**Post-legislative Scrutiny of the Social Care (Self-directed Support) (Scotland) Act 2013**

**Self Directed Support Scotland response**

**December 2023**

**Introduction**

1. Self Directed Support Scotland (SDSS) welcomes the opportunity to respond to this call for views to inform the Post-Legislative Scrutiny of the Social Care (Self-directed Support) (Scotland) Act 2013.
2. Self Directed Support Scotland is Scottish Government’s strategic delivery partner supporting the national implementation of SDS policy. We are a Disabled People’s Organisation and a membership organisation. Our members are present in all Scottish Local Authority areas and include Independent SDS Support organisations (including those funded by Scottish Government through the Support in the Right Direction (SiRD) funding stream), user-led organisations, advocacy organisations, third sector organisations and others supporting the implementation of SDS. Our members support tens of thousands of people across Scotland with their social care support choices every year.
3. We responded to the previous post-legislative review process in 2017-18. Since that time, we and others in the sector have worked actively on targeted interventions to bring about SDS improvement. Despite this, in our response to this call for views, we have highlighted the fact that many of the issues we identified six years ago preventing true implementation of SDS legislation, remain today.
4. Our response reflects on the positive changes the SDS Act has brought about, and our members’ perspectives on the most pressing current challenges in implementation.
5. In writing our response we consulted directly with 24 of our members (representing Independent SDS Support organisations, advocacy organisations, third sector organisations, and disabled people). Our response is also informed by our ongoing work with our members across Scotland and our analysis of enquiries received directly from members of the public.
6. Throughout our response we also make reference to the [My Support My Choice](https://www.sdsscotland.org.uk/mysupportmychoice/) research, published in 2020. We undertook this research in partnership with the Health and Social Care Alliance Scotland, and it remains the most extensive piece of research on individuals’ experiences of SDS yet undertaken since the passing of the legislation.

**Positive effects of SDS legislation**

1. When SDS legislation was introduced to Scotland in 2013, it was a pioneering, forward thinking piece of law that was based on sound values and principles. Building on the campaigning efforts of the Disabled People’s Movement and Independent Living Movement, as well as prior legislation enabling people to receive a Direct Payment to control their social care, it recognises that individuals are the experts in their own lives and should have the opportunity to exercise choice, control and flexibility around their support, to help them live a good life.
2. We and our member organisations, who work with tens of thousands of people seeking access to social care every year, still believe those values and principles are valid.
3. When the legislation works well, it can have a transformative effect on people’s lives, as we heard from participants in the *My Support My Choice* research. 74% of survey respondents said they agreed with the statement, “SDS would improve/has improved my social care experience”. They reflected on how SDS had enabled them to live a better life:

*“SDS basically is the a la carte of the care system. Previously the local authority provided this care, you had no choice. […] But now with SDS I have control. I can choose what option I want (within the rules, of course!). I find this is much more liberating. […] Basically, it has been the passport to independence. Whereas before, oftentimes, especially if you’re disabled you have to take what you get, you haven’t really any choice. But to have the ability to decide for yourself is liberating. So, it makes a big difference.”*

*“I am now living my life to its full potential.”*

*“It is a great way to shape the care you need.”*

*“The […] flexibility and choice it gives is priceless.”*

*“Self-directed support is a fantastic idea; it has improved my life no end. I would recommend it to anyone […]. Once you get through the initial paperwork, setup etc. it gets easier.”*

*“It has been the best decision. I now have a lot more freedom to go out and about. My Personal Assistants are lovely, and they understand my needs and how to help me. Being able to employ staff myself a lot better than agency staff as they turn up on time and I get more for my payments.”*

*“If I didn’t have [SDS-funded activities], I don’t know if I would still be here. I was overdosing at such a rate [that] they didn’t expect me to recover. […] [My social worker] pushed really hard at me to get into the groups because I was just shutting down myself in the house. If it wasn’t for SDS, I don’t think I would be here.”*

1. In our response to this Post-Legislative Scrutiny Process, we believe it’s important not to lose sight of the transformational difference Self-directed Support can – and has – made to people’s lives. This is not to downplay the significant challenges in implementation. But we wish to acknowledge that when the legislation is implemented properly – as it has been and continues to be in some instances – it has a significant positive impact on individuals’ lives.
2. We also believe it is important to recognise that the introduction of the SDS Act has enshrined the right to choice around social care in law. Whereas previous strategies aimed at implementing the SDS model encouraged and promoted choice, control and flexibility, the legislation has turned these principles into rights. The challenge now remains ensuring individuals can realise those rights.

**Challenges in implementation**

1. Many of the following challenges we have identified as factors preventing the implementation of SDS legislation are the same as those we highlighted in the post-legislative scrutiny process of 2017/18, and continue to be reflected in ongoing sector-wide discussions around SDS improvement. This indicates some of these challenges are systemic, and that further measures – legislative or otherwise – are needed to overcome these significant hurdles.
2. At the same time we also believe these problems are not insurmountable, given the right legal mechanisms, culture, leadership and supporting climate.
3. While some of the challenges are due to the way the legislation is written leaving it open to varied interpretation and implementation, others, detailed below under ‘wider contexts’ are the cultural, political, economic and social influences that we feel are the major disabling factors preventing the implementation of Self-directed Support as intended.

