My Support My Choice:

People’s Experiences of Self-directed Support and Social Care in South Lanarkshire

September 2021

Self Directed Support Scotland
the organisation of choice

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people at the centre

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Acknowledgements and Dedication

This report is published with thanks to the people who shared their experiences and facilitated the research in South Lanarkshire. It is dedicated to members of the research team and those who shared their experiences as participants who have since passed away.

About this Report

This report uses data[1] from "My Support, My Choice: User Experiences of Self-directed Support and Social Care in Scotland" (MSMC), a research project run by the Health and Social Care Alliance Scotland (the ALLIANCE) and Self Directed Support Scotland (SDSS), funded by the Scottish Government. Focused on people's experiences in South Lanarkshire, the report starts by broadly setting out the national and local context for Self-directed Support (SDS) and social care, followed by information about the participants.[2] Subsequent chapters explore people's experiences of SDS/ social care across South Lanarkshire. Key findings are highlighted throughout, with a separate chapter on recommendations. The report concludes with a response to the research from South Lanarkshire Council and Health and Social Care Partnership.

The document is part of a suite of MSMC reports that also contains a national report, other local authority area reports, and thematic reports, which are published separately.[3]

COVID-19

Data collection ran from 1 November 2018 to 14 February 2020. As such, all responses reflect people's experiences of SDS/ social care before the appearance of COVID-19 in Scotland and people's experiences during the pandemic are not covered by the MSMC project.

Nevertheless, this research represents the most recent and comprehensive reflection of people's experiences of SDS/ social care in Scotland prior to COVID-19. As such, MSMC provides vital evidence, analysis of good practice and recommendations for improvement in the review and reform of SDS/ social care in the aftermath of COVID-19, based on people's experiences.

Executive Summary

This report uses data from "My Support, My Choice: User Experiences of Self-directed Support and Social Care in Scotland" (MSMC), a mixed-methods research project run by the Health and Social Care Alliance Scotland and Self Directed Support Scotland, funded by the Scottish Government.

The aim of this research is to gain a better understanding of people's experiences in South Lanarkshire, filling a data gap and complementing the work of other independent evaluations. By highlighting evidence of good practice and where improvements can be made, we can assist strategic planning and delivery of future SDS/ social care.

Between November 2018 and February 2020, MSMC heard from 89 people in South Lanarkshire who received SDS (or had been assessed in the previous 12 months) via a survey and interviews. Research took place prior to the appearance COVID-19 in Scotland. Overall, MSMC heard from 637 people across Scotland via a survey, interviews and focus groups. As the largest direct national consultation of its kind to date, the national report provides vital evidence, analysis and recommendations for improvement to SDS/ social care in the aftermath of the pandemic, based on people's experiences. This report provides analysis of the results from South Lanarkshire within that larger context.

Research participants in South Lanarkshire acknowledged SDS as important to achieving a higher quality of life and independent living, and reported positive experiences across several aspects. However, there are key improvements that would respond to people's concerns, build on existing good practice, and increase the effectiveness and reach of positive SDS/ social care experiences. The views expressed by research participants and analysis of the findings have led to a number of recommendations, many of which echo other independent reviews of SDS.[4]

Poverty and SDS

An estimated 24% of Scottish households with a disabled person live in relative poverty after housing costs. MSMC found that 63% of research respondents in South Lanarkshire who provided income data lived below the poverty threshold. National and local public bodies should take action to ensure that reductions in SDS budgets and tightened eligibility criteria do not negatively impact people on low incomes who access or are trying to access social care, given that they can lead to people having to manage without support, deteriorating physical and mental health, and demands on family and friends to assume roles as unpaid carers.

Data Gathering and Analysis

There are concerning gaps in national and regional SDS data gathering and analysis. Disaggregated data and intersectional analysis by local and national public bodies is essential to develop policy and practice that prioritises equal access to social care for everyone, following human rights principles of equality, non-discrimination, participation and inclusion.

Overall Experiences of SDS

Most participants in South Lanarkshire reported that SDS had improved their social care experience and shared a range of positive and negative feedback when asked to summarise their experiences.

Information About SDS

Participants in South Lanarkshire found out about SDS from a range of sources. Most people highlighted the value of face-to-face communication with independent support organisations and social work, and recommended that those wanting to know more about SDS should get in touch with social work, independent advocacy and independent advice services as soon as possible.

Many participants in South Lanarkshire indicated they required more high-quality information at an earlier stage (before needs assessments) to support their decision making about how support would be arranged. Nearly half of people had not been told about all four options when they started the process of accessing SDS. Some had not been provided with accessible information or documentation, even after requesting it from social work.

This pattern of variable information about the four options continued into people's needs assessments. Half of the respondents in South Lanarkshire reported that they had "all four options" discussed with them during their assessments, with one third either receiving "some but not enough" or no information. Overall, most people reported that all their questions were answered during their needs assessments, and social work professionals explained things clearly to them.

Just under two-thirds of the respondents in South Lanarkshire indicated that they had received information about how much money they could spend on their care and support. However, over a quarter had not received that information, while the remainder were unsure.

Recommendations include ensuring people have good access to high quality information about SDS/social care, in a range of accessible and tailored formats at different points in their journey through the system. In general, work is needed to ensure everyone is informed about all four SDS options, and supported to consider the advantages and disadvantages of each SDS option before making decisions – rather than being given information about a more limited list of options. Measures should also be taken to ensure that people are given full and accessible information about their budgets and other relevant financial information.

Informed Choice and Control

Overall, nearly two-thirds of participants in South Lanarkshire felt they had enough time to choose their SDS option. People reported variable wait times for assessments and those who waited the longest also generally reported the highest levels of stress and difficulty in accessing SDS.

A substantial majority of respondents in South Lanarkshire indicated that they were on their preferred SDS option and felt involved in decisions and arrangements about their care and support. While this is encouraging, the finding that more than a quarter of people had their SDS option chosen for them by a health or social work professional – rather than choosing themselves – is more problematic. Professionals play an important role in supporting access to appropriate services; however, this should not extend to making decisions on people's behalf while the principles of choice and control are clearly embedded in SDS policy.

Similarly, while it is positive that nearly two-thirds of the respondents in South Lanarkshire were offered the choice of who would manage their personal budget, it is concerning that just over a third either reported being offered no choice or were unsure; this also demonstrates that, amongst other things, they were not fully offered all four SDS options.

