaped by availability, not preference, directly undermining the intent of both the SDS legislation and the SDS Framework of Standards, which is clear that no option should be treated as a default.

Theme 2: Option 1 works when its supported and chosen

Option 1 was the most commonly reported SDS option among participants.

Where it was freely chosen and appropriately supported, it was often described positively. Some participants spoke about managing Direct Payments successfully for many years, while others highlighted the autonomy Option 1 gave them to live independently, participate in their community, and shape support around their lives. One participant described Option 1 simply as ***“allowing me to live a great life.”***

Another said, ***“I have managed direct payments for a number of years and it works really well for us,”*** with another commenting ***“We get an Option 1 which meets our needs”***

However, these positive experiences were not evenly distributed. More commonly, Option 1 was described as something people had arrived at through exhaustion rather than choice. One person shared ***“That’s when I realised I had no option and would need to be an employer...it left me worn down, exhausted and I had to give up my job to look after my granddaughter”***

Many participants said they had been clear that they did not want to be employers or financial guardians, but felt they had no realistic alternative.

One participant stated plainly: ***“I was very clear I didn’t want to be an employer... it’s a lot of pressure, and there is very little advice or support.”***

Whilst another shared ***“Got to the point that I had to close my complaint and just accept I had no option but to be an option 1 employer. I had no support”***

Participants described taking on employer, payroll, and legal responsibilities at points of crisis, including hospital discharge, service withdrawal, or family breakdown. The absence of timely reviews compounded this pressure, leaving people unsupported as circumstances changed. Several carers described severe exhaustion, giving up paid work, and declining physical and mental health as a direct result of managing unsupported arrangements.

One participant reflected, ***“I nearly didn’t make it. Trying to manage this was incredibly stressful.”***

QUESTION 2
(CONTINUED)

These experiences sit in clear tension with the SDS National Improvement Plan's commitment to proportionate support, sustainability, and dignity, particularly for unpaid carers, and risk undermining the significance of Option 1 as an achievement fought for by disabled people to secure autonomy and control, not a last resort response to commissioning failure.

They also raise concern against the SDS Framework of Standards, which emphasises sustainability, respect for individual circumstances, and avoiding arrangements that place people at risk. Option 1 emerges not as inherently problematic but as highly sensitive to the presence or absence of adequate support, contingency, and review. When imposed without these safeguards, it becomes unsustainable and, for some, actively harmful.

Theme 3: Barriers to access, information, and review

A significant number of participants were not accessing SDS at all. People described being told they did not meet eligibility thresholds, being unable to contact social work, or receiving inaccurate or incomplete information about their rights. Some were discouraged from applying altogether, including being told by health or mental health professionals that there was no point in contacting social work because of system pressures

Where assessments did take place, participants frequently described them as rushed, inconsistent, or conducted by staff with a limited understanding of SDS. One participant noted, ***"I had a social work assistant do my assessment, and I knew she was so uninformed about the process"***

One participant described an assessment lasting just twenty minutes, where they felt the social worker ***"didn't listen or hear me,"*** and where decisions felt driven by opinion rather than entitlement. Others reported that it was independent organisations, not statutory services, that ultimately helped them understand what SDS could be used for.

QUESTION 2
(CONTINUED)

Reviews were frequently described as missing, significantly delayed, or focused on reducing support rather than responding to changes in need.

Several people said they had not had a meaningful review for years. In some cases, budgets were removed or reduced without warning, or children's budgets failed to transition appropriately into adulthood. As one participant noted, ***"No one picks up the phone these days,"*** capturing a wider sense of disengagement and inaccessibility.

These experiences undermine the SDS National Improvement Plan's commitments to transparency, informed choice, and early intervention. They also indicate inconsistent application of the SDS Framework of Standards, particularly regarding skilled practice, access to information, and timely review.

Theme 4: The need to fight the system

Many participants described having to "fight" the system to secure the SDS option or budget they believed they were entitled to. This included making formal complaints, escalating to senior managers, involving elected representatives, or pursuing legal action.