*Lack of accountability*

1. In 2017/18 we reflected that the lack of accountability for SDS legislation was an overriding factor in preventing it working as intended, and we still believe this is the case.
2. There is currently no effective legal mechanism for individuals who need social care support to be able to uphold their rights under the legislation. When seeking to challenge decisions, individuals’ primary course of action is through Local Authority complaints processes, which have been recognised as being opaque and bureaucratic ([see research from Equality and Human Rights Commission, 2023](https://www.equalityhumanrights.com/our-work/inquiries-and-investigations/challenging-decisions-about-adult-social-care-scotland)).
3. Although some individuals do choose to proceed to judicial review, there are many barriers (structural, knowledge, relational, legal support and legal process) to this being effective, [as summarised in research carried out by the University of Strathclyde and In Control Scotland in 2021](https://www.strath.ac.uk/media/1newwebsite/departmentsubject/law/cshrl/Final_report_October_2021.pdf).
4. When compared to, for example, Additional Support Needs tribunals, where parents and young people have a mechanism for appealing decisions of a Local Authority in respect of the Education (Additional Support for Learning) (Scotland) Act 2004, the accessible avenues available to people wishing to challenge social care decisions under the SDS Act are inadequate.
5. Another factor influencing accountability is the fact that the legislation and statutory guidance does not define timescales for each stage of the process of putting social care support in place (with the exception of Free Personal Care, which provides an example of the impact that having defined timescales can achieve). This means individuals find it very difficult to challenge processes which can be incredibly lengthy, having an enormous knock-on effect on people’s lives, as well as their mental and physical wellbeing. 56% of respondents to the *My Support My Choice* research said that “*waiting times, or waiting for responses, makes SDS more difficult for me*”. Our members have supported people who have been unable to get social care support in place for more than a year due to delays in the system. Without timescales defined in legislation or statutory guidance, and without an effective mechanism to challenge drawn-out, bureaucratic and stressful processes, many people are effectively left in limbo.
6. Contributing to the lack of accountability that we feel is preventing true implementation, is the very limited capture of data on individuals accessing SDS, their experience of the process, and levels of unmet need for social care more widely. When compared to data available within the NHS on waiting times, patient numbers and levels of patient satisfaction, comparable data on social care is largely absent. Were this data available, we feel it would contribute to a learning and improvement culture that would enable fuller implementation of SDS than exists at present.

*Local interpretation of legislation*

1. As reflected in our response to the 2017/18 review, we believe another factor preventing effective implementation of SDS is the local interpretation of the legislation. Many of our member organisations offer in-depth, one-to-one support to individuals navigating their way through SDS, and they often report that their comprehensive knowledge of local rules and regulations around SDS is a crucial factor in their being able to provide good quality support throughout the person’s journey. While we support this local knowledge, we also feel it is a symptom of the variance in implementation across Scotland which contributes to a lack of awareness and understanding of SDS, and inequalities in access to social care support.
2. The local variation in implementation of SDS also has a profound effect on individuals who move from one Local Authority area to another, where local policies and procedures can vary significantly. Our members have dealt with examples of individuals whose support has been reassessed and reduced drastically as a consequence of moving area.
3. We feel that the legislation gives many powers to Local Authorities, which enable this local interpretation, but there is not enough emphasis on accountability for the duties under that same legislation.

*Lack of availability of services preventing true choice*

1. The intention of the 2013 Act is to enable individuals to exercise as much choice and control as they wish over their social care support. However, in practice, a range of factors are preventing true choice from being available, therefore limiting the efficacy of the legislation.
2. These factors include high vacancy and turnover rates in the social care workforce and inadequate funding to cover the true cost of care. This means care providers are unable to provide the levels of service required to meet demand, so there are, in turn, limited options available to individuals who wish to direct their support using any of the four SDS Options.
3. While some sporadic efforts have been made to reform commissioning practices to make them more outcome-focused and to enable services to flex to the needs of individuals, we believe current commissioning practice across Scotland, which remains largely output-focused, exacerbates problems with service provision and is a barrier to developing more innovative solutions to meet need, such as micro-providers and co-operatives.
4. The SDS legislation presumes that there will be adequate services available under each of the four Options, meaning individuals would have genuine choice over how their social care support is delivered and how much personal control and responsibility they want to have in the process. In reality, inadequate service provision means in some areas, all four options are not equally viable, so the individual essentially has to – or is encouraged to – take whatever is available.

1. These challenges are especially acute in remote and rural areas, where it has been recognised that issues such as inadequate funding to cover greater travel costs has led to care providers cancelling contracts, further reducing the choice available to individuals.
2. The lack of adequate availability of services has a further knock-on effect for social work practitioners, many of whom report feeling unwilling or unable to explain the four SDS Options, as required under legislation, for fear of raising expectations when all four options are not equally viable. Only 41% of participants in the *My Support My Choice* research indicated that a social work professional discussed all four SDS Options with them – despite this being one of the clearest provisions in the legislation.