Most people in South Lanarkshire indicated that having sufficient budget to meet their outcomes made SDS easier for them – and highlighted the importance of providing support for social activities as well as personal care to ensure a good quality of life. People who used SDS budgets to access short breaks described them as benefiting both individuals and their families – an important chance for people to relax.

Budgets and waiting times were prevailing themes when respondents in South Lanarkshire discussed ongoing concerns with their needs assessments. Reductions to budgets and support has significant negative impacts on people's mental and physical health. Any proposed reductions in SDS budgets or support should be communicated clearly and discussed with people well in advance of any changes being introduced. Health and social care staff should consider the possibility of isolation or mental health crisis when changing packages and eligibility criteria and be able to arrange reassessments and signpost support services where needed. People also raised the need for future and contingency planning – especially in situations where unpaid carers may become less able to provide essential support.

Recommendations include providing social work professionals with training in supported decision making, and targeted efforts to ensure that all people enjoy equal decision making about their SDS option and support.

Communication and Relationships with Social Work

Participants in South Lanarkshire highlighted that good, consistent, trusting relationships with social workers and clear lines of communication are all essential for positive and effective experiences of SDS. Most participants reported positive and favourable experiences of assessments and reviews with professionals, providing a range of good practice examples. However, over a quarter of people outlined concerns about their conversations with social work professionals, including about not receiving full answers to questions raised during assessments and a lack of information about SDS.

Several people raised the need for greater transparency about how care decisions are made and by whom, alongside inclusive communication and easy access to information. Some people reported difficulty obtaining paperwork and documentation concerning their care arrangements, even after repeated requests to social work departments.

Recommendations include ensuring that social workers have the time and skills to build relationships and trust with the people accessing SDS and unpaid carers that they are working with, building on existing good practice in South Lanarkshire. People should be informed promptly if their social worker changes and have a right to request a new social worker if trust breaks down. More work is needed to improve the transparency of process – including around how decisions are made about budgets and accessing SDS.

Care Staff Recruitment, Training and Quality

People in South Lanarkshire reported mixed experiences of support worker recruitment, training and quality. Several participants wrote or spoke eloquently about the positive impact of good care workers. However, some respondents indicated difficulties finding and retaining personal assistants (PAs) and care workers that were suitable for their requirements, and some people would welcome more assistance with staff recruitment and training. South Lanarkshire Council and HSCP should work with people who access SDS and unpaid carers to improve systems and processes related to care staff recruitment, training and quality.

Independent Advocacy and Support

Respondents in South Lanarkshire indicated that they value and benefit from the provision of independent advocacy, independent advice and support services, which need sustainable resourcing to continue their important role. Focused efforts are required to ensure all people are aware of – and can access – independent advocacy and support services. Local peer networks should also be encouraged and supported. Take Control South Lanarkshire were mentioned several times as helpful in supporting people to navigate and access SDS.

Recommendations

People in South Lanarkshire generally reported that SDS had improved their social care experience and have shared examples of good practice from across the region, particularly about good conversations and relationships with social work professionals, and involvement in care decisions. However, as this research highlights, there are key areas where improvements could be made to respond to people's concerns and increase the effectiveness and reach of positive SDS experiences. The recommendations in the MSMC national and thematic reports would also usefully inform practice in South Lanarkshire.[5]

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

2. 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

3. People (service users and unpaid carers) need good access to publicly available, high quality information about SDS/ social care, in a range of accessible and tailored formats (e.g. hard copy and digital; face-to-face; large print; Braille; Easy Read; BSL). Information is required at different points in a person's journey through the social care system, e.g. finding out/ first enquiry about SDS, pre-needs assessment, during needs assessment, after needs assessment, once support is in place.

4. A wider pool of professionals (health, education) should be taught about SDS and how to signpost people to social work, independent support, and appropriate resources.

5. More information should be publicly available for people about what to expect from interactions with social work, and about their rights.

6. 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. Transparency would be improved by sharing more publicly available information in accessible formats.

7. Sufficient time must be allocated for needs assessments and review meetings, to allow for detailed questions and consideration of the four SDS options.

8. Further information and training for professionals may be required about the SDS options and supported decision making.

9. Everyone should be informed about all four SDS options, rather than being given information about a more limited list of options, and

supported to consider the advantages and disadvantages of each SDS option before making decisions.

10. Professionals should proactively check back in with people after assessments to ensure any outstanding concerns are addressed and resolved, and their care is working well.

11. 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.

12. People should always have access to independent advocacy and support for assessments and review meetings if they desire.

13. 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.

14. Everyone must have access to information about the budget available to them for their care and support.

15. 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.

16. 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.

Informed Choice and Control

17. 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, and deteriorations in their physical and mental health and wellbeing.

18. People must be treated with dignity and respect in all interactions with health and social care professionals.

19. Any proposed reductions in SDS budgets/support should be communicated clearly and discussed with people well in advance of any changes being introduced. Health and social care staff should consider the possibility of isolation or mental health crisis when changing packages and eligibility criteria and be able to arrange reassessments and signpost support services where needed.

20. If the support required by an individual is not available then any records should reflect that lack of availability and unmet need, rather than indicating that people refused services.

21. 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.

22. Flexible, regular access to short breaks should be strongly encouraged because they are an essential element of SDS that result in good personal outcomes for people who access social care, families and unpaid carers.

23. Professionals should fully incorporate equality assessments into their processes for service users and families.

Communication and Relationships with Social Work

24. Work should continue to increase positive conversations and meaningful, consistent relationships, with ongoing planning to guarantee high quality practice for all people using SDS.

25. 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.

26. 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.

27. 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.

28. No-one should be pressured to 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 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.

29. 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).

30. 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.

31. Professionals should ensure that all unpaid carers are offered carer's assessments and have their rights explained to them.

32. 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.

33. 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.

34. We encourage South Lanarkshire Council to indicate document publication dates and webpage timestamps. The Council's website could also provide further information on their Equality Impact Assessments

and the role these play in SDS/ social care decision making. To strengthen participatory decision making, South Lanarkshire Council could set out the steps taken to involve people who use support, unpaid carers, and partner organisations in the development of eligibility criteria and the delivery of support. Further details of other engagement with people with lived experience would support greater transparency.