One participant reported having to undertake a Judicial Review simply to secure control over their budget.

Others described withdrawing complaints or accepting unsuitable arrangements because they were exhausted or felt nothing would change.

Participants consistently highlighted that where a person lives continues to shape what options are available and how flexibly SDS is applied. Comparisons between neighbouring local authorities were common, with one person noting that while one area seemed to have options, they themselves had experienced ***"years without support."***

These accounts point to the emergence of a two-tier decision-making system: those with the knowledge, confidence, health and resources to challenge decisions, and those without.

This directly contradicts the SDS National Improvement Plan's commitment to fairness and equality of access, and conflicts with the SDS Framework of Standards' emphasis on collaboration, dignity, and transparent decision-making.

Where conflict becomes the primary route to securing support, SDS cannot be said to be operating as a rights-based system.

Final Reflection

Participants' feedback makes clear that SDS can work and, when it does, it can be life-changing.

Many people are managing well on their chosen option, particularly where support is stable, information is clear, and reviews are meaningful. However, too often these positive outcomes exist *despite* the system rather than because of it.

Choice is frequently constrained, control is conditional, and dignity is compromised by service gaps, inconsistent practice, and postcode variation.

The statutory duty to offer all four SDS options is not always realised in practice, particularly where people are steered into Option 1 due to a lack of alternatives or insufficient commissioning. In these circumstances, SDS risks becoming a mechanism for managing scarcity rather than enabling good lives.

Both the SDS Framework of Standards and the National SDS Improvement Plan clearly set out what good practice should look like: informed and supported choice, respect for individual circumstances, transparency in decision making, and a focus on wellbeing and outcomes. What participants are consistently telling us is that these principles are not yet embedded consistently in everyday practice.

QUESTION 2

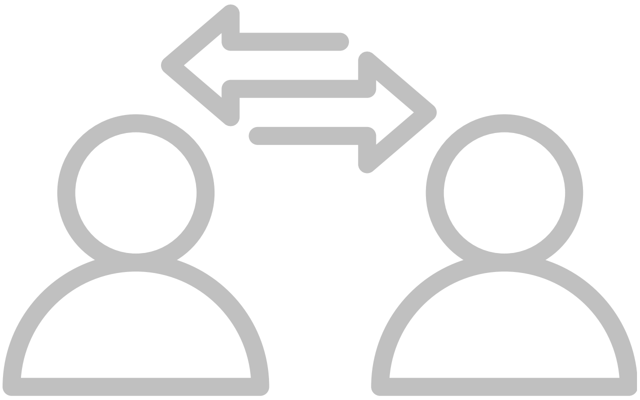
(CONTINUED)

To close the gap between life as it is and a good life, people are calling on leaders to:

- Ensure all four SDS options are genuinely available in every area, not just in policy
- End practices that steer people into Option 1 without informed consent, adequate support, or viable alternatives
- Strengthen access to advice, independent support, and timely reviews
- Reduce reliance on crisis and conflict as a route to entitlement
- Tackle postcode inequality through stronger national oversight and accountability
- Embed the SDS Framework of Standards consistently in practice

Until these changes are made, SDS will continue to work well for some while failing too many others.

Participants are clear that closing this gap is not about lowering expectations, but about delivering on the legal, policy, and practice commitments that SDS was built upon so that everyone has a fair and equal chance to live a good life.



QUESTION 3

Have you heard of the SDS Framework of Standards? If so, have you used them and how?

Participants were asked whether they were aware of the SDS Framework of Standards and, where they were, how the framework had been used in practice.

Responses point to a consistent and concerning disconnect between the framework's national importance and its visibility, understanding, and impact in people's everyday experience of Self-Directed Support.