*“[I received] Absolutely nothing, [the social worker] came in and she showed me a sheet which she took away, and she said this is what type 1 care is, type 2, type 3, type 4. She said, ‘but we can discard type 3 and 4 because they’re not available here.’”*

1. A further consequence of the lack of availability of support services has been the increasing trend for individuals needing support to be placed in the position of having to use SDS Option 1 to employ Personal Assistants, simply because the lack of available services means this is the only viable option. This problem is particularly acute in remote and rural areas, with the latest statistics from Highland and Argyll & Bute showing the proportion of the population using SDS Option 1 is 20 times higher than for Glasgow[[1]](#footnote-2).

*“[My] social worker […] sat and told me my options in November, along the lines of […], ‘Well, there is 4 options. You can’t have Option 3 because we don’t have any statutory services in the area. We don’t have any agencies, so you can’t have Option 2. So it’s Option 1 or nothing.’*”

1. This leads to further unintended consequences for individuals who are having to take on an enormous amount of responsibility for recruiting and managing Personal Assistants, or doing so on behalf of a family member. There is some support available for people becoming PA Employers from our members and other organisations funded through the Support in the Right Direction (SiRD) stream. While this support is hugely valued by those who are able to access it – many of our members report their clients saying it made the difference between them feeling able to take on the responsibilities of an Option 1 package, and going without support – these services are incredibly stretched by demand, and not available consistently in all parts of Scotland.
2. This situation further undermines the original intention of the legislation, whereby Option 1 was designed as an avenue for individuals who actively wished to have more responsibility and direct control over their social care support, to do so. Currently, the reality is that an increasing proportion of people using Option 1 to employ Personal Assistants are doing so out of desperation, and they are ill-equipped and inadequately supported to do so. Some of our members have reported instances of harmful situations experienced by supported people and Personal Assistants due to the lack of capacity and skills to fulfil the responsibilities of managing an Option 1 package.
3. In relation to Option 2, which is where the 2013 Act made the most significant changes to previous legislation – as an effort to bridge the gap between more traditional services and the responsibility that comes with Option 1 – it has been highlighted ([in research by InControl Scotland](https://www.in-controlscotland.org/_files/ugd/fd9368_438ce0e5a9b746179378b11d9148bec7.pdf) and elsewhere) that this Option is under-used and does not have the supporting infrastructure in place to be effective.
4. Research also suggests that many people accessing support via Option 3 are unaware of their rights to choice and control, especially around the selection of SDS Options. We believe further steps need to be taken to ensure all people eligible for social care support are aware of their rights under SDS legislation.
5. Alongside challenges in the availability of services preventing true choice, participants in the *My Support My Choice* research identified the following factors in preventing choice as intended by the legislation:

* lack of awareness and understanding of all four SDS Options among social work professionals
* attitudes of some social work professionals in not feeling it is necessary to explain all four Options objectively or equally
* a lack of accessible information, both in alternative formats and languages, about the SDS Options.

*“I don’t think that the professionals explained Option 1 properly, that’s really common. And I don’t think they explained Option 4 either. Just Option 3. People didn’t get enough information about the options available. And I don’t think that the professionals knew enough about the options either and all the things that go into them. […] They are not explaining the options properly. They are just giving one option and they are not giving people the chance to decide what option they’d like to have. Basically, there only are Option 3s because that’s the easiest option to do.”*

*“I wasn’t even told what all of these different options were. All I was told was there was two. I wasn’t told that there were extra ones. […] I was told I could go down the route of having everything by myself [Option 1] or I had the choice of going through the local authority [Option 3]. I wasn’t told about the other options at all. They were choosing what information to give.”*

*Poor awareness and understanding of the legislation*

1. A further challenge that we believe is preventing full implementation of SDS legislation is the lack of awareness and understanding of the law among members of the public, social work professionals and others involved in the social care support system.
2. Our member organisations who provide Independent SDS Support services work closely with their local social work teams, and often report very low levels of awareness and understanding within these teams of the duties they have under SDS legislation. Many have developed training programmes to educate social work professionals on the principles and practical application of SDS, as a necessary intervention to ensure that the individuals they are supporting to access social care can have a good outcome.
3. 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. This means newly qualified social work professionals – and those who have been working in the field for some time – often have a poor understanding of the intentions of SDS and how it works (or should work) in practice. This is emphasised by responses collected in *My Support My Choice:*

*“I was disappointed that [the social worker] couldn’t give me any advice about SDS as they didn’t seem to know what I was talking about. I received more information from [third sector organisation] than social work.”*

“*The social worker has no experience of SDS. She is very good at listening but doesn’t know the first thing about SDS and how it works. Her managers […] dictate stuff to her, some of which seems barely legal.”*

1. Alongside social work professionals, effective implementation of SDS requires a knowledgeable and confident network of other professionals involved in the process, such as Local Authority commissioning and finance teams. Where we have seen SDS working most effectively, this is supported by an understanding of SDS legislation and its principles and values within this supporting structure; unfortunately, these examples are rare.
2. A symptom of some of the challenges inherent in SDS implementation is the need we witness for individuals to familiarise themselves with legislation and statutory guidance in order to uphold their rights. Many enquiries received by our members and by us directly, as well as in posts on our public online SDS Forum, are from people seeking detailed information about specific pieces of legislation that will support their case when challenging a decision. Anecdotally, we hear that individuals often believe they have a better understanding of the law than their social worker, and report needing to obtain detailed legal knowledge for themselves in order to feel confident to challenge decisions and advocate for their or their family member’s needs. We believe that if the legislation were working as intended this would not be necessary for individuals to do.
3. While we have reflected on the transformative effect of Self-directed Support for individuals for whom it has worked well, we also understand that it is not as available to specific client groups, or people with particular needs, as it should be. [Our recent research into the barriers Autistic people face in accessing SDS](https://www.sdsscotland.org.uk/report-highlights-barriers-to-social-care-support-for-autistic-people/) is just one example of the disparity of approach for people with different needs.

