

Health Social Care and Sport Committee

Post-legislative scrutiny of Social Care (Self-directed support) (Scotland) Act 2013 – Summary of Evidence to support Phase 1

Contents

Background	2
Respondent Characteristics	2
Summary of Responses	3
Data Visualisation	3
Areas of Good Practice	4
Theme 1: Increased choice, flexibility, and control.....	4
Theme 2: Respite for unpaid carers	5
Theme 3: Independent organisations.....	5
Areas for Improvement.....	6
Theme 4: Knowledge, clarity, and support during assessment.....	6
Theme 5: Inconsistency between local authorities	7
Theme 6: Workforce-related issues.....	8
Theme 7: Moving goalposts	10
Theme 8: User responsibility	11
Theme 9: Services	12
Theme 10: Processes and their impact on flexibility	13
Theme 11: Investment, funding, regulation, and accountability.....	15

Background

The main provisions of the Social Care (Self-directed Support) (Scotland Act) 2013 (“the Act”) came in to effect in April 2014. The intentions were to ensure that care and support be arranged, managed, and delivered in a way that puts individual choice and control at the forefront of social care.

The Act contains a duty on local authorities to offer four options to people who have been assessed as needing a community care service.

- Option 1: The individual or carer chooses and arranges the support and manages the budget as a direct payment.
- Option 2: The individual chooses the support, and the local authority or other organisation arranges the chosen support and manages the budget.
- Option 3: The local authority chooses and arranges the support.
- Option 4: A mixture of options 1, 2 and 3.

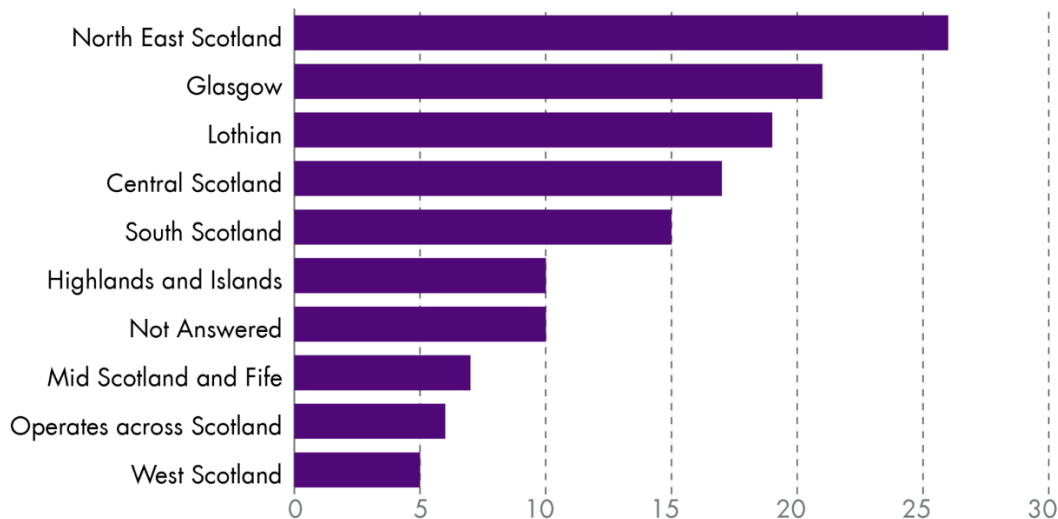
The Health, Social Care and Sport Committee (“the Committee”) conducted a call for views to support phase 1 of the post-legislative scrutiny of the Act. The consultation ran from 3 November 2023 to 12 January 2024. Respondents were invited to provide their thoughts on the implementation of self-directed support (SDS) to date. The individual responses have not been published.

The purpose of Phase 1 is to assist the Committee to decide on areas where it might wish to focus its scrutiny. This has been done by gathering evidence through a call general call for views asking about people’s experiences of SDS, whether they work in implementing it or are in receipt of SDS. In addition, Parliament staff have worked more closely with groups of stakeholders to suggest and present recommendations for where they believe the Committee should focus their scrutiny. These recommendations will be presented by representatives of the groups on 20 February 2024.

