Self Directed Support Scotland (SDSS) represents organisations run by and for disabled people. Our members support thousands of people across Scotland with their social care choices, making use of their local knowledge and often their own lived experience. We work together to ensure that the voice of disabled people is heard at both local and national level. We highlight excellence in social care delivery to ensure that disabled people have full choice and control over their lives in line with the vision and key principles of the Social Care (Self-directed Support) (Scotland) Act 2013.

SDSS welcomes the opportunity to respond to this call for views on the future delivery of social care in Scotland.

<https://yourviews.parliament.scot/health/social-care-inquiry/>

**Experiences of social care in Scotland**

1. Your story and experience of social care in Scotland
2. What you would change about your experience of social care?

**‘My Support My Choice: User Experiences of Self-directed Support in Scotland’ (MSMC)** is a joint project between the Health and Social Care Alliance Scotland (the ALLIANCE) and Self Directed Support Scotland (SDSS), funded by the Scottish Government. MSMC stems from two pilot projects carried out separately by SDSS and the ALLIANCE in 2016-2017, and is part of the Scottish Government Self-directed Support Implementation Plan.

MSMC seeks the experiences of anyone who receives SDS or has been assessed in the last 12 months, regardless of the outcome of this process. It is the largest direct consultation with self-selecting respondents who access or have attempted to access SDS in Scotland: <https://www.sdsscotland.org.uk/mysupportmychoice/>

The aim is to gain a better understanding of the personal experiences of SDS among people who access social care and support across Scotland. In addition to research activity within specific local authority areas, focus groups are being carried out across Scotland with seldom heard groups who are often under-represented in policymaking. This project adopted a coproduction approach and involved disabled people throughout. There were three key elements to this process, namely the founding of a Project Advisory Group (PAG), the recruitment and training of peer researchers, and organising feedback sessions in each locality.

Early findings from the MSMC research highlight that:

* **People who can access SDS see an improvement in the support they receive** with 74% of survey respondents feeling that SDS has improved their social care experience. **Around a third of people chose how their support was arranged,** whilst around a quarter indicate that professionals chose for them, a further quarter state that friends or family chose how support was arranged.

* Many people report uncertainty of how to start the process of an SDS assessment and **information about SDS is not consistently available.** Older people, in particular, report difficulty in accessing information about SDS, and confusion about what parts of available support are included under SDS. Many respondents report that they do not fully understand the four options of SDS.
* Many respondents describe **assessments and reviews as a source of considerable anxiety and stress** to them.
* **Geography can play a significant part in people’s experiences of SDS** with respondents in rural areas reporting a lack of service choice, effectively limiting their options. People living in rural areas also report difficulties in recruiting staff and confusion over whether travel costs (for themselves and/or personal assistants) are included in their budget.
* **Parents with children who use SDS report widespread difficulties in transitioning from children’s social services to adult social services.** Many respondents have reported a break in service provision over several months, and a negative impact on family life.
* **Support through the process of accessing and using SDS is reported as particularly important.** Respondents placed emphasis on the value of peer support and independent advocacy in supporting them. Effective and transparent complaints procedures for SDS are limited.

Full research findings, analysis and recommendations will be published online in national, regional and thematic reports over Spring/Summer 2020.

**SDSS request that the Committee also consider the views and recommendations to be published in the My Support, My Choice research reports in June 2020.**

1. How should the public be involved in planning their own and their community’s social care services?

Since the Social Care (Self-directed Support) (Scotland) was introduced[[1]](#footnote-2), it has been a key principle within social care in Scotland that a person must have as much involvement as they wish in both their assessment and the provision of their support. Initial findings from the My Support, My Choice research, as well as feedback from SDSS members[[2]](#footnote-3), strongly suggest that this is not yet happening for everyone receiving social care in Scotland. The Care Inspectorate’s recent thematic review of self-directed support[[3]](#footnote-4) also found this; ‘flexibility, choice and control were not available to all, should they wish it’.