*Responsibilities of different agencie*s

1. Another factor affecting the effective implementation of SDS legislation is difficulties around understanding where legal duties lie when many services are involved in a person’s life – for example, health, education, and social work. This has the consequence that individuals, families, and professionals themselves are often unclear about who is legally responsible for what, meaning individuals who require support are passed between services again and again, with no clear decisions made about their support.

*Lack of alignment with other legislation*

1. Lastly, our members and ourselves have identified a lack of alignment between SDS legislation and other relevant pieces of legislation, contributing to confused and contradictory decision making which has a profound impact on individuals’ lives.
2. A Scottish Government publication, [Guidance on Managing Self-Directed Support for Adults with Incapacity](https://www.gov.scot/publications/managing-self-directed-support-for-adults-with-incapacity-guidance/) states “*There is disparity between the Adults with Incapacity (Scotland) Act and Social Care (Self-directed Support) (Scotland) Act 2013 (SDS Act) as to the age at which one becomes ‘adult’, which can create both confusion and tension. In the case of a person who lacks capacity, and thus a person who comes under the ambit of the AWI, an ‘adult’ is a person aged 16 or over. The SDS Act draws its definition from the Children (Scotland) Act 1995; for the purposes of the relevant sections, a person is an adult if they are age 18 years or over.”*
3. This contradiction becomes important when a young person may lack capacity but there is no-one who has any relevant legal authority to make welfare or financial decisions on their behalf. The Guidance states “*If the supported person is now incapable and if there is no attorney or guardian, or none with a relevant power on which they can rely, then Option 3 is the only option available.”* SDSS has dealt with enquiries from families who have been allocated an SDS budget under Option 1 for the young person they care for, who is aged 16 or 17. The Local Authority then realise that there are no family members with relevant legal authority in place, and stop the Direct Payment. This has significant implications for any Personal Assistants employed by the family, and for the young person’s continuity of care.

**Wider context for SDS legislation**

1. Since the post-legislative review of the SDS Act carried out in 2017/2018, much focused work has been undertaken across the sector to improve the implementation of Self-directed Support, including:

* The activities of the SDS Implementation Plan 2019 – 2021
* The activities of the SDS Improvement Plan 2023 – 2027, the first year of which is nearing completion
* Updating of the SDS Statutory Guidance (2022)
* The publication of the SDS Framework of Standards (2021-2022)
* The introduction of the Carers’ Act (implemented 2018) and updated statutory guidance (2021) introducing the right to SDS for carers who are eligible for support
* The continuation of Support in the Right Direction (SiRD) funding to enable the provision of independent SDS support
* The National SDS Collaboration (established April 2022), a cross-sector space which meets monthly to connect those working on SDS improvement.

1. Self Directed Support Scotland has also had significant involvement in the setting up and development of the [Personal Assistant Programme Board](https://www.sdsscotland.org.uk/pa-programme-board/), established in August 2021, which aims to support those employing Personal Assistants through SDS Option 1 by recognising and developing the PA workforce. The Programme Board has made significant developments in this area, including the publication of the online Personal Assistant and Employer Handbook, work to raise awareness of the PA role and improve the infrastructure for recruitment, the ongoing development of a national training framework for PAs and their employers, and work, led by Social Work Scotland, to develop a national agreement for Direct Payments (Option 1).

1. There are further examples of local improvement work, such as that done to develop an SDS strategy in Highland, which came about as a consequence of findings of the *My Support My Choice* research into individuals’ experience in this area. The approach here, which has involved a wider group of stakeholders (including those accessing SDS themselves) alongside the NHS and Local Authority, has been praised as forward-thinking and innovative. One example of good practice arising from this work has been the recent agreement to pay enhanced hourly rates to Personal Assistants employed through SDS Option 1 depending on whether they are working in urban, rural or remote locations, recognising the extra costs associated in providing care in rural and remote areas and the additional barriers to recruitment in these areas.

1. There is no doubt this improvement work has brought about positive results, but we feel its potential for wider impact has been limited by its taking place within a broader national context of cultural, political and economic factors which have hindered progress.

