The Health and Social Care Alliance Scotland (the ALLIANCE)

ALLIANCE
HEALTH AND SOCIAL CARE
ALLIANCE SCOTLAND
people at the centre

Access to Self-directed Support (SDS) – ALLIANCE Briefing

May 2025

Introduction

In early 2025, the Health and Social Care Alliance Scotland (the ALLIANCE) was informed by a small number of members that people with lived experience were facing new or increased barriers to accessing Self-directed Support (SDS).

To explore this further, we designed and published a small research survey asking our members and the people they represent about their experiences.

We asked our members and people with lived experience of SDS whether they had come across any of the following in the past year and whether this seemed to be happening more often than it previously was:

- Care packages being reassessed or reviewed
- Cuts in packages
- Caps to payment amounts or support
- Pre-determined decisions

Respondents were also asked whether there was any detailed information they wanted to share with us about their experiences of these issues.

This briefing provides an overview of the results from the survey and a summary of the more detailed responses.

It is important to note that the results are limited due to the low number of respondents. However, given the public finance crises reported by local authorities and Integrated Joint Boards (IJBs), we believe that the findings could be indicative of a more widespread issue of concerning practice across Scotland.

What is SDS?

Self-directed Support (SDS) is the name for how people get social care and support in Scotland. It was introduced to give people who need care and support more choice, control and flexibility, through co-production and an outcomes based approach.

The Social Care (Self-Directed Support) (Scotland) Act 2013 came into effect in April 2014 and introduced new legal duties for local authorities (LAs) outlined in the statutory guidance, including to:

- Have regard to the general principles of collaboration, informed choice and involvement as part of the assessment and the provision of support
- Take reasonable steps to facilitate the person's dignity and participation in the life of the community
- Offer four options to the supported person
- Explain the nature and effect of the four options and to ‘signpost’ to other sources of information and additional support

Survey results

The survey received 47 responses between 8 January and 3 March 2025.

In response to our survey, the respondents told us that they or someone they represented had experienced the following issues in the past year:

Issues	Number	Percentage
Care packages being reassessed or reviewed	30	64%
Pre-determined decisions	23	49%
Cuts in packages	22	47%
Caps to payment amounts or support	10	21%
Other	16	34%
None of the above	2	4%

Respondents were able to select more than one option. 16 people (34%) told us they had experienced several of the issues highlighted above. Eight respondents (17%) said they had experienced all of the issues. 13 people (28%) told us that they had experienced one of the issues, whilst 16 (34%) said they had experienced other issues either in conjunction with those listed above or additional ones.

The additional issues people have referred to include:

- People accessing SDS and unpaid carers receiving “long, convoluted, threatening emails” from local authorities.
- Local authorities provide inconsistent and low amounts of financial support and pay for carers.
- Local authorities assessing applicants without meeting or communicating with them.
- Requests for care being questioned by Care Managers despite SDS already being in place.
- Referrals being “ignored”, and respondents told to “exhaust the list of charities” for support instead.
- People not receiving the money for the support they need.
- Long waiting lists for certain Options.
- People living in remote and rural areas being told by social workers that they could only access support packages in towns.
- Relatives of people needing SDS have been told that their application will only be approved if they agree to look after their finances.
- No social or transport support available in specific local authority areas.

Respondents were also asked if the issues were happening more often than they were prior to the past year:

Answer	**Number**	**Percentage**
More often	30	64%
Not sure/don’t know	12	26%

About the same	3	6%
Did not answer	2	4%

Respondents were asked if there was more information they wanted to share. The following summarises the qualitative responses we received to this question:

Lack of person centredness

Several people stated that SDS is no longer person centred and that legislation is not being followed. They shared some of the following examples:

- Reassessments and budget cuts were not based on a person's needs but on the local authorities' need to save money.
- SDS payments have seemingly been lowered every year over the last few years.
- Assessments are always late, so there is a gap between payments, leaving people without money to live on.
- They were awarded a budget, but have not received it or cannot access it. One respondent noted the significantly negative impact that this has had:

> "Trying to get care is destroying our mental and physical health".