The SDS Framework of Standards, jointly recognised by the Scottish Government and COSLA, sets out what good, person-centred Self Directed Support should look like in practice. It is intended to be a shared guide for everyone involved in SDS, disabled people, unpaid carers, families, professionals, and organisations grounded in principles of choice, control, dignity, respect, participation, collaboration, and informed decision making.

What people describe, however, is not a failure of the framework itself, but a failure to embed, share, and give authority to it in practice.

Summary of key themes identified in response to Q3:

Theme 1: Invisible to most

For the majority of disabled people and unpaid carers who responded, the SDS Framework of Standards is simply not part of their lived experience. Many had never heard of it at all. Others were vaguely aware that something existed, but had no understanding of what it was for or how it might help them. As one participant put it, ***"No, I haven't heard of this, but it sounds like a great idea, its not something I've come across."*** Another noted that even where interest exists, capacity does not: ***"Many carers wouldn't have the capacity to research and read up on these; most carers rely on information from the local authority or carers centres, and I'm not sure how well they're known there."***

Awareness of the framework is rarely built into routine SDS processes. Participants described assessments, option discussions, reviews, and care planning taking place without any reference to the standards that are meant to define good practice. Instead of being proactively shared as a rights based-guide, people are left to discover the framework by chance, during periods of crisis or exhaustion.

QUESTION 3
(CONTINUED)

This absence matters. The Framework is intended to provide a clear benchmark against which people can understand decisions, identify poor practice, and advocate for their rights. Where it remains invisible, disabled people and unpaid carers are left without a shared language or reference point. As one participant said bluntly, ***"They mean nothing when the local authority is not listening, acting, or even understanding the issues facing us."***

The result is that the Framework exists nationally, but it feels largely absent locally, undermining its purpose as a standard that should protect dignity, fairness, and consistency.

Theme 2: Used by professionals, not people

Where the SDS Framework of Standards is known, awareness is largely concentrated among disabled people and unpaid carers who are also professionals working in advocacy, brokerage, or social care. These respondents described using the framework as a tool to challenge practice, support arguments for flexibility, and highlight inconsistencies with SDS principles.

One advocate with lived experience explained, **"I know about the standards because of the work that I do. I use them a lot, but when I raise transparency which is one of the standards, it feels pointless because they aren't enforced and there's no accountability."**

Others described using the standards during disputes, noting that ***"it's helpful when arguing for choice and control,"*** or that they had cited them in complaints to show that ***"flexibility and pooling budgets were permitted."***

While this professional use is important, it also reveals a structural problem. Knowledge of the standards is often mediated through professionals, rather than being routinely accessible to the people they are meant to protect. One participant reflected that they first encountered the framework through training, saying, ***"I heard about them doing the Community Brokerage awards, and now I share them with families when there are practice issues with social workers."***

As a result, the Framework functions more as a technical or advocacy tool than as a shared, rights based- reference that disabled people and unpaid carers are supported to understand and use themselves.

This places an unreasonable burden on individuals who are already navigating complex systems, often under significant pressure.

Theme 3: Little weight in local practice

Even where the SDS Framework of Standards is known and referenced, participants consistently reported that it does not reliably influence local decision making. Many described local authorities interpreting the standards selectively, or deprioritising them in favour of local policy, resource pressures, or budget constraints.

One respondent explained, ***“I’ve heard of it, but my social worker said I can’t use it, my council doesn’t allow it.”*** Another stated simply, ***“It means nothing when the local authority isn’t listening.”*** Another participant echoed this frustration, noting, ***“I use it to support others, but our local authority ignores legislation and the SDS framework of standards because of funding and budget restrictions.”***

Although non-statutory, the Framework represents nationally agreed expectations of good practice. Where it is side-lined or inconsistently applied, people experience SDS as arbitrary and unpredictable. Trust is eroded, and the framework’s ability to drive improvement is fundamentally weakened.

Participants were clear that without recognised authority and clear expectations, the SDS Framework of Standards cannot fulfil its intended role. When standards exist but carry no consequence, they become aspirational rather than operational.