Care Staff, Recruitment, Training and Quality

35. 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.

36. 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.

Independent Advocacy and Support

37. Independent advocacy, independent advice and support services need sustainable resources to continue their important role in South Lanarkshire.

38. 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.

39. Social work professionals should proactively provide people with information about independent advocacy, advice and support organisations in accessible formats.

40. Local peer networks should be encouraged and supported.

National and Local Context for SDS/ Social Care

National Context

Self-directed Support (SDS) is Scotland's approach to social care. It is defined as "the support individuals and families have after making an informed choice on how their Individual Budget is used to meet the outcomes they have agreed."[6] For more information about the national context of SDS/ social care in Scotland, please refer to the MSMC national report.[7]

Local Context

South Lanarkshire is one of the largest council areas in Scotland, with an approximate population of 320,000 people over 145,000 households.[8] It combines both urban and rural areas and is situated in the central belt, with Greater Glasgow to the north, Ayrshire to the west, Scottish Borders to the east, and Dumfries and Galloway to the south.

South Lanarkshire Council publishes a range of information for people who access or wish to access SDS on their website (searchable via the search bar on the council website). Links to the SDS page are also provided under the Council pages on "Care for the elderly", "Disabilities", "Carers and caring", and "Children and families" – although not the page for "Mental health".[9] This main page provides people with a definition of SDS, an outline of the four options, and a brief summary of what a needs assessment and support plan entail.

South Lanarkshire Council also provide a range of additional information on social care via links from their SDS page – including examples of SDS, details of the eligibility criteria and how they link with timescales for necessary support, and a range of links to additional resources and support organisations. South Lanarkshire also links to published information for unpaid carers, including written and audio-visual resources from MECOPP in a range of languages (English, Bengali, Cantonese, Punjabi, and Urdu). They also link to BSL versions of Scottish Government documents on SDS.[10] We welcome the multilingual publication of information for carers – which is unusual in Scottish local authority websites – as an example of good practice.

The eligibility criteria and associated examples do not state which eligibility criteria are linked to support via SDS in South Lanarkshire. However, that information is available in the South Lanarkshire HSCP Strategic Commissioning Plan 2019-22, which is publicly available online and states that that direct financial support is only available to people who have "critical or substantial needs".[11] This document also states that "support will still be offered to those assessed as being low and moderate, but this will involve less formal supports such as signposting to universal services and Third Sector supports." [12]

South Lanarkshire Council go on to provide information on timescales for the eligibility categories (referred to as "intensity of risk" on their website):

> *"Critical/immediate – required now or within approximately 1-2 days*
>
> *Substantial/imminent – required within 1-3 months*
>
> *Moderate within the foreseeable future – not within 6 months*
>
> *Low longer term – not required within the next 12 months or subsequently."*[13]

The eligibility criteria outlined on the South Lanarkshire Council website and strategic plan reflect the National Eligibility Framework, which categorises risk as being critical, substantial, moderate, or low:

> *Critical risk: indicates that there are major risks to an individual's independent living or health and wellbeing and likely to call for the immediate or imminent provision of social care services.*
>
> *Substantial risk: indicates that there are significant risks to an individual's independence or health and wellbeing and likely to call for the immediate or imminent provision of social care services.*
>
> *Moderate risk: indicates that there are some risks to an individual's independence or health and wellbeing. These may call for the provision of some social care services managed and prioritised on an on-going basis or they may simply be manageable over the foreseeable future without service provision, with appropriate arrangements for review.*
>
> *Low risk: indicates that there may be some quality of life issues, but low risks to an individual's independence or health and wellbeing with very limited, if any, requirement for the provision of social care services. There may be some need for alternative support or advice and appropriate arrangements for review over the foreseeable future or longer term.*

At time of writing, to obtain more information on how to access SDS or request an assessment, people are invited to contact their local social work office (with four links to available options). In each instance, a generic email address is provided alongside a phone number (an 0303 number). There is no option to call a freephone number, which would enable people from low-income households to call without being charged. This consideration is particularly important given the number of people in South Lanarkshire – and respondents to MSMC specifically – who live below the poverty line. South Lanarkshire also includes useful information about the accessibility of the individual social work offices on each page, alongside maps of the locations.

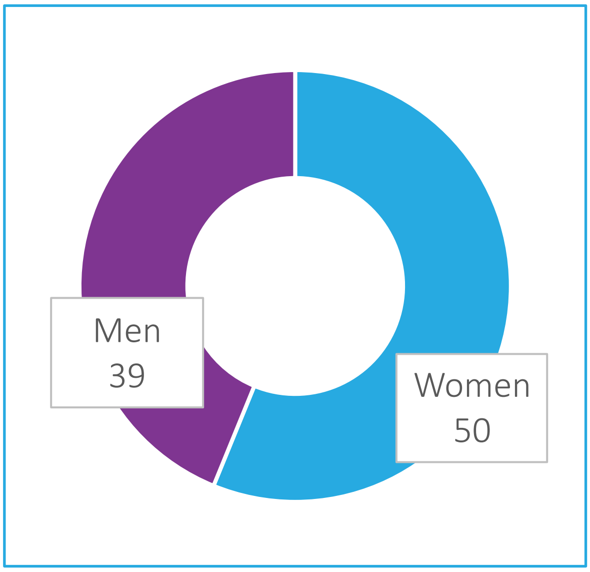
We encourage South Lanarkshire Council to indicate document publication dates and webpage timestamps. The Council's website could also provide further information on their Equality Impact Assessments and the role these play in SDS/ social care decision making. Finally, to strengthen participatory decision making, South Lanarkshire Council could set out the steps taken to involve people who use support, unpaid carers, and partner organisations in the development of eligibility criteria and the delivery of support. For example, further details of engagement with people with lived experience of accessing social care/SDS would support greater transparency.

Research Participants

MSMC heard about the experiences of 89 people who use or were being assessed for SDS in South Lanarkshire. We interviewed 12 people who spoke about their own experiences and the experiences of other members of their household (spanning the experiences of 18 people who use SDS or who were being assessed for SDS). A further 71 people from South Lanarkshire completed the survey. Throughout this report some participant details (e.g. age) have been changed slightly to preserve anonymity, while maintaining the most important information. Where changes have been made to quotations those alterations are indicated via square brackets (e.g. "My advocate, [Name], was great").