Respondent Characteristics



The Committee received 140 responses to their call for views: 83 individuals and 57 organisations.



The consultation received responses from individuals and organisations in regions across Scotland, primarily North-East Scotland (26), Glasgow (21) and Lothian (19).

110 respondents reported they, or the person they're representing, have had direct experience with SDS; 19 have had no experience whilst 11 did not answer.

Summary of Responses

The responses touched upon several key themes which are outlined below. The report breaks these down into areas of good practice and areas where respondents expressed a need for improvement. Some quotes are provided from organisations and individuals to highlight the issues and lived experiences of those who use and work in SDS.

Data Visualisation

SPICe carried out automated textual analysis of the responses to highlight words and phrases frequently mentioned by individuals and organisations.

Below are two sets of diagrammatic analyses, organised as a word cloud on the left-hand side and a network map on the right-hand side, distinguishing between responses from individuals and organisations.

- A “word cloud” shows the frequency of words used in the submissions, excluding very regularly used words.
- A “network map” shows the frequency with which words are connected to each other. A darker line indicates a stronger, more regular connection.

“[...] because the individual budget allows for flexibility, it has been possible to pool resources and share support with others supported by our organisation in the local area.”

Some individuals highlighted the benefit of increased control for the user as it allowed them to schedule their care around their existing schedule. One stated:

“I can direct my care staff and support hours to fit with a working life.”

Another individual said that SDS provides “flexibility to lead an independent life and be spontaneous about arranging support when I need it.” Several respondents highlighted that SDS provides them with more choice around the support they receive. Individuals noted that they can engage with services and receive opportunities that may not otherwise be available to them such as crafting, church and sport activities, and short holidays.

Theme 2: Respite for unpaid carers

Respondents highlighted that SDS has allowed unpaid carers to receive respite from their caring duties. One individual said:

“I use it to pay my son to support me with my husband who is in later stages of dementia he also looks after his dad to give me respite.”

Another stated:

“[...] the package includes a budget for personal care and day activities for my husband and respite for me.”

Theme 3: Independent organisations

A national organisation that supports the use of SDS highlighted the importance of local independent support organisations in SDS implementation. They said:

“Independent SDS Support services have, since before the introduction of the legislation, played a fundamental role in raising awareness of SDS among people who may need social care, and providing the services which enable the SDS Act to be implemented as intended.”

An organisation that provides information and advice about SDS highlighted the broad range of support that such organisations can provide. They said:

“They have advocated for people, offered community brokerage support, connected people into informal support arrangements to reduce the need for formal support, and have supported people through the end-to-end process of gaining support. The end-to-end

process involves from referral to the independent support organisations, pre and post assessment and all that is needed to put support in place using any of the 4 SDS options.”

However, many people do not or cannot access this independent support and find that little information or comprehensive support is available from some local authorities/social work teams.

Areas for Improvement

An overarching theme across most responses is that SDS is a good idea, that has largely failed due to poor implementation. One individual said:

“I believe the policy is excellent. Fully engaging the individual served in deciding and planning the care they receive is truly transformational. Or it could be were it to be comprehensively implemented.”

Many respondents provided views that ‘unpacked’ the experience of poor implementation. Several others reflected that implementation had started well following the Act, but has deteriorated over time in many areas, including:

- the reduction of budgets,
- the reduction in overall funding of social care,
- the disappearance of flexibility,
- the loss of services,
- the lack of clarity about what is ‘allowed’ in terms of support,
- the pressures caused by lack of staff, both social care and social work
- the impact of financial pressures on eligibility, and the perceived manipulation by local authorities of eligibility criteria
- the lack of information and knowledge in local authorities, and among social work staff
- the challenge of managing a direct payment (as an employer, complex reporting requirements).
- The lack of accountability and support when things go wrong – no independent process

Views on these issues are covered thematically through this summary.