1. Some of these disabling contexts preventing the effective implementation of SDS legislation include:
2. **Workforce challenges**, with poor pay and conditions across social care roles, including social work, highlighted repeatedly as a factor in the current challenges faced by the social care sector and therefore SDS. This also includes the impact of Brexit on the availability of workers to fulfil demand.
3. **The cost of living crisis**, which has an acute impact on the low-paid social care workforce, further disincentivising them from remaining in the sector, and also impacts on service providers’ ability to provide support within available budgets.
4. **The Covid-19 pandemic**, which led to a decrease in available services which some feel has not recovered to pre-pandemic levels, and caused significant stress across the social care sector which has led to burnout and increased vacancy rates. Additionally, the pandemic created significant local shifts in SDS practice, some of which our members have reported are proving hard to shift back. While some alarming changes to practice during Covid were successfully challenged (such as the withdrawal of access to a formal complaints process in some Local Authorities), other areas of poor practice, particularly around inflexibility of spend in SDS budgets, persist.
5. **Health and social care integration**, [which has been recognised](https://www.audit-scotland.gov.uk/publications/self-directed-support-2017-progress-report) as drawing attention away from the implementation of Self-directed Support.
6. The introduction of **eligibility criteria for social care support**. Our member organisations say that they are consistently supporting people who have been unable to access social care via their Local Authority until they are at crisis point, by which time the options available are extremely narrow, and they are forced into accepting whatever is available – directly in contradiction to the principles and values of the SDS Act.
7. The introduction of **free personal care** in Scotland, which while very welcome, has had the unintended consequence of creating a cultural divide between personal care and other forms of support. SDS legislation is intended to ensure individuals are able to participate in the life of their community, not just have their basic human needs met. The provision of free personal care has meant that these needs are often prioritised, with other types of support sidelined. As highlighted above, the fact that Local Authorities have a duty to provide Free Personal Care for those at critical or substantial risk within a fixed timeframe, whereas support through SDS has no legal timeframes attached, further incentivises Local Authorities to prioritise this type of care. Furthermore, our members highlight that although Free Personal Care legally includes wider personal support, such as behaviour management and psychological support, this is little understood or promoted by social work professionals.
8. **Financial constraints across the system**. Our members report that eligibility criteria are preventing many people from obtaining an SDS budget to meet even their most basic needs, while those who *are* allocated a budget find it is not high enough to meet their outcomes and to be able to participate in the life of their community, as defined in the legislation.

While care charging means many people eligible for social care support are required to make personal contributions towards the cost of that care, people also find that when they are allocated an SDS budget, even this is not enough to cover the cost of the care they require. We are aware of many cases of individuals having to make further contributions from their own funds to pay for the cost of care services they have been assessed as needing, but which their SDS budget does not fully cover. This also applies to people using SDS Option 1, with individuals having to contribute further funds of their own to top up wages for Personal Assistants, as their Direct Payment rate is inadequate to recruit or retain appropriate staff. This clearly has consequences for the equality of social care provision.

Furthermore, while it is common practice for Local Authorities to ‘claw back’ unspent funds from SDS budgets during annual audit processes, in many Local Authorities this process does not go as far as separating out any contributions the individual themselves has made from their personal funds into the budget. So effectively the Local Authority does not return a person’s own unspent money to them but absorbs it back into their own funds.

It is widely felt that there has been a consistent lack of investment in social care, however the lack of transparent data on social care spending at Local Authority level means it is difficult to unpick the detail of where spending has been prioritised and to understand the rationale behind individual budget decisions.

We feel that without financial controls such as ringfencing, Local Authorities will continue to deprioritise spending on social care support, exacerbating the situation further.

Evidence from our members’ work with individuals makes the case that enabling early access to social care support, and enabling greater choice, control and flexibility, represents an economic saving as well as achieving better outcomes for the individual.

1. A further context influencing the implementation of Self-directed Support legislation is the agenda around developing a National Care Service for Scotland. While SDSS and many of our members support the desire to improve national accountability and consistency, we feel the ongoing discussion around the development of the NCS has distracted Local Authorities from the immediate improvement work needed to implement Self-directed Support, with an expectation that policy and practice may soon change again. Self Directed Support Scotland, our members and the people they represent are also concerned that the values of and principles of Self-directed Support, and the vital role of Independent SDS Support organisations, is not being fully recognised in NCS developments.

**The role of local independent SDS support in enabling SDS implementation**

1. Legislation is not implemented in a vacuum, it needs a supporting infrastructure to enable the various functions of the legislation to be effective. One part of that supporting infrastructure we feel has played a vital role over the lifetime of the SDS Act is the work of Independent SDS Support organisations.
2. 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.
3. These services range from promoting and raising awareness of SDS to providing pre-assessment support, independent advice and information around the four SDS Options, to assisting with support planning, managing Individual Service Funds, providing payroll services, facilitating PA recruitment, and supporting individuals to challenge decisions around SDS where this is required.
4. We feel the role of Independent SDS Support in enabling any successful implementation of SDS legislation cannot be understated. 71% of respondents to the *My Support My Choice* research agreed that “Access to independent information and support makes SDS easier for me”. Comments from participants identified the role that independent support and advocacy had played in enabling them to access SDS as intended in the legislation:

*“[Local independent advice and support organisation] was the key to unlocking Self-directed Support […] and I can’t thank them enough for that.”*

*“Seek help from an independent support organisation who provides information and support to people looking to get SDS as they are knowledgeable about the processes in your area and can help you prepare for your assessment and get support in place.”*