Where possible, we have compared our participant data to local data and figures from Public Health Scotland's (PHS, formerly Information Services Division) 2017-2018 experimental statistics on social care in Scotland. While not comprehensive, PHS have demographic statistics on people using SDS, and accessing social care support services more generally, that is provided by local authorities, including South Lanarkshire Council. PHS include people who use SDS within their wider discussions of people receiving "social care support", but also include care home residents and people who use community alarms and telecare services (with or without SDS) in that wider definition.

Chart 1: Respondents' gender



Gender

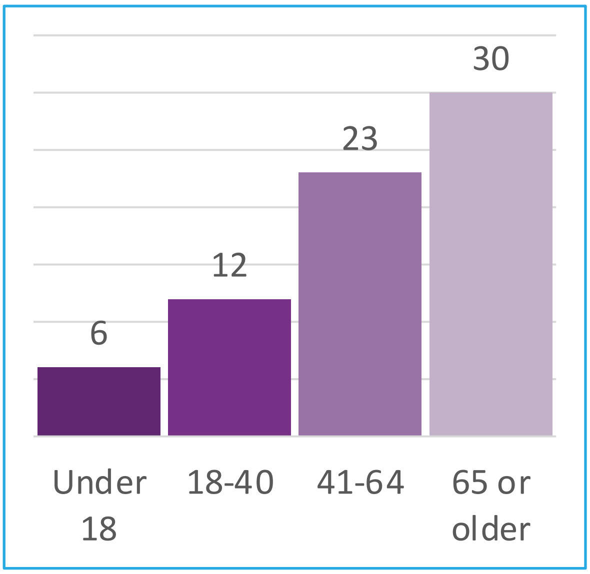
Overall, 50 women (56% of respondents) and 39 men (44% of respondents) participated in MSMC in South Lanarkshire.

While PHS figures are not available for the division of men and women accessing SDS (nationally or in South Lanarkshire), they do publish statistics on the number of men and women receiving social care support services more generally (of whom an estimated 30% access SDS). PHS reported that in 2017-2018 64% of people accessing social care support in South Lanarkshire were women and 36% were men.[14]

Age

We asked all participants to share their age. Of the 71 people who chose to answer the question, six (8%) were under 18 years old, 12 (17%) were between 18 and 40 years old, 23 (32%) were between 41 and 64 years old, and 30 (42%) were 65 years or older.[15]

Chart 2: Respondents' age



In mid-2018 49% of the population of South Lanarkshire was over 45 years old (higher than the Scottish average of 47%), with the average age expected to increase, especially in the 75 and over age group.[16]

PHS do not provide an overall breakdown of age groups accessing SDS, although age group data is provided by SDS Option Chosen and Client Group Profile. PHS provide age disaggregated data on people receiving social care support services more generally within South Lanarkshire (of whom an estimated 30% access SDS). PHS reported that in 2017-2018 in South Lanarkshire, 81% of people accessing social care support were over 65 years old, 19% were aged 18-64, and 1% were under 18 years old.[17]

Ethnicity

70 MSMC survey respondents in South Lanarkshire identified as white. One respondent chose not to describe their ethnicity. Most interviewees did not disclose their ethnicity when self-describing themselves, and the majority of those that did described themselves as "white".

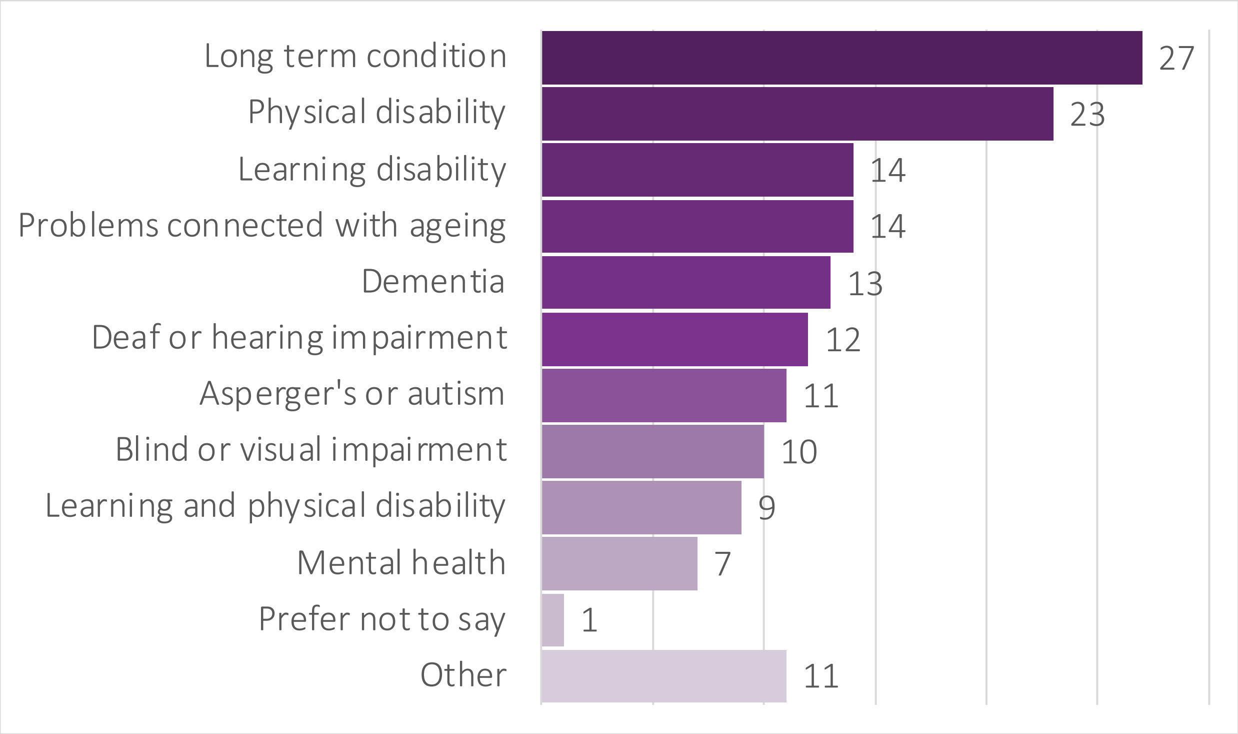
The 2011 Scottish Census indicated that 95.4% of the population of South Lanarkshire identified as "White: Scottish" (91.6%) or "White: Other British" (3.8%), with a further 2.3% selecting "White: Irish" (1%), "White: Polish" (0.4%), or "White: Other" (0.9%). The remaining people identified as being part of minority ethnic groups: 1.6% of the population identified as "Asian", "Scottish Asian", or "British Asian", and 0.7% as belonging to "other ethnic groups".[18]