Theme 4: Knowledge, clarity, and support during assessment

A common issue raised was the clear knowledge gap and uncertainty around SDS legislation. Many respondents stated that in the early stages of pursuing SDS they were not provided with sufficient information to inform their decisions. One individual said:

“The SDS advisor from the council seemed to be unaware of key facts about the service or the legislation that underpins it and it was a continuous back and forth to change set ideas about exactly how the service should work.”

This same individual highlighted their struggle dealing with the local authority, and that they did not feel urged to pursue SDS:

“Trying to get information from the council regarding the service was near impossible and I felt that there was a concerted effort not to offer it or dissuade us from requesting it.”

One individual highlighted a distinct lack of guidance and information to help with their situation:

“There is very little advice or guidance available for people in our position - everything online including at SDS Scotland seems to be predicated on SDS as a scheme for disabled young people/adults and young people/adults with learning disabilities and that SDS budgets are only ever used to employ a personal assistant. I have found no sources of public sector, third sector or peer advice/guidance about SDS that is very relevant to our particular situation, i.e. an SDS package awarded to an older person with debilitating long-term conditions that have arisen late in life.”

Another individual highlighted that they struggled to find services and agencies as local authorities couldn't offer suggestions or recommendations. They said:

“It took me a long time to put the package together because the care providers are so varied and do different things, with very different charging rates. It was really hard to navigate this very crowded arena on my own, as local authorities can't recommend or suggest particular agencies. It took months to find the right agencies who could offer the right service; this also had to change quite frequently, as my husband's needs changed.”

Respondents stated that legislation and guidance is vague and has impacted the implementation of SDS. One Health and Social Care Partnership said:

“Staff have highlighted that the legislation and guidance for the spending of Option 1 budgets are too vague and open to interpretation, leading to inconsistent practice within the partnership.”

Theme 5: Inconsistency between local authorities

A commonly cited issue by respondents is the inconsistency of SDS implementation between local authorities. A few respondents refer to this as a “Postcode Lottery” of delivery.

There are nationally agreed eligibility criteria and statutory guidance, however the “nuanced and complex” legislation means this criteria is subjective and open to interpretation – an issue that has been identified by respondents. One individual said:

“Allowing each council to set their own eligibility criteria based on what leftovers they have in their budgets is shameful and wrong. Time the Scottish Government did their job and held councils to account.”

Respondents have highlighted their own personal experiences of the inconsistencies between local authorities, where they have seen their support being “reassessed and reduced drastically as a consequence of moving area.” An organisation that provides information and advice about SDS said:

“[...] when people move from one local authority/HSCP area to another [they] cannot take any support arrangement with them and there is no guarantee of the same level or even kind of support available in their new location. This has restricted the social mobility of people who need support and impinges on their rights.”

On the other hand, one individual stated they moved to a different local authority area because they knew they would receive better social care services and support.

Theme 6: Workforce-related issues

Staff shortages

Recruitment and retention of the social care and the social work workforce was highlighted to be an issue affecting SDS implementation. These issues have an impact on local authorities carrying out assessments in the way the Act requires – with choice and control at their heart, and the number of social care staff available to deliver services. One unpaid carer stated:

“Social work have a staffing shortage, and there’s been no social worker since his social worker left for maternity leave in the summer.”

An occupational therapist stated:

“[...] inadequate staffing in social work teams causes delays in assessments, reviews, etc. [Also,] lengthy processes plus inadequate staffing cause huge delays in getting SDS packages up and running - identity checks for banking paperwork etc takes time”

Another occupational therapist, working with SDS assessment and authorisation, noted the lack of social care staff, and a lack of diversity within the existing workforce, namely a shortage of Black, Asian and Minority Ethnic (BAME) carers.

In addition to workforce shortages in social work, a shortage of social care staff was also highlighted by an individual:

“There’s basically no staff available and no providers are taking on new packages.”

Another respondent said:

“Ultimately my family ask the question, what chance do you have of choice and control through SDS when Social Care appears to be so utterly devalued as a profession and is starved of resources in material and financial terms. Carers are paid so little for what they do [...]. Whilst I agree and support the values and intentions behind Self Directed Support, this cannot be done on the cheap. We can put all the bells and whistles we like on our legislation, without adequate resources care services will die on their feet and choice will be further limited.”