Co-production is essential both at the individual level, as the SDS legislation already requires, and at the wider community level. This can only be achieved by supporting, through funding and capacity building, peer-led and disabled people’s organisations to work locally, to campaign, influence, and provide independent information and support, to ensure that local people can claim their own rights under the SDS legislation and come together to work collectively with local authorities in planning their approaches to social care.

As a signatory of ‘Our shared ambition for the future of social care support in Scotland’[[4]](#footnote-5) [the Shared Ambition] SDSS continue to commend the approach outlined in the Shared Ambition, putting people requiring support in control, and in particular highlight the need for:

* Disabled people and carers to coproduce the legislation, policies and practices in which they are stakeholders.
* A framework for supported decision-making, including advice, information and independent advocacy.
* Investment in support structures to encourage people to choose more empowering options for self-directed support, including platforms for peer support and a sustainable future for Disabled People’s Organisations in Scotland.

2. How should Integration Joint Boards commission and procure social care to ensure it is person-centred?

Integration Joint Boards must ensure that local people using social care are fully involved in decisions around commissioning and procurement to ensure that support is person-centred. Through ongoing consultation events and feedback, SDSS members consistently express that they are keen to see disabled people being involved in all local plans around SDS and social care, and particularly in strategic commissioning as well as in delivering training at all levels.

As the Shared Ambition states:

* Models of coproduction and involvement should be employed in the commissioning, delivery and inspection of social care support services and be adequately resourced.

**Consideration should also be given to the commitment outlined on p69 of the 2018 Programme for Government[[5]](#footnote-6)** : 'We will also gather views and consider evidence for a potential new national scheme to provide extra financial support to people with the highest social care needs, so that they can choose to live independently in their homes and in their local communities.'. **SDSS believes the Committee has a unique opportunity to consider how taking this work forward through a co-production approach could support new approaches to commissioning and procurement in social care.**

3. Looking ahead, what are the essential elements in an ideal model of social care (e.g. workforce, technology, housing etc.)?

SDSS and our members believe that good social care should support people in Independent Living[[6]](#footnote-7), must focus on preventative approaches, and should be developed in coproduction with service users. Ultimately, an ideal model of social care will work to protect, promote and ensure human rights, ensuring disabled people enjoy their right to live independently and to be included in the community. In line with the Shared Ambition, putting human rights at the centre of social care means:

* Preventing disabled people’s isolation and segregation from the wider community.
* Supporting disabled people to participate in and contribute to Scotland’s economic, social, civic, and cultural life as equal citizens.
* Respecting, protecting and ensuring disabled people’s human right to be the author of their own lives, to choose where and with whom to live and to control their own support.

The way social care support is organised and funded must also respect the rights of families and unpaid carers. This means:

* Social care support must enable families to enjoy ordinary relationships with one another and not force people to assume unwanted roles and relationships as ‘carer’ and ‘cared for’ which can damage health and wellbeing.
* Support for unpaid carers must be based upon the level of care they are genuinely able and willing to provide.
* Protecting the rights of children, who should never be required to act as carers for others.
* Promoting the fuller participation of women in Scottish society and ensure that patterns of informal or paid care-giving do not further entrench gender inequality.
* Disabled people and carers coproducing the legislation, policies and practices in which they are stakeholders.

4. What needs to happen to ensure the equitable provision of social care across the country?

Through ongoing consultation, SDSS Members raise concerns about the lack of accountability for local authorities in terms of their implementation of SDS, and the sense of powerlessness that they, (SDSS members) and their members and service users often experience regarding addressing issues. Lack of accountability, and a disconnect between Scottish Government policies and local implementation, are an underpinning obstacle, to any successful implementation of SDS and the equitable provision of social care across Scotland.

SDSS continue to support the Shared Ambition in requiring:

* Enhanced transparency and accountability measures including publicly available information on the amounts of funding devoted to each of the different options of self-directed support, the support given to structures such as disabled people’s and carer’s organisations, and the levels of unmet need.

Members reported concern that local authorities are not held accountable for failing to deliver on the SDS and Carers legislation and felt this must change before authorities will improve their approaches. Members consistently express frustration at the slow pace of change and believe that local authorities should be more strongly encouraged by the Scottish Government to deliver on both the SDS and Carers legislation.