PHS do not provide a disaggregated breakdown of the ethnicity of people accessing SDS. They have some disaggregated data on the ethnicity of people receiving social care support services more generally (of whom an estimated 30% access SDS), using the limited categories of "White", "Other", and "Not provided/Not known". PHS reported that in 2017/2018 in South Lanarkshire, 93% of people accessing social care support were "White", 6% were listed as ethnicity "not provided/ not known", and 46 people (0.6%) were categorised as "Other" (including "Caribbean or Black, African, Asian and Other Ethnic Groups").[19]

Client Group/Disability/ Long Term Condition

MSMC survey respondents in South Lanarkshire self-identified as living with a range of conditions, with the majority reporting that they were living with multiple conditions. 27 people (38%) said they live with a long term condition, 23 people (32%) selected physical disability, and 14 people (20%) selected "learning disability".[20]

Chart 3: Client Group/Disability/Long Term Condition (Survey)

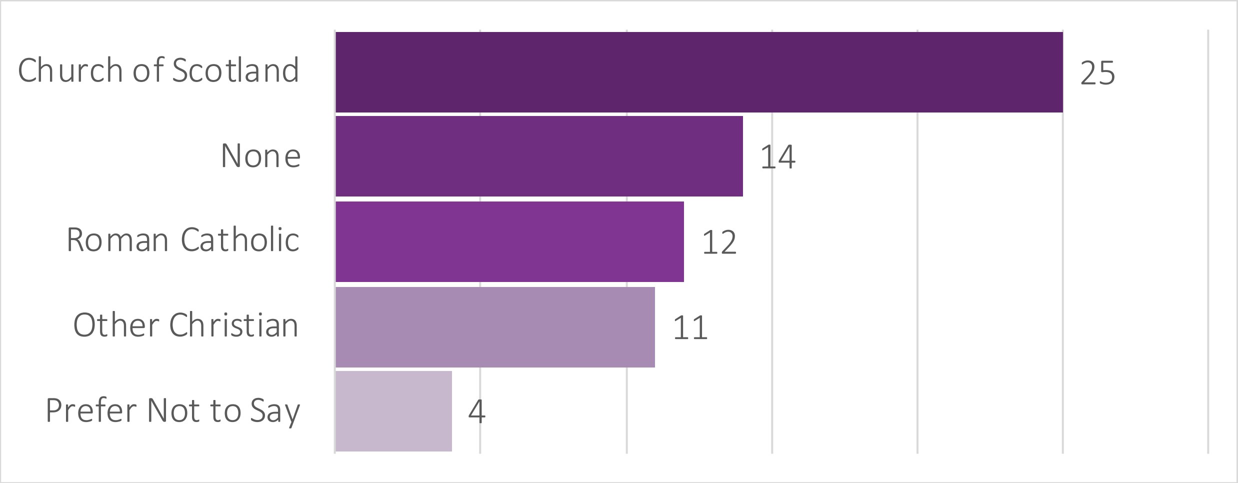


Interviewees also discussed their conditions, and – if they were unpaid carers – those of the people for whom they care. Their reasons for accessing SDS were broadly in keeping with survey respondents'. Of the 18 people whose experiences of SDS we heard about during interviews, 15 accessed SDS because of their own conditions, and three accessed SDS as unpaid carers.

Religion

When asked about their religion (if any), 25 survey respondents (35%) were part of the Church of Scotland, 14 stated "none" (20%), 12 were Roman Catholic (17%), and 11 described themselves as "other Christian" (15%). Four people (6%) preferred not to answer.

Chart 4: Survey respondents' religion

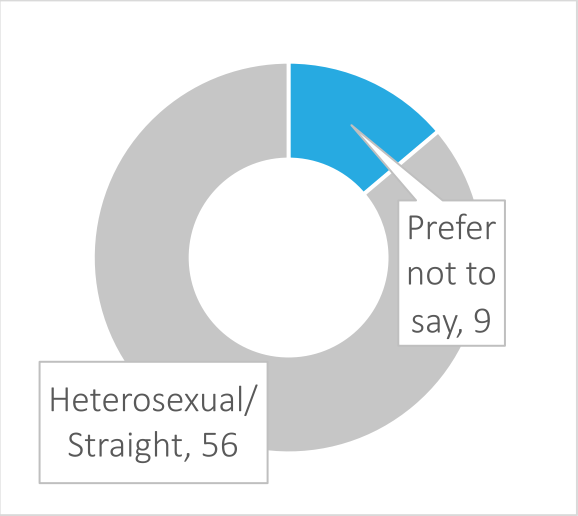


None of the interviewees chose to explicitly disclose their religion when self-describing themselves. The overall spread of MSMC respondents is slightly less diverse than the 2011 Scottish Census data for South Lanarkshire.[21] Data about people's religion is not available on the PHS dashboard.

Sexual Orientation

56 survey respondents described their sexual orientation as heterosexual or straight. A further nine people stated that they preferred not to disclose their sexual orientation, and six people did not answer the question. The 2011 Scottish Census did not record data on sexual orientation at local authority level (although the 2022 Scottish Census is expected to do so); as such, we do not have local statistics on sexual orientation available as a comparison. Data on people's sexual orientation is not available on the PHS dashboard.