Final Reflection

The SDS Framework of Standards is widely recognised at national level as a strong and credible articulation of what good, person centred Self- Directed Support should look like. Among those who are aware of it, the framework is valued and seen as aligning closely with the original intent of SDS.

However, this evidence highlights a persistent and systemic gap between intent and impact. For most disabled people and unpaid carers, the framework remains unknown, inaccessible, or perceived as powerless in the face of local decision making. As a result, it is not functioning as the shared, rights- based reference point it was designed to be.

QUESTION 3
(CONTINUED)

These findings do not point to a failure of the framework itself. They point to failures in communication, embedding, authority, and accountability. Where nationally agreed standards are not actively shared with the people they are meant to protect, and are applied inconsistently by those responsible for delivery, they cannot drive equitable or meaningful change.

Leaders therefore have a clear responsibility to act. If the SDS Framework of Standards is to fulfil its purpose, it must be:

- Proactively introduced and explained to disabled people and unpaid carers as part of SDS processes
- Embedded in assessments, reviews, care planning, and complaints
- Understood and consistently applied by staff
- Backed by clarity about how departures from the standards are justified and challenged

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Without clear expectations, visibility, and consequence, the SDS Framework of Standards will continue to sit on the margins of practice.

If it is to move from aspiration to action, it must become a shared standard with real weight, understood by people using SDS, respected by professionals, and upheld through leadership and accountability. Only then can it serve as a genuine safeguard for rights and a foundation for people to live a good life.

Self-directed Support Framework of Standards

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Standards Wheel

QUESTION 4

What would it take to close the gap between life as it is and a good life?

Participants were asked what needs to change to close the gap between their current experience of support and living a good life. Their responses are strikingly consistent across age, geography, disability and caring role. People do not describe a system that is merely under-resourced; they describe one that has drifted away from its own values and legal commitments.

Self-directed Support was intended to embed choice, control, dignity and recognition of individual lives. In policy, the statutory duty is clear: people should be offered all four SDS options, supported to make informed choices, and enabled to shape support around outcomes and wellbeing. The National SDS Improvement Plan and the SDS Framework of Standards reinforce this, emphasising relationship-based practice, transparency, consistency, coproduction, and trust.

What people describe in practice is something very different.

Many experience social care as adversarial, budget driven, risk averse and emotionally exhausting. Trust has been eroded. Relationships have been replaced by process. People feel judged, disbelieved and afraid to be honest, knowing that openness can result in support being reduced rather than strengthened. While participants understand funding pressures, they are clear that the most serious failures lie in culture, implementation, accountability and leadership.

Importantly, this is not a rejection of SDS. People continue to believe in its original promise. What they are asking for is not unreasonable: to be listened to, treated as people, and supported in ways that genuinely enable a good life.

Summary of key themes identified in response to Q4:

Theme 1: Trust and human connection

Participants are clear that living a good life depends on trust, empathy and relationship-based practice. People want to be known, understood and believed, rather than processed through systems that feel distant, formal and fear-driven.

QUESTION 4

(CONTINUED)

Many described how interactions with social work now feel transactional rather than human. One carer reflected that social work ***"has become too formal, rather than personal and that time needs to be spent building relationships rather than completing procedures"***

Others spoke about the fear that shapes assessments and reviews, where honesty feels risky. As one person explained, ***"Assessments shouldn't be about people losing their hours, people are too scared to share their true feelings."***

What people want is not unreasonable or new. Relationship-based practice is already a stated commitment within the National SDS Improvement Plan and the SDS Framework of Standards. Yet participants describe a reality where risk management and budget protection have displaced empathy and compassion.

One participant was explicit: ***"If empathy and compassion isn't at the core of a social care organisation, then change it."***

People are telling us that without trust, SDS cannot work. Trust is not a 'soft' extra; it is a core condition for early intervention, honesty, sustainability and wellbeing.

Theme 2: Real choice and control

Participants continue to believe in the original purpose of Self-Directed Support. What they want is for SDS to do what it says it will do: provide genuine choice, meaningful control and support shaped around their lives.