Employment conditions

The rate of pay and terms and conditions of employment of social care staff were identified by respondents as a reason for staff shortages. Respondents said that they believed social care staff are not appropriately compensated for the nature of the job they undertake, and further difficulties arise as pay rates are determined by local authorities. One individual stated that:

“Staff can make more in less stressful and demanding environments making the roles in social care unattractive.”

A third sector organisation highlighted that existing terms and conditions of employment do not accurately reflect the role of the social care workforce in the community. They also said:

“There is a clear correlation between terms and conditions, recruitment and retention, and quality of care provided.”

Workforce training

Respondents expressed a need for social work staff to receive more, and better, SDS-specific training and education. A national organisation that supports the use of SDS said:

“We understand there is currently very little coverage of SDS in social workers’ undergraduate education, with some courses offering as little as half a day’s teaching on Self-directed support across a whole degree programme.”

They stated that this impacts on the social worker’s understanding of the intentions of SDS and how to implement social care in practice to realise these intentions. One individual said:

“[Social workers] develop their own take on what Self-Directed Support should look like.”

A national organisation that supports the use of SDS said the extended team of professionals responsible for effective SDS implementation also require the appropriate training to do so – including local authority commissioning and finance teams.

Some respondents highlighted that personal assistants have insufficient access to training and support, and they should have to achieve certain qualifications to do their job. One said:

“It should also be compulsory for PAs to register with SSSC whereas it currently isn’t, and there should be a facility to enable option 1 PAs to do their SVQ II minimum, again this is not an option currently.”

Theme 7: Moving goalposts

Many respondents highlighted that the goalposts, regarding eligibility criteria and how funding can be spent, have been moved since the Act was introduced. Some said that the flexibility they initially had has become more restrictive over the years.

Several individuals noted that in recent years the package they access can now only be used for “hours” of support, with less of a focus on personal outcomes. One unpaid carer said:

“Since his review in April this year his budget can only be used for ‘hours’. This has left us having to financially support him to still [attend] his clubs as we could not take them away from him. This is proving a burden and a huge worry once we are no longer here. He needs so much more than somebody providing ‘hours’. The recent experience has left us wondering [if] it is worth it anymore.”

A third sector organisation conducted research of their own, and said:

“One person was informed by their social worker at their last review that the criteria had changed, and their support package would now be reduced.”

One individual noted that the intentions of widening eligibility criteria with SDS have not been recognised – this has led to less focus on preventative care and early intervention. They stated:

“The intention was to widen eligibility for accessing support but in fact this has reduced greatly. Thresholds for accessing support have been raised and every local authority is operating at the critical risk level with occasionally addressing substantial risk Individuals, where the risk is moderate or low are unlikely to receive support.”

Some respondents highlighted that unspent funding – often unspent due to insufficient service availability or to save money for certain periods of the year – is often “clawed back” by local authorities. An organisation that provides information and advice about SDS commented on this:

“To achieve balanced budgets many local authorities/HSCP clawback funds by reducing support arrangements or failing to recognise that for some people money is accumulated to meet needs which are far greater at some points in the year than others.”

Theme 8: User responsibility

Stress and second job responsibilities

The introduction of SDS proposed a shift in power, where the user, or the unpaid carer, had more responsibility and control over how the social care was organised and delivered. As a result, respondents have highlighted they have experienced stress, often due to the employer responsibilities they take on with option 1. One individual said:

“The problem comes when your staff go sick and no one can cover, this has [led] to some really stressful and upsetting times.”

Another individual said they have experienced ongoing stress as their mother’s carer and power of attorney, as their mother is £8,000 out of pocket, pending reimbursement after becoming entitled to SDS 16 months prior.

Many stated that opting for option 1 is akin to taking on a second job. One said:

“People should be in no doubt that option 1 is indeed like having an additional job running alongside your caring role and responsibilities, and in our case our paid employment.”

Another individual said that despite having the legal responsibilities of an employer they could not make decisions that an employer should be able to make. They said:

“I also do not like having the legal responsibility of being an employer but without the control or discretion to use the funds accordingly. [For example,] why can’t I give my son’s carer a pay rise.”