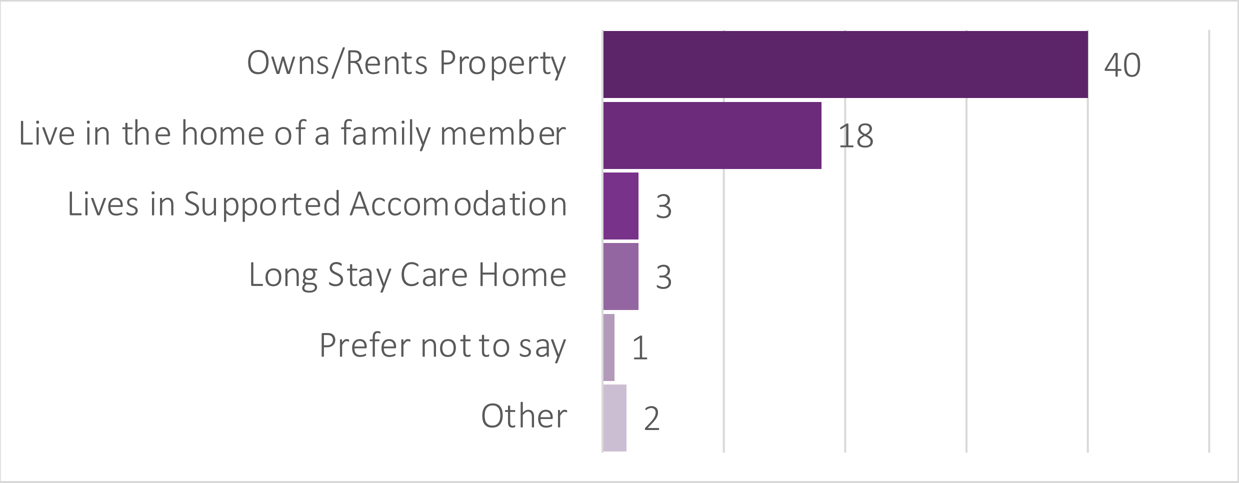
Chart 5: Survey respondents' sexual orientation



Housing

40 survey respondents (60%) either rented or owned their own home, 18 people (27%) reported that they lived in the home of a family member, three people (4%) lived in supported accommodation, and three people (4%) resided in a long stay care home. Two further people (3%) selected "other", and one person selected "prefer not to say" (1%). Data on people's housing situations (other than residential care) is not available on the PHS dashboard.

Chart 6: Survey respondents' housing arrangements



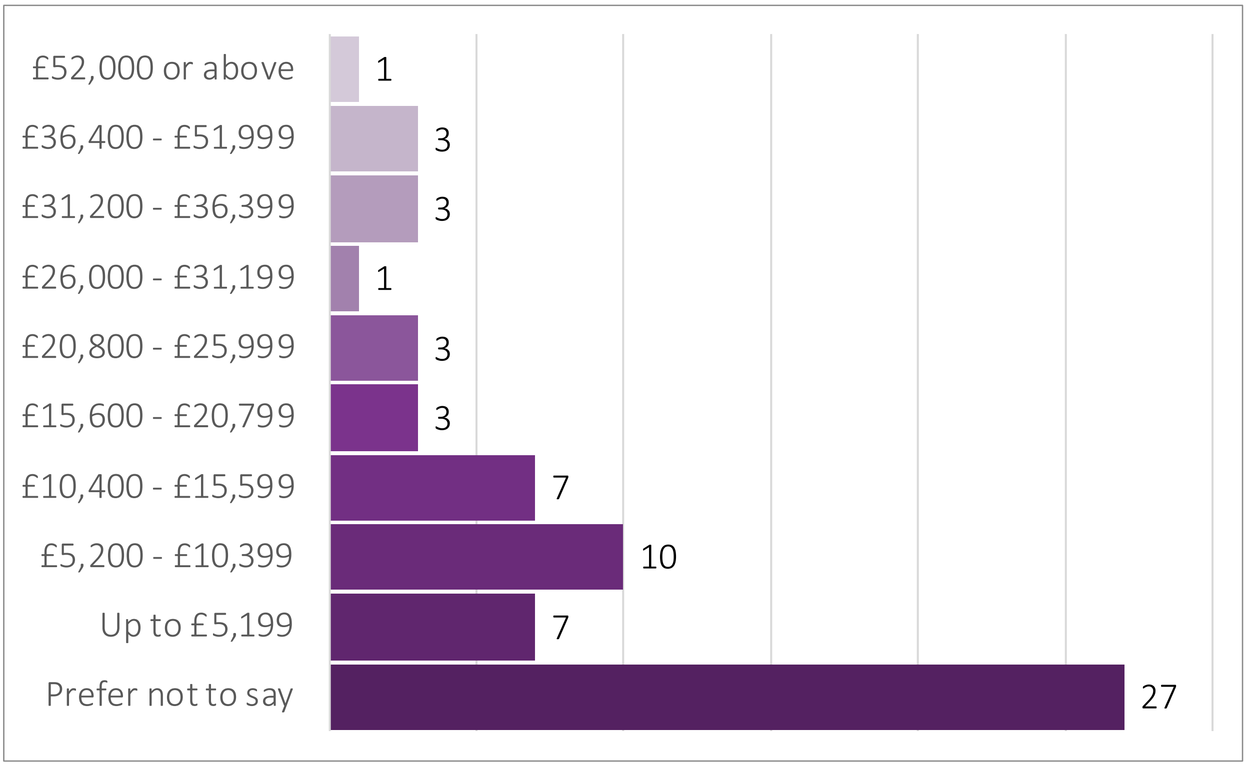
When discussing housing, several interviewees spoke about their current situations, spanning a similar range of options to survey respondents. Of those who discussed their housing arrangements, most people lived independently in their own home, followed by those who lived with a family member.

Household Income

We asked survey respondents about their household income. We were interested in this information because in Scotland an estimated 24% of households with a disabled person live in relative poverty after housing costs, compared to 17% of the population with nobody with a disability in the household.[22]

None of the interviewees disclosed their household income when self-describing themselves, although many commented on the negative impact that limited or reduced SDS/ social care budgets and social security entitlements had on their quality of life.

Chart 7: Survey respondents' annual household income



According to Scottish Government data, the median housing income in Scotland in 2015-2018, before housing costs, was £499 per week (£25,948 per annum).[23] The relative poverty threshold was defined as household income below 60% of the median, which for the same period was defined as £302 per week (£15,704 per annum).[24] Based on this definition, 24 (63%) of the respondents in South Lanarkshire who chose to provide details of their household income are living below the poverty threshold. Data on the household incomes of people accessing SDS is not available on the PHS dashboard.

Poverty and SDS: Reductions in SDS budgets and tightened eligibility criteria can pose serious risks to people on low incomes who access or are trying to access social care. It can result in people having to manage without support, risks deterioration in physical and mental health, and unacceptable demands on family and friends to assume roles as unpaid carers.