All members reported a consistent and high level of concern around the financial strain the social care system is under, and many identified tightening eligibility criteria and budget restrictions as the key factor in preventing successful SDS implementation, telling us, ‘Some packages are very limited.’, ‘Service user funding awards not meeting additional costs due to Scottish Living Wage, auto-enrolment, sleepover cost rises etc’, ‘Eligibility criteria resulting in people not accessing support’, ‘Lack of appropriately funded budgets’, ‘SDS funding (and social care funding in general) is totally inadequate - eligibility criteria are increasingly restrictive - budgets cannot be used as flexibly as legislation and guidance intended.’. Members recognise that SDS cannot be properly delivered in the current financial climate, as with smaller packages it is very difficult to facilitate the kind of choice and control that is crucial to good social care. Members reported the impact of restricted budgets not only in terms of the support people were [un]able to access, but also, for current recipients of care, how their support could be at risk; ‘People are afraid they will lose support hours’, ‘People are overwhelmed by the process and feel intimidated’. The Care Inspectorate’s recent thematic review of self-directed support also found that ‘Eligibility criteria frameworks were hindering staff from working in a way that supported the principles of SDS.’ This must be addressed in order to improve equitable provision of social care across the country. Additionally, a member reported:

‘Another problem we are now suddenly receiving is Age Discrimination, with people told the their SDS package will have to be reviewed now they have reached 65. I can see no logic to this and strikes me as a latent case of Age Discrimination, which may have to be taken through the court.’ (Chair, Self-Directed Support Network South Lanarkshire)

SDSS members have previously noted that the complexities around portability of care further build unfairness into the system and have identified this as a priority for action.

The cost of care and how it is paid for is also a priority for members who believe it is unfair to expect individual service users to pay for their social or personal care and that the costs of care should be shared by society as a whole. Members strongly agree that social care needs to be better funded to meet people’s needs properly and that ongoing tightening of eligibility criteria is damaging the system, removing its ability to work in a preventative way. One of our members provided specific feedback surrounding care charges, as follows:

‘We are very concerned about the failed effect of Frank's Law, which promised free personal care for all, which includes some members with [the highest level of support need.] Some of our members are in the same situation as myself, who was paying £277 per four weeks for my care package but now that Frank's Law has been implemented, I am now paying £300 per four weeks, although my package has risen slightly but the council considered that my Personal Care amounts to 50% of my assessment/package.

[Others with the highest level of support need] who require the most care are in the same situation and because the Personal Care definition is so limited to what the council classes as Personal Care, such as no assistance outwith the house, no housework for people who are unable to carry out housework, which is needed to carry out infection control, in the homes of the very people who are the most prone to infection, which in their case could be life threatening if they have such things as open sores. There are many other examples. I fail to understand why there should be winners and losers concerning Franks Law. Surely anyone who receives SDS should benefit from Franks Law. ‘(Chair, Self-Directed Support Network South Lanarkshire)

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1. <http://www.legislation.gov.uk/asp/2013/1/section/1/enacted> [↑](#footnote-ref-2)
2. In consultation, members told us that where SDS was discussed, people were often not supported to have a genuine choice. Members gave examples of people being directed towards a particular Option rather than supported to make a choice, for example being ‘guided down the DP route [Option 1] to engage with a care and support provider when option 2 would be easier for them’, ‘People still being offered traditional services [Option 3] and not being given the choice of what to use their SDS budget on’, ‘Too many people having to accept option one when it is not their choice’. [↑](#footnote-ref-3)
3. <https://www.careinspectorate.com/index.php/low-graphics/120-publications/inspection-reports-local-authority/self-directed-support/5139-selfdirectedsupport> [↑](#footnote-ref-4)
4. <http://new2.ilis.co.uk/uploads/documents/Shared%20Ambition%20for%20social%20care%20-%20final.pdf> [↑](#footnote-ref-5)
5. <https://www.gov.scot/publications/delivering-today-investing-tomorrow-governments-programme-scotland-2018-19/> [↑](#footnote-ref-6)
6. <http://www.ilis.co.uk/> [↑](#footnote-ref-7)