Such inappropriate implementation hinders the person centred and outcome focused assessment and support planning that is essential to deliver SDS.[1]

Pre-determined decisions

Respondents indicated a belief that pre-determined decisions are made as a way for local authorities to decrease budgets and reduce costs. This results in people losing a significant amount of their payments either when reassessed, when their packages are reviewed, or without any notice at all. For example:

“I have experienced a cut to my care package within the last year which I feel is based more on social work's need to save money than on my needs. Why is it that when my needs increase the council think it is ok to reduce my budget/support? They are simply making me more disabled, and acting like accountants more than social workers. Their assessment does not feel genuine, but an exercise with a pre-determined outcome - a cut.”

A respondent told us that when their budget was cut, their social worker said, “You have to understand that there are budget cuts”. Another was told by their local authority that “they had no budget and I had to exhaust the list of charities sent to me”.

In a care package review, one respondent was told by their social worker, “We have a £10 million deficit in our budget and I am here to make sure you don't have more than your fair share.”

Reviews, reassessments and restrictions

Our survey findings appear to demonstrate that local authorities are heavily scrutinising SDS spending, and restrictions have been put in place on what payments can be used for. A few people told us that flexible direct payments and carers' direct payments are being reviewed or outright refused. For example, a respondent working for an organisation supporting people told us:

“We support people in receipt of Option 1 Direct Payments (DP) - there is definitely a push on reviews/reassessments and the results are usually a cut in hours or the package remains unchanged… The ability to use DP in a flexible way is always questioned and more times than not - the request doesn't meet the eligibility criteria, and the request is declined”.

As a result, people feel that their spending must fit into the local authorities' reduced budget.

However, in other circumstances, people have had to wait over a year for reassessments to take place, only to receive a budget increase when they phone the emergency out of hours crisis number.

Local authorities are given guidance that states that reviews and reassessments should take place once a year[2]. However, there is nothing stated in legislation that dictates this. This appears to be causing inconsistency in the support people receive, and a service and postcode lottery in how SDS is delivered. No one should feel like they have to phone a crisis number in order to access SDS.

Impact on unpaid carers

Under SDS legislation, local authorities must offer SDS to anyone who needs support. Carers can also get support to help them maintain their caring role and should have choice and control over the support they want and need.

However, in this survey, carers told us they have to “battle” or “fight for support” and that “there’s a limit to how much fighting for things you can do”. There has been an overall cut to respite care, with some opportunities being removed altogether. One respondent said they were told that because they looked like they were coping with their caring responsibilities, their SDS application was closed.

Others requested assessments but were told by social workers that they did not meet the eligibility criteria despite having ‘critical disabilities, long term and degenerative conditions’.

One respondent, who lives in a remote and rural area, stated that they were informed by the local authority that unless they agreed to manage their relative's finances, they would not receive SDS. They were also told that the support package they had previously received was not available in remote areas and that they would not receive any additional support.

Generally, respondents felt that the support they needed and requested was being “questioned”, and they felt pressured to accept a lower payment or level of support for fear of their application being rejected. If applications were rejected, people were “made to feel this was [their] fault”.

A carer was told by their social worker that their daughter, who has ‘complex physical difficulties’, “should do more to care for herself” because she looked “normal”.

Children and young people

SDS should mean enjoying rights to practical assistance and support that children need to reach their full potential, participate in society and live an ordinary life. SDS guidance specifies that it is 'designed to ensure that what matters to the child is central to every decision made’[3].

In response to the survey, several people highlighted the poor provision made for children and young people. Despite varied, substantial and critical life limiting conditions, respondents are being told that SDS has to be given out equally rather than via care packages tailored to individual need.

References were made to care package reviews, removing transport and social supports, and placing financial barriers to accessing services. For example, a parent and child now have a four hour journey to their care provision a day because they have to use public transport, whereas in the past, taxis were arranged for them. Another respondent said that it seemed like anything that is not work or education is classified as social and will not be funded, including exercise activities.

Poor communication

In SDS, effective communication is crucial for empowering individuals to make informed choices and manage their own support, ensuring they have control over their care.

However, there appears to be a lack of communication from local authorities, providers and staff about changes to people's budgets. In several instances, respondents had never met their social worker.

"I felt they were very reluctant to give any information, with how much financial support was available from social work".