SDS Option

Of the 75 participants in South Lanarkshire who shared which SDS option they used, 33 people (44%) indicated they used Option 1, three people (4%) used Option 2, 29 people (39%) used Option 3, and four people (5%) used Option 4. Six people (8%) stated that they did not know what option they used.

Within the largest respondent age group (people aged 65 or older), 10 were on Option 1, two were on Option 2, 11 were on Option 3, and two were on Option 4. One person was unsure which option they use.

Figures from PHS indicate that in 2017-18 there were 451 people in South Lanarkshire using SDS Option 1, 53 using Option 2, 2203 using Option 3, and 124 using Option 4.[25] In some instances, people are logged as being on two options simultaneously (e.g. Options 1 and 3) rather than Option 4, which distorts these figures.

Data Gathering and Analysis

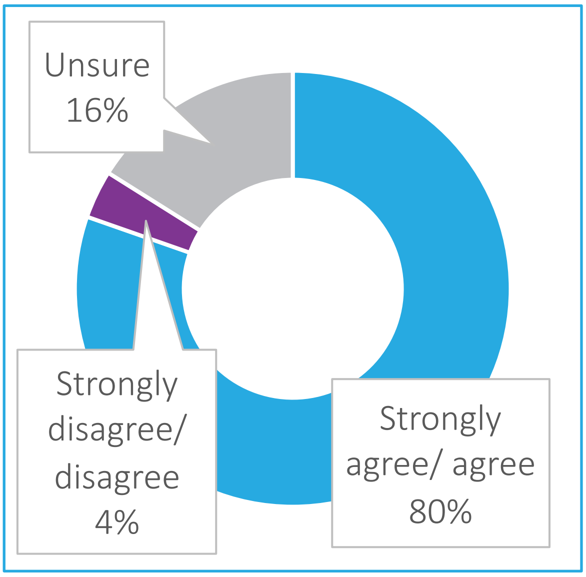
As the chapter on research participants demonstrates, there are concerning gaps in SDS data gathering, analysis and reporting across Scotland. PHS have reflected on difficulties gathering disaggregated data on people’s use of and experiences of SDS/ social care in their experimental statistics publication *Insights into Social Care in Scotland*.[26] They highlight differences in reporting periods for social care data across local authorities, and that some local authorities and social care partnerships were either not tracking or not able to share disaggregated data about SDS and the people using it.[27] Data gaps are also in part due to existing patterns of data collation – leading, for example, to the PHS Social Care Information Dashboard tracking ethnicity via the limited and problematic categories of “White”, “Other”, and “Not provided/ Not known”.[28]

Data Gathering and Analysis: Disaggregated data gathering and intersectional analysis is essential to develop fully realised policies and practices that prioritise equal access to SDS/ social care for everyone, following human rights principles of equality, non-discrimination, participation and inclusion. To avoid gaps and improve analysis, we recommend systematic and robust data gathering by local and national public bodies on people who access SDS, disaggregated by all protected characteristics, including age, gender, sexual orientation, ethnicity, and religion, as well as socio-economic information like household income and the Scottish Index of Multiple Deprivation (SIMD).

Overall Experiences of SDS/ Social Care

We asked survey respondents whether they felt that SDS had improved their social care experience. Of the 56 people who answered this question in South Lanarkshire, 45 (80%) stated that they "strongly agree" or "agree" with the statement "SDS would/has improve/d my social care experience". Two people (4%) disagreed or strongly disagreed and nine (16%) were unsure.

Chart 8: "SDS has improved my social care experience" (Survey)



Survey respondents and interviewees were asked to share an overall summary of their experiences and any advice they might have to offer other people considering using SDS. Several of the participants' statements were positive, such as:

> *"Go for it!"*
>
> *"It gives you greater options and choices."*
>
> *"Not to be worried about it – it has been very helpful."*
>
> *"SDS gives more flexibility and independence."*
>
> *"I would strongly advise [SDS]. Work out what matters to you and go for it."*
>
> *"I believe it is a personal choice as every individual has different needs. It works for me, giving me more choices."*
>
> *"The bureaucracy is a nightmare, but the flexibility and choice it gives is priceless."*

Interviewees identified a range of ways that SDS has positively impacted their lives, with interviewees summarising their experience as follows:

> *"Well, the impact on the family... They're extremely happy for me now. Whereas years ago I was just cooped up in the house, doing nothing apart from waiting for somebody to come and pick me up to take me to the voluntary work and all these other meetings and things like that, having to rely on somebody (this was long before Self-directed Support even happened). And of course having to depend on my [partner] all the time, but now [they're] depending on me, because my [partner] has had [a health condition] for a good ten years now and it's beginning to get worse."*
>
> *"It's taken the pressure off. [...] I work two days a week and I'm now thinking of looking for something else more than the two days a week because I feel I can. Whereas before it was very tight, we couldn't. Which gives me more self-worth; I think that I can go and do something for me. I can do more."*

> *"I came out of hospital and […] I was actually getting depressed, because the winter was coming in, and I was sitting there, in the house on my own all afternoon. […] I had to go on to antidepressants for a time. Once I got my support […] it completely changed everything, because I was getting out and about. […] And I was very lucky because the two [care workers] the agency sent me I got on really well with, and we're still friends, you know? The fact that the people are good. I got my life back; obviously it changed, but I was back doing things."*

Another interviewee, an unpaid carer, outlined how empowering their child (now a young adult) found SDS:

> *"[Name] can get up and go to the café, […] because [they've] got the support to do it. [They] can go to the gym because [there is] the support there to do it. The cinema, [they] can go there without us because [they've] got the support there to do it. It's just really good. It's wonderful and nice and worth all the worry before it. I've sat here at this table and thought are we doing the right thing? Employment and police checks and wages… But yeah, it's all been worth it. If I could turn the clock back I wouldn't change a thing."*

A different interviewee disclosed that as a parent of a disabled child, they had always assumed that they would care for their child. However, the introduction of SDS has transformed their child's life. They now feel that their child's views are being recognised through SDS, and that they are pursuing a life that they want rather one chosen by their parent.