Administrative support for employer and unpaid carer responsibilities

A respondent who organises SDS on behalf of their husband said that the system has worked for them. However, they expressed that help with the administrative duties is required and proposed that an online register of providers is developed to help supported users access services suitable to them. They said:

“Help with all of this admin would have been so good; plus help with identifying suitable agencies, or an online register of providers and of care homes offering respite would have been a massive help.”

A human rights organisation also expressed a wish for “infrastructure and mechanisms” to support employers with their obligations and to fill gaps in care times when they cannot do so themselves.

Theme 9: Services

Access to services

Inadequate access to a broad range of services was a theme, commonly cited amongst respondents, that is believed to be hampering the effective implementation of SDS. An unpaid carer said:

“There is a budget available but he has not been able to spend it due to a lack of resources. Part of his package is option 1, and some of the agreed options have no availability leaving the money unspent.”

Some respondents believe group provision of services should be incorporated into social care delivery again. One respondent said that doing so may see individual costs decrease and staff availability increase. They also said:

“Individual one to one support should always be available where needed, but group support and social inclusion is equally important, as well as being both cost and resource effective.”

Difficulty accessing services in specific groups

An inadequate number of services is an issue that can be amplified in remote and rural areas, as staff shortages and scattered services have a more profound impact in such locations. One Health and Social Care Partnership said:

“Those living in rural areas are particularly disadvantaged. Even if people do manage to get an Option 3 as their preferred choice, due to the availability of staff, most of the time people either don’t get all the support hours they need, or they are receiving support times out with their preferences.”

Respondents said some people, such as those with dementia, autism, or sensory loss, are also affected greatly by the lack of service availability. One third sector organisation said:

“Certain groups of people still struggle to access SDS. These groups include people with dementia, autism, addictions, mental health conditions, or sensory loss; people from black and ethnic minority communities; and unpaid carers. Many ISOs describe how young people can ‘fall off a cliff’ at the point of transitioning from children to

adult services. Where there is provision for these groups, services are often under-resourced.”

Theme 10: Processes and their impact on flexibility

Respondents noted the processes involved in accessing and utilising SDS are often tiresome, time-consuming and a barrier to accessing care services.

Assessment process and personal outcomes

Some respondents highlighted a flawed assessment process and the damaging effect this can have on developing the personal outcomes for a user. A human rights organisation conducted research of their own on ‘Self-directed Support and personal outcomes’. One personal assistant said:

“Too often I believe assessments are not done properly and they end up getting the sort of support service that suits the [local authority] rather than what suits them.”

The human rights organisation added:

“In [the] view [of some participants], the decision about their care was made before the assessment, so their opinions about their personal outcomes did not have an impact on the final decision”

Several responses expressed a need for group services (i.e., day centres) that would better suit a supported user and their personal outcomes. One respondent said:

“SDS needs an overhaul, the pendulum has swung too far to individualised support, and needs to balance back to the middle. The options available should not just be individual support, there needs to be elements and availability of group support within the system... bringing back group support options will decrease costs and increase staff availability.”

Following assessment processes, some respondents to the call for views said that they felt too encouraged to pursue a particular SDS option. One said:

“Too many people [are] being encouraged to take Option 1 or Option 1 [is] being seen as an easy fix as it is the only option available.”

A number of organisations highlighted a need to move towards a “relationship-based” approach, away from the current time-and-task approach that social care operates in. A social work representative indicated that this style of approach would facilitate better personalisation of outcomes for users:

“[...] success in a relationship-based practice model looks like whatever works for the supported person - bolstering family supports, making use of community services, nurturing

independence, navigating systems to get the best outcomes, and only if then needed, funded support.”

Waiting times and approval processes

The time taken for decisions to be made and long waits throughout the needs assessment phase of SDS were commonly mentioned. A third sector organisation reported hearing that some people have had to wait longer than six months for a needs assessment or a review. They also said:

“One individual reported waiting for two years to get a care plan signed off. When she contacted her local authority, she was told that her support plan is waiting to be signed off by a social worker.”