People repeatedly spoke about SDS being narrowed in practice. Many described SDS as being treated as synonymous with Option 1, with limited understanding or promotion of the other options. ***"Workers continue to call SDS Option 1, they forget there is another three options,"*** one participant noted. This is not just frustrating; it represents a failure to meet the statutory duty to offer and support all four options.

People also want flexibility to use their budgets in ways that make sense for their circumstances and outcomes. Instead, they described fear-based refusals and rigid interpretations of what SDS can be used for. One participant captured this clearly, saying SDS ***"should not be weaponised as a tool for local authority control."*** Another asked, ***"Why spend money promoting SDS if you do not make sure it's happening in local authorities?"***

QUESTION 4
(CONTINUED)

This gap between policy promise and lived reality undermines trust and erodes empowerment. What people want is straightforward: for the flexibility and person-led approach already embedded in SDS policy to be honoured consistently in practice.

Theme 3: Fairness and consistency

Participants repeatedly describe fairness as central to their ability to live a good life. ***"There has been so much work in this sector to advance disabled people's rights, and they are being lost, and that's a disgrace",*** a participant noted. People want a system where rights do not change depending on geography, and where national legislation and statutory guidance is applied consistently and transparently across local authorities.

One person said, ***"It feels that COSLA have a stranglehold over the Scottish Government, and this needs to be called out and changed as disabled people and unpaid carers are caught in the middle of a bun fight."***

Many described stark differences between areas, with eligibility thresholds, allowable spend and interpretations of policy varying widely. One participant called for ***"a clear understanding set in stone for all councils of what policy is, and that all must follow it."*** Others spoke about being forced into complaints or legal action simply to secure assessed need, describing local authority behaviour as bullying or unlawful.

People are not asking for special treatment. They are asking that national legislation and policy be applied as intended. This aligns directly with the National SDS Improvement Plan's commitments to consistency, transparency and accountability. Where local interpretation routinely overrides rights, people experience SDS as arbitrary and unjust.

One participant acknowledged, ***"It's easy for leaders to hide away from what's happening on the frontline that they become desensitised to the reality of life".*** Whilst another gave a direct message to leaders, ***"Whilst you keep talking about changing the system, many of us are stuck living a life that is making us desperately unhappy"***

What people want is assurance that fairness and accountability are built into the system so that obtaining support does not depend on how hard someone can fight.

QUESTION 4
(CONTINUED)

Theme 4: A valued workforce

Participants consistently link their ability to live a good life to the availability of skilled, reliable staff. A stable workforce is not a side issue. It is fundamental to choice, control and continuity of support.

People described struggling to recruit and retain Personal Assistants due to poor pay, capped rates and lack of career recognition. One participant stated simply, ***"PA wages are appalling."*** Another highlighted the injustice that ***"people stacking shelves earn more than people providing complex care, it is not sustainable."***

When support breaks down, families step in to fill gaps, often at significant personal cost. Several participants spoke about stress and anxiety when shifts are uncovered, particularly at weekends, and the fear of leaving loved ones unsupported.

What people want is proper investment in the workforce, fair pay and flexibility in funding so they can recruit the right support. This directly reflects commitments within the National SDS Improvement Plan, which participants feel have yet to translate into real change on the ground.

Theme 5: Shared power

Participants are clear that being asked for views is not the same as sharing power. Disabled people and unpaid carers want to be involved in decision-making, governance and leadership, not just consulted when it suits organisations.

"The decision makers need to be disabled people who are employed and valued," one participant said. Others echoed the need for lived experience to be embedded in panels and decision-making structures, with rotation and transparency to avoid gatekeeping. ***"We need more autistic voices leading systems,"*** another stated.

This directly aligns with the co-production commitments in the National SDS Improvement Plan. Participants are telling us that systems designed without them will continue to fail them. Sharing power is not optional; it is essential to delivering effective, rights-based social care.