Respondents stated they had been moved from Option 1 (also known as a Direct Payment, where an individual's local council will pays an agreed amount of money directly to the person, and they purchase support and other things that will help them meet their outcomes) to Option 3 (the option where the local council, not the individual, are responsible for arranging for them) without consultation or were only given short notice of the changes.

Recouping of budgets

Although six people from our survey chose Option 1 for their support, they are now unable to find personal assistants or support services. As a result of this unspent money, local authorities are "clawing it back" despite pre-existing funding cuts.

Another respondent told us that, after a long wait for their SDS package to be confirmed, they were given a week to withdraw the payment or it would be recouped.

It is possible for local authorities to recover unspent funds from SDS budgets. However, if a budget is unspent, people should be able to use the money in other ways to meet their outcomes[4]. If any money is recouped, there should be clear communication with every individual about this and a discussion of options available.

Increase in disputes

As a result of the growing issues people are experiencing trying to access and benefit from SDS, third sector organisations have seen an increase in applicants seeking support to dispute decisions made in reviews.

Respondents from third sector organisations told us that this increase in support need is impacting their workload and that “there is never enough time now to complete tasks”.

The ALLIANCE has long advocated for changes to complaints systems across health and social care services. Whilst it is positive that people are aware of and accessing their rights, everyone should have the right to access a simple, timely and accessible formal complaints system. Third sector organisations providing support with disputes should be given sufficient training and resources to ensure that workloads are manageable and backlogs are mitigated.

Conclusion

The ALLIANCE began this exploration after hearing from a small number of our members that people with lived experience were experiencing new or increased barriers to accessing Self-Directed Support (SDS) over the past year.

We have heard that SDS budget cuts, poor communication and decision making are negatively impacting people’s independence, quality of life, ability to worship, carers’ respite, ability to see family and friends, exercise, have a social life, and attend clubs or holiday activities.

The findings set out in this report are deeply concerning and echoes those from our earlier ‘My Support, My Choice’ research, carried out with SDS Scotland in 2020[5]. There are clear indications that these unacceptable experiences are occurring on a larger scale than mere 'anecdotal evidence’ and may be indicative of a much wider issue across the country.

Our evidence demonstrates that the decisions and actions of some local authorities and practitioners are in direct contradiction with the SDS law, guidance and Improvement Plan[6].

Our survey has found that people are experiencing key issues in accessing SDS, including more, bigger and unannounced budget cuts, and predetermined decisions, reviews and reassessments. Respondents told us that predetermined decisions, reviews and reassessments have several negative consequences that impact more than just the amount of money they receive, including their health and wellbeing.

Most of the people we heard from indicate that decisions and processes surrounding SDS have not prioritised people's needs. At its most basic, people have not been spoken to or treated with empathy, dignity and respect. This may reflect increased pressure on local authority staff to tighten eligibility criteria. For example, many respondents with lived experience were explicitly told by their social workers that issues with SDS were due to local authority budget cuts.

Whichever SDS Option, or level of control and responsibility, a person has chosen for their social care support, local authorities must work with individuals as the leaders of their own care and support. However, lack of or poor communication of decisions, which leave changes to people's budgets unexplained, is disempowering and disrespectful.

Some people shared that they felt like they are facing more and more barriers because of year on year reductions in budgets and/or support. This is compounded by instances where people are subject to late assessments leading to delayed (as well as lower) payments.

As well as people with lived experience, there has been significant impact on unpaid carers, parents and children and young people who have found that their lives are made smaller and more difficult because of an increasingly restrictive approach to SDS, rather than being encouraged and empowered to have choice, independence and flexibility.

Third sector organisations are trying to support people who experience issues in accessing SDS and wish to dispute a decision. However, the scale of the issues that people are experiencing is placing even greater

pressure on an already overwhelmed sector. Organisations need capacity and resources to provide people with good quality support, and people should also have access to a fully equipped complaints system.

Social care, paid and unpaid care are under resourced and under valued. There are ongoing, well-known issues with the recruitment and retention of social care staff who are so vital in enabling people to use their SDS budgets. For example, cutting, removing and recouping SDS budgets/support is directly linked to people's ability to hire Personal Assistants, and their severe shortage across Scotland.