This highlights another process that respondents noted as being a barrier to effective SDS implementation – the need for a care plan to be approved by care managers and financial officers. One individual highlighted their frustration at having a care plan agreed that still required authorisation for individual items. Another said:

“The only disappointment is that we have to have expenditure approved by a Care Manager before applying the funds.”

Administrative processes – financial returns and complaints

Respondents stated that administrative procedures, including financial returns, processing payments and complaints procedures, could be far clearer and more streamlined. Regarding financial returns, one individual said:

“I still haven’t quite got the answer of what exactly the financial records need to be - an example proforma would be useful.”

Other respondents mentioned the “cumbersome” financial returns process, and one individual touches on the difficulties they have faced as the system does not accept Google Drive files. One HSCP noted the issues with IT systems experienced in their area:

“[...] we are going through an IT system change for social care functions, but some finance work is still ongoing on the old system, which staff feel is slow and paperwork heavy, resulting in more bureaucracy and it [is] taking more time to set up SDS for people we support. It has been said that a shared system across Scotland, where information could be shared, would be of huge benefit to everyone involved, especially when there is movement for people we support, between partnerships/local authorities.”

Respondents noted the complaints procedure and the difficulties they have experienced navigating it. Several stated it is an “in house”, and “biased”, procedure that bounces SDS users round in circles reaching no resolution. One social care provider that champions SDS highlighted the tenacity and persistence often required on the part of those making the complaint to reach the point of review and resolution.

Some expressed that an independent body responsible for investigating complaints would be beneficial.

Online systems

A handful of responses stated that they have had issues with the SDS systems they're required to use being online. One individual highlighted that they require additional help from their family to use the systems, which influences their control of their SDS package, whilst another respondent highlights that many may have difficulties with the system if they're not "digitally literate" – digital systems may increase accessibility to some people, however it may ostracize others.

Theme 11: Investment, funding, regulation, and accountability

Scottish Government investment

A running theme throughout the responses is a desperate need for greater investment from the Scottish Government to support better SDS implementation, to recognise its value and deliver on its initial vision. A HSCP said:

“[...] the lack of adequate and sustained funding from Scottish Government is not congruent with the expectation of consistent and fair positive outcomes for the community through SDS.”

Respondents stated they believe that SDS is underfunded, starved financially, and may be because social care is an undervalued profession. This underfunding leads to a short-staffed workforce and a lack of adequate resources, in areas across Scotland, hampering access to services. A local government representative said:

“For the principles of Self-directed Support – promoting choice and control over support in a way that meets the needs and outcomes of the individual – to be fully embedded there must be improvements to the way social care, and Local Government more broadly, are valued and invested in to create the conditions for success.”

Regulation, accountability, and data collection

A national organisation that supports the use of SDS and other respondents highlighted the need for a regulatory body to ensure accountability. The former said:

“There is currently no effective legal mechanism for individuals who need social care support to uphold their rights under the legislation.”

Independent regulatory bodies and more stringent regulation procedures have previously been mentioned – concerning complaints – as respondents believed these would help them to overcome the “opaque” and “bureaucratic” processes associated with SDS. Local authorities are provided with statutory guidance and

powers to ensure the implementation of SDS, yet at present, there are not appropriate measures in place to ensure the accountability of the local authorities.

There is very little data and information available in the public domain pertaining to the number of people accessing SDS, their experiences with the system and its processes, and importantly the level of unmet need. An organisation that provides information and advice about SDS stated that by failing to quantify unmet need, there will never be a true understanding of how much a holistic, comprehensive social care service would cost:

“Unmet need must be captured and reported on to ensure the demand and need for social care is what ‘politically’ influences the budget allocation.”

Ring-fenced funding

Several respondents said that funding provided to local authorities should be ring-fenced, so that it can only be spent on SDS delivery. One individual stated:

“The money given to local governments should be ring fenced. It is used for other things and supported people have to go without.”

David Collins & Anne Jepson, Health and Social Care Team, SPICe Research

9th February 2024