Theme 6: People before budgets

Finally, participants spoke powerfully about the wider narrative shaping social care. People want a system that values them as people, not as financial burdens.

Many described feeling blamed or judged, with decisions framed almost entirely around budgets. ***"Money shouldn't be the driving force of an organisation; empathy and compassion should be,"*** one participant stated. Another said, ***"Finances are dictating how social care services are delivered, leading to inhumane practices."***

What people want is a reframing of social care as an investment in people, rights and communities. Until this narrative changes, participants believe that dignity, equality and good lives will remain secondary to cost containment.

Final Reflection

Taken together, this feedback sets out a clear, values-led vision of what needs to change for people to live a good life. People understand financial pressures, but they are not asking for perfection or privilege. They are asking for delivery of what SDS already promises and is currently written in policy and national guidance.

They want:

- Trust, empathy and relationship-based practice
- Real choice and flexibility, across all four SDS options
- Fair and consistent application of policy
- A valued, properly paid workforce
- Shared power with lived experience
- A narrative that prioritises people over budgets

As one participant put it: ***"This is our life hanging in the balance, we don't get to switch off at 5pm."***

What people are telling us here is not aspirational or unrealistic. It reflects the statutory duties, standards and commitments already set out in Scotland's SDS legislation and guidance. Closing the gap is not about inventing something new; it is about aligning practice with purpose, policy and the lives of the people SDS exists to support.

CONCLUSION

From policy promise to lived reality

Taken together, this evidence presents a clear and consistent message from disabled people and unpaid carers across Scotland. Self Directed Support is underpinned by strong statutory duties and national commitments: to promote **choice, control, dignity, participation, and human rights**. These principles are clearly articulated in the SDS Act, statutory guidance, the National SDS Improvement Plan, and the SDS Framework of Standards.

What people are telling us echoes the findings of the recent Post-Legislative Scrutiny of the SDS Act; it is not that SDS is the wrong approach, but that it is not being delivered as intended.

Across feedback, access to options, use of standards, and opportunities to influence decisions, participants describe experiences that fall short of what local authorities are already required to provide. Feedback systems exist but are often experienced as unsafe or ineffective. Choice exists in policy but is constrained in practice. Standards exist but lack authority and consistent application. As a result, trust has eroded, power imbalances have deepened, and people are left exhausted and fearful of speaking up, relying on crisis, conflict, or personal resilience to secure basic entitlements.

People are not asking for more consultation or better wording of policy. They are asking for action.

They want a system that makes feedback safe, choice real, and standards meaningful in everyday practice. They want a system that listens early, responds humanely, and is accountable when things go wrong. Until this shift happens, further engagement exercises or policy refinement will not rebuild trust and will not close the gap between rights on paper and lived reality.

Crucially, many of the issues raised relate to statutory duties and nationally agreed expectations that already exist, including:

- safe and meaningful participation
- regular, effective and transparent reviews
- informed choice across all four SDS options
- access to independent advocacy
- consistent application of standards and guidance

CONCLUSION

(CONTINUED)

Where these are absent, inconsistent, or experienced as risky, SDS cannot operate as a person-centred or rights-based system, regardless of policy intent.

Participants recognise the financial pressures facing social care. However, they are clear that the most serious failures lie not solely in resources, but in culture, implementation, accountability and leadership. SDS continues to work for some people, often where relationships are strong and support is stable, but these successes are too often achieved *despite* the system rather than because of it.

Closing the gap between life as it is and a good life is not about inventing new frameworks or lowering expectations. It is about delivering on existing legal and policy commitments, embedding standards consistently in practice, and ensuring that power, responsibility and accountability sit where they should.

Until feedback is trusted, choice is genuinely available, standards carry real weight, and leadership is accountable for delivery, SDS will continue to fall short of its promise.

Rebuilding trust and credibility is not optional. It is the foundation on which a fair, humane and effective system of social care must be built.

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

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