1. The *My Support My Choice* research also revealed that access to independent SDS support and advocacy was most valued by people living in SIMD quintiles 1 and 2 (the most deprived communities in Scotland), and that one respondent stated that advocacy and peer support is “critical” for Black and Minority Ethnic individuals in accessing social care. This data emphasises the fact that these services play an important role ensuring equality of access to information, advice, and subsequently social care support itself.
2. The independence of these services (from the Local Authority) has also been highlighted as a vital factor in their being able to provide the support needed to help people navigate the complexities of SDS:

*“I would advise people to try to get as much information/ advice from organisations other than social work as to how the process of SDS is supposed to be carried out. In my experience, it depends on how good the social worker is at SDS.”*

*“You need somebody that is not involved with your social worker, not involved with anything, they’re just there to let you see what the options are and how you can do them easily without confusion.”*

1. At the same time, we believe the efficacy of Independent SDS Support and advocacy is maximised when good relationships and referral pathways exist between these services and Local Authorities. Our members who work across multiple Local Authorities report very different experiences from one area to another, largely dependent on local leadership, staff and culture. In areas where the relationship between Local Authority and Independent SDS Support organisation is more supportive and there is a level of mutual trust and respect, this leads to better outcomes for supported people as the Independent SDS Support service can be involved at an earlier stage in the process. Where relationships are not as effective, our members report they are more often involved when a situation has already reached crisis point, or at the stage when an individual is seeking to challenge a Local Authority decision or make an official complaint. We feel further measures could be taken through legislation and guidance to strengthen the role of Independent SDS Support throughout the SDS process.
2. Independent SDS Support services are also an important resource for social work professionals to be able to understand and implement SDS. As detailed above, several of our member organisations have developed and delivered information and training sessions to Local Authority social work teams to increase their understanding of SDS. Many Independent SDS support services also work closely and collaboratively with social work professionals to ensure the best outcomes for supported people when it comes to SDS. One participant in *My Support My Choice* described the benefits of this approach:

“*The social worker wasn’t too sure […] after the assessment so I know what she did [...] I know she’s spoken to [local independent advice and support organisation] as well to get information from them and advice from them. And it added to sort of a good team effort between the three, between the social worker, [local independent advice and support organisation], and myself.”*

1. Funding available from Scottish Government via the Support in the Right Direction (SiRD) funding stream, commenced in 2012 and recently made available for a new three-year funding period starting April 2024, has made a significant difference to the provision of independent SDS support across Scotland. [The most recent report indicates](https://www.inspiringscotland.org.uk/wp-content/uploads/2023/02/SiRD-Year-5-mid-year-update_FINAL.pdf) that more than 70,000 people have been provided with general information and advice on Self-directed Support over four years from 2018-2022.
2. Our members, many of whom are funding through SiRD, report that without access to independent SDS Support, many of the people they work with would not be able to exercise their rights under SDS legislation to be able to have the level of control they wish over their social care, and for this care to be flexible to meet their needs and identified outcomes.
3. Despite this, SDSS believes that independent SDS support services are inadequately resourced to meet the levels of demand placed on them, and that further investment is needed to ensure consistent and comprehensive coverage in all parts of Scotland. We are currently undertaking research, funded by Scottish Government, into the provision of independent SDS support in Scotland, identifying gaps and areas for improvement, the results of which will be published in March 2024.
4. Furthermore, as a Disabled People’s Organisation (DPO), we believe that the DPO and the Centre for Inclusive Living models, where services are governed and directed by disabled people themselves, are important to recognise and develop further in Scotland. The original intention of the SDS legislation is to empower individuals around their social care support choices, and we believe this empowerment can be maximised by building the capacity of disabled people and those who require social care collectively, as well as on an individual basis. Disabled People’s Organisations and the existing Centres for Inclusive living play a vital role in this and we would like to see these models expanded to further support the successful implementation of SDS legislation.  At the same time, we would like to see alternative mechanisms for collective, disabled person-led services explored to ensure they are meeting the needs of diverse communities, including rural, remote and island communities.
5. As well as Independent SDS Support services, we also wish to recognise the important role that peer support groups, such as the Highland SDS Peer Support group, the Borders SDS Forum and recently established West Lothian SDS Forum, play in helping people understand their rights around SDS, and upholding those rights.

**Conclusion**

1. In conclusion, our work as an organisation, and that of our members across Scotland, is grounded in the belief that the principles and values of Self-directed Support have the power to transform the lives of individuals, their families, and the wider community.
2. We strongly believe that the barriers and challenges identified by us and others as part of this post-legislative review process are not insurmountable, and welcome the opportunity this review provides to determine what further measures are needed to bring about full implementation of the SDS Act as intended.
3. We also welcome the chance this review provides to further implement the principles and values of Self-directed Support in the development of the National Care Service, to build upon the good practice that has been identified in this response and elsewhere, and to examine what further measures are needed to improve consistency in approach across the country. As reflected in our response to the last post-legislative review of 2017/18, we believe that improved accountability for the delivery of social care through Self-directed Support will make the biggest difference to the realisation of the intentions of the original legislation.

**Appendix: *My Support My Choice* recommendations**

The following recommendations were made at the conclusion of the *My Support My Choice* research in 2020 and remain valid as priority areas to address the implementation of Self-directed Support:

*Poverty and SDS*

1. Action is required by national and local public bodies to ensure that SDS budget cuts and tightened eligibility criteria do not negatively affect the physical and mental health of people on low incomes who access or are applying for SDS/ social care.