Recommendations

- Local authorities and staff must fully adhere to and implement SDS legislation and accompanying guidance.
- COSLA and local authorities should conduct a thorough review of SDS implementation and practice across Scotland.
- SDS legislation should be reviewed and amended so any gaps or loopholes causing inconsistency and a lack of clarity can be filled.
- Assessments and reviews must follow a person centred, rights based approach and be co-produced with people who access SDS.
- Third sector organisations providing support for people with lived experience who dispute decisions should receive fair and sufficient training and resourcing, in line with SCVO's definition[7].
- Budget cuts should not compromise the choice, control and independence of those receiving and/or applying for SDS.
- The concerns raised by people with lived experience in this small scale research, and elsewhere, must be listened to and remedied.
- Staff at all levels should receive regular training in inclusive and accessible communication, human rights and disability awareness.
- Fair Work must be consistently delivered across the social care sector.

- The recommendations of our My Support, My Choice research should be reviewed and implemented by local authorities, as many still remain as relevant as when they were first published five years ago.

About the ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for health and social care, bringing together a diverse range of people and organisations who share our vision, which is a Scotland where everyone has a strong voice and enjoys their right to live well with dignity and respect.

We are a strategic partner of the Scottish Government and have close working relationships with many NHS Boards, academic institutions and key organisations spanning health, social care, housing and digital technology.

Our purpose is to improve the wellbeing of people and communities across Scotland. We bring together the expertise of people with lived experience, the third sector, and organisations across health and social care to inform policy, practice and service delivery. Together our voice is stronger and we use it to make meaningful change at the local and national level.

The ALLIANCE has a strong and diverse membership of over 3,500 organisations and individuals. Our broad range of programmes and activities deliver support, research and policy development, digital innovation and knowledge sharing. We manage funding and spotlight innovative projects; working with our members and partners to ensure lived experience and third sector expertise is listened to and acted upon by informing national policy and campaigns, and putting people at the centre of designing support and services.

We aim to:

- Ensure disabled people, people with long term conditions and unpaid carers voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.
- Support transformational change that works with individual and community assets, helping people to live well, supporting human rights, self management, co-production and independent living.
- Champion and support the third sector as a vital strategic and delivery partner, and foster cross-sector understanding and partnership.

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[1] Scottish Government, *Self-directed Support: Practitioners Guide,* (2014) available at: https://www.gov.scot/publications/self-directed-support-practitioners-guidance/pages/6/.
[2] The SDS Handbook, *Reviewing your support,* available at: https://handbook.scot/sds-handbook/article/reviewing-your-support/.
[3] Self-directed Support Scotland, *Factsheet: Self-directed Support (SDS) for Children What to Expect – Information for Parents,* (2023) available at: https://www.sdsscotland.org.uk/wp-content/uploads/2023/01/Final-CYP-SDS-Factsheet-5-Jan-2023.pdf#:~:text=It%20means%20having%20rights%20to%20practical%20assistance%20and,greater%20control%20over%20the%20support%20provided%20to%20them.
[4] The SDS Handbook, *What happens if you do not spend all your support budget?* Available at: https://handbook.scot/sds-handbook/article/what-happens-if-you-do-not-spend-all-your-support-budget/.
[5] Health and Social Care Alliance Scotland (the ALLIANCE) and Self Directed Support Scotland, *My Support, My Choice,* (2020) available at: https://www.alliance-scotland.org.uk/policy-and-research/research/my-support-my-choice/.

[6] Scottish Parliament, Social Care (Self-directed Support) (Scotland) Act, (2023) available at: https://www.legislation.gov.uk/asp/2013/1/contents; Scottish Government, *Social Care (Self-directed Support) (Scotland) Act 2013: statutory guidance*, (2022) available at: https://www.gov.scot/publications/statutory-guidance-accompany-social-care-self-directed-support-scotland-act-2013-2/; Scottish Government, *Self-directed support: improvement plan 2023 to 202,* (2023) available at: https://www.gov.scot/publications/self-directed-support-improvement-plan-20232027/.
[7] SCVO, *What is Fair Funding?,* available at: https://scvo.scot/policy/fair-funding-procurement/fair-funding/what-is-fair-funding.