*Data Gathering and Analysis*

1. There is a pressing need for local and national public bodies to improve systematic and robust disaggregated data gathering and intersectional analysis about people who access and apply for SDS/ social care.

*Information About SDS*

1. People (service users and unpaid carers) need good access to high quality information about SDS/ social care, in a range of accessible and tailored formats (e.g. hard copy and digital; face-to-face; foreign languages; large print; Braille; Easy Read; BSL). Information is required at different points in a person’s journey, e.g. finding out / first enquiry about SDS, pre-needs assessment, during needs assessment, after needs assessment, once support is in place.
2. A wider pool of professionals (health, education) should be educated about SDS and able to signpost people to social work and appropriate resources. This includes professionals working in addiction, housing and homelessness services.
3. Work should be done to dismantle communication barriers faced by Black and minority ethnic people and older people.
4. Specific population groups like women, people with lived experience of homelessness, and younger people would benefit from targeted initiatives on information.
5. People’s socioeconomic status should help inform tailored communications.
6. More information should be available for people about what to expect from interactions with social work, and about their rights.
7. People should be provided with timelines for each stage of the process for accessing SDS, and transparency about where and when decisions about support are made.
8. Sufficient time must be allocated for needs assessments and review meetings, to allow for detailed questions and consideration of the four SDS options.
9. Further information and training for professionals may be required about the SDS options and supported decision making.
10. People should be informed about all four SDS options, rather than being given information about a more limited list of options.
11. People should be supported to consider the advantages and disadvantages of each SDS option before making decisions.
12. Parent/guardian unpaid carers, who often need support with accessing and understanding information about SDS, should be encouraged to complete carers’ assessments and support plans.
13. If emergency support is put in place following hospital discharge, people should receive follow-up information and conversations to ensure that the original arrangements continue to suit their needs and preferences.
14. Professionals should (be able to) spend more time reviewing case notes before meetings and reviews/assessments and getting to know the people they support.
15. Professionals should proactively check back in with people after assessments to ensure any outstanding concerns are addressed and resolved.
16. People should be offered a variety of ways to contact social work, as best fits their access needs and preferences. Social work departments should consider different opportunities, including online chat functions, a freephone support line, and direct email addresses so that people can communicate effectively with social work professionals.
17. People should always have access to independent advocacy and support, including translators, for assessments and review meetings, if they desire.
18. People should be provided with paper or digital (as preferred) copies of all documentation pertaining to their SDS, including Personal Outcome Plans, budget agreements, and decisions about their support package. These documents should be provided promptly and all materials should be available in a variety of accessible formats.
19. Everyone must have access to information about the budget available to them and specific work may be required to ensure this extends to all population groups including women and people living in areas of deprivation.
20. People may want to take part in several conversations to support informed decision making about care charges, budgets and how they interact with other income like social security.
21. Any proposed changes (particularly increases) in care charges should be communicated clearly to - and discussed with - people who access SDS/social care well in advance of the changes being introduced. Local authorities and health and social care partnerships should ensure that corrective measures are in place to rapidly respond to errors or delays in payments so that people are not negatively impacted.

*Informed Choice and Control*

1. People should be given longer than a week to consider their SDS options.
2. Systems could be improved to guarantee short waiting times – for a needs assessment, review, or for support to be put in place – to help people avoid unnecessary stress and anxiety, deteriorations in their physical and mental health and wellbeing, and from reaching crisis point and the potential for more serious and expensive intervention later on.
3. Work is needed to ensure people fully enjoy their right to a reasonable notice period for needs assessments or reviews.
4. More work is needed to ensure everyone is offered and can make their own meaningful choice between all four SDS options.
5. Professionals should be trained in supported decision making (and co-production methods more broadly) to help reduce the number of cases of substitute decision making where they choose the SDS option and/or who manages person budgets instead of the service user.
6. Targeted efforts are required to ensure that women, people with lived experience of homelessness and people living in deprived areas enjoy equal decision making about their SDS option, how support is arranged, and access to appropriate support.
7. Targeted work is required to ensure people with learning disabilities and Black and minority ethnic people are offered the four SDS options and that their support is person centred and rights based.
8. Targeted efforts are required to ensure that people living in rural areas of Scotland have a meaningful choice between - and can access - all four SDS options and appropriate person centred, rights based care, without having to incur disproportionate expenditure or move house.
9. Ensuring non-discriminatory attitudes and behaviour and a lack of gender bias in the support offered and provided to disabled parents is essential to ensure parity of support.
10. Professionals should provide people with up to date lists and contact details for service providers and other forms of support in the local area in accessible formats (e.g. housing assistance, occupational therapy).
11. People must be treated with dignity and respect in all interactions with health and social care professionals and assessments and support must be adequate and tailored to people’s requirements and way of life, taking into account all clinical, dietary, religious, cultural, or any other considerations based on protected characteristics and other self-identities.
12. Health and social care staff should consider the possibility of mental health crisis if changing packages and eligibility criteria and be able to arrange reassessments and signpost support services where needed.
13. No-one should feel or be pressured to share their support with others or move into residential care against their wishes – particularly not as a result of a desire to reduce funding for support via SDS. All resources should be maximised and options exhausted to enable people to enjoy tailored social care and remain – with appropriate support – in their own homes for as long as possible, if that is what they want.
14. People need flexible budgets and a focus on outcomes to enable them to live as independently as possible and enjoy the full range of their human rights. Flexibility is required in a range of ways: to change SDS option; to be able to choose how, where and when to spend personal budgets; with different amounts of spend and support at different times of the year.
15. Flexible, regular access to respite should be strongly encouraged because it is an essential element of SDS that results in good personal outcomes for people who access social care, families and unpaid carers.
16. People – particularly those living in rural areas and those who are blind or partially sighted – require more acknowledgement and accommodation of travel costs in their SDS budgets.
17. Many people could benefit from assistance from social workers and third sector organisations in navigating the bureaucratic processes to obtain mobility vehicles and travel passes.
18. Professionals should fully incorporate equality assessments into their processes for service users and families.

*Communication and Relationships with Social Work*

1. Work to ensure positive conversations and meaningful, consistent relationships between social work professionals, service users, families and unpaid carers should continue, with ongoing planning to guarantee high quality practice for all people using SDS – especially around clear and accessible communication.
2. Social workers need to have the time and skills to build relationships and trust with the people accessing SDS and unpaid carers that they are working with.
3. People should be informed if their social worker changes and have a right to request a new social worker if trust breaks down.
4. People’s opinions (spoken or written) should be recorded and acknowledged during needs assessments and review meetings to demonstrate the level of choice and control exercised over their support.
5. Social work professionals should be given training on how to support disabled LGBT+ people with targeted support and information if required, and local support groups should be appropriately funded.
6. Appropriate training and ongoing support on equalities, human rights, intersectionality, conscious and unconscious bias and anger management should be provided to social work staff at regular intervals.
7. Social work professionals should proactively gather regular feedback – good and bad – from service users, families and unpaid carers as a way to support continuous improvement.
8. Social work professionals should pro-actively inform service users, families and unpaid carers on a regular basis about how they can challenge decisions, access independent advocacy and support, local authority complaints procedures and the independent oversight of the Scottish Public Services Ombudsman (SPSO).
9. Work is needed to ensure systematic good practice and consistent transparency across several elements of SDS/ social care, including eligibility criteria, needs assessments, budgets and support packages, changes to support, participation in decision making and how to challenge decisions. People should not have to resort to Freedom of Information requests or court action to acquire information about their SDS/ social care.

*Impact of SDS on Family/ Relationships*

1. Professionals should ensure that all unpaid careers are offered carers assessments and have their rights explained to them.
2. Professionals should not assume that family members and friends are able or suitable to provide unpaid care. People who wish to reduce the amount of unpaid care they provide should be promptly supported by professionals, with appropriate future planning for contingencies.
3. Health and social work professionals should respect service users’ preferences if they do not wish to be reliant on family members and friends for their care and support.
4. Work is still required to improve systems for transition between children’s and adult services so they work well for people who use SDS/social care, their families and unpaid carers. SDS and Mental Health.
5. Social work professionals and decision-makers should consider the impact on people’s mental health of any reductions or changes to support arrangements – particularly reductions in budgets and increases in care charges.
6. People with mental health problems should be supported to access local mental health support services, which should be appropriately funded and resourced.

*Care Staff, Recruitment, Training and Quality*

1. Some people need more help to recruit and train care staff. Local authorities and health and social care partnerships should work with people who access SDS and unpaid carers to improve systems and processes related to care staff recruitment, training and quality, including diversification of the workforce.
2. Care staff training costs (e.g. specialist first aid or medical training required for them to carry out their job appropriately) should be included in people’s SDS budgets. This would help ensure a quality care workforce (including personal assistants) in each local area.
3. Social care and social work professionals should be trained to support and acknowledge the concerns of people who have had traumatic or poor experiences with social care in the past. This is particularly important for the victims of crime.
4. Targeted work is required to ensure that particular population groups, including LGBT+ people, Black and minority ethnic people, people with lived experience of mental health issues, and people with lived experience of homelessness do not experience stigma, discrimination or inequality when accessing SDS/ social care.
5. Independent advocacy, independent advice and support services need sustainable resources to continue their important role.
6. Focused efforts are required to ensure older people, Black and minority ethnic people, and people from all socioeconomic backgrounds are aware of – and can access – independent advocacy and support services.
7. Local authority and health and social care partnership staff should be given information and training about local independent advocacy, advice and support organisations, so they can refer people to these resources.
8. Social work professionals should proactively provide people with information about independent advocacy, advice and support organisations in accessible formats.
9. A free, independent and accessible national helpline and/or designated contact for any questions about SDS would be useful to people seeking/ accessing support.
10. Local peer networks should be encouraged and supported.

1. SDS Option 1 recipients, Highland – 0.3% of population; Argyll and Bute, 0.4% of population; Glasgow – 0.02% of population. Statistics from NHS Highland, Argyll & Bute Health and Social Care Partnership, Glasgow Centre for Inclusive Living, September 2023. [↑](#footnote-ref-2)