However, some people were more cautious or explicitly negative about SDS, particularly relating to waiting times and difficulties with paperwork:

> *"Make sure you know your rights."*

> *"Be prepared to wait – expect delays."*

> *"The process is frustrating and time consuming."*

> *"Do not take it on as the council keep on trying to reduce hours."*

Information About SDS

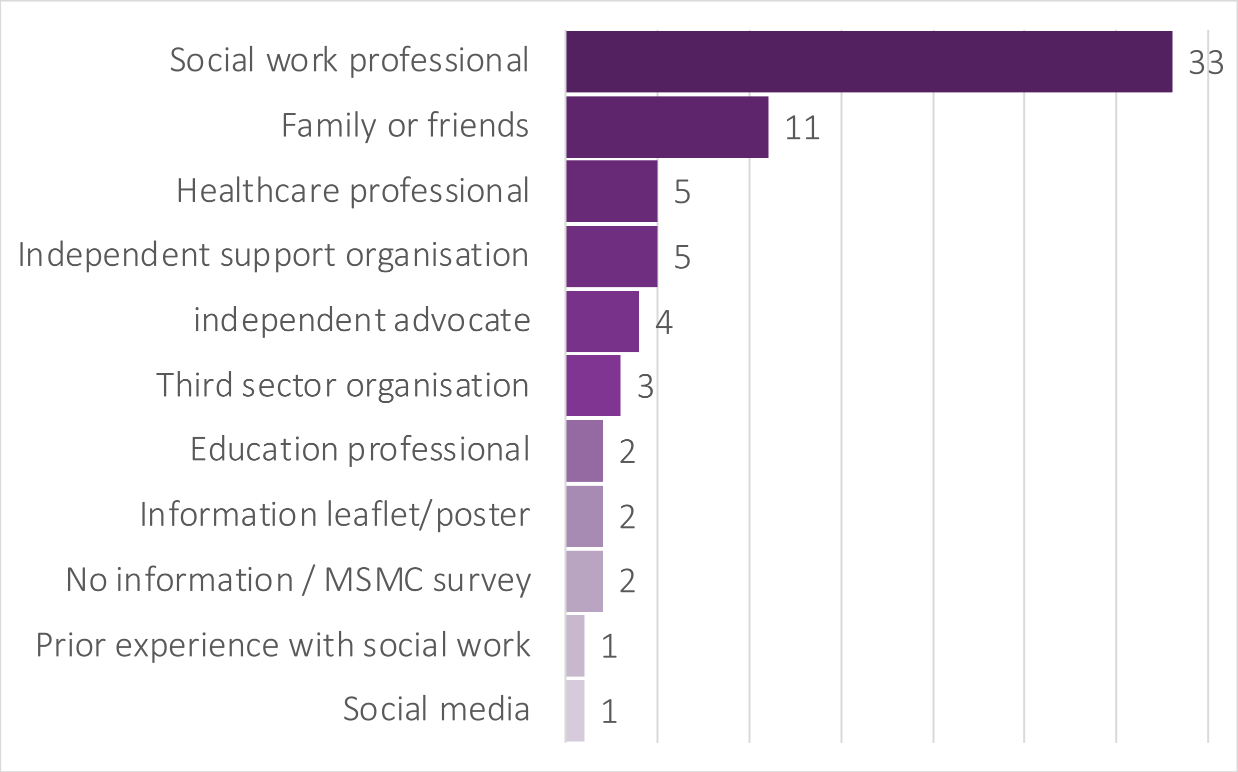
Finding Out About SDS

We asked participants in South Lanarkshire how they first found out about SDS.

33 survey respondents (48%) first heard from a social work professional (e.g. a social worker/social work assistant or an occupational therapist), 11 (16%) heard from friends or family members, and five (7%) from NHS health staff, including nurses working in the community. A further five people (7%) first head about SDS from an independent support organisation, four (6%) from an independent advocate, three (4%) from a third sector organisation, two (3%) from an information leaflet/poster, two (3%) from an educational professional, one from social media, and one from previous experience with social care.

Two survey respondents reported that they had never received information about SDS and that they first heard about SDS via this research project. One interviewee also said that they did not understand or had not had SDS fully explained to them, even though they used SDS, and had done for some time.

Chart 9: How did survey respondents first hear about SDS?



Among the interviewees, social work was the most common method through which people first heard about SDS. Two people first learned about SDS from information posters or leaflets, one from a friend, one from their professional work, and one through a course for parents of disabled children.

Of the two interviewees who heard about SDS through information leaflets, both expressed concern about the limitations of this method compared to face-to-face communication – particularly for initial introductions to SDS. One summarised their experience as follows:

> *"I just didn't seem to get any support from anyone anywhere. I kept asking and I kept getting, for want of a better description, poo-poohed. I went to various events around about and […] I kept getting leaflets. All these leaflets on their own were okay, but they didn't sort of help you to get started. They're just leaflets from people, and I struggled to have time to look at them and at these kind of events, people don't have time to talk to you. […] It got to the point I wrote to my MSP at three in the morning […] and she got somebody from social work to come out because they'd got a moany letter. They sort of talked through the problems and everything and said they'd get it sorted it out because I was having a problem because nobody cared about me."*

Finding Out About SDS: The research indicates that people in South Lanarkshire generally had good experiences finding out about SDS from social work professionals and local independent support and advice organisations. There are some people in South Lanarkshire who require improved access to information about SDS, and it would be helpful to widen the pool of professionals who are informed about SDS and can encourage people to access it. Making more use of educational professionals, hospital staff, GPs and other community health practitioners would be valuable in increasing the range of sources of information for people, as well as building on the existing expertise and resourcing of social workers and independent advice and support organisations. This recommendation aligns with the Care Inspectorate recommendation that "the partnership should ensure that health staff at all levels understand their role in relation to self-directed support and have had adequate training to allow them to fulfil those roles".[29]

Information and Preparedness Before Assessments

We asked survey respondents how much information they received on each of the SDS options before meeting with a professional to discuss their support, and whether it was enough information for their requirements.

As the chart indicates, across the SDS options most respondents in South Lanarkshire received "all the information [they] wanted" (respectively, 52% for Option 1, 49% for Option 2, 57% for Option 3, and 55% for Option 4). However, it is concerning that over a third of people for Option 1, Option 3, and Option 4, and nearly half of people for Option 2, either had no information or were left wanting more in advance of their assessment. The detail of those who wanted more information is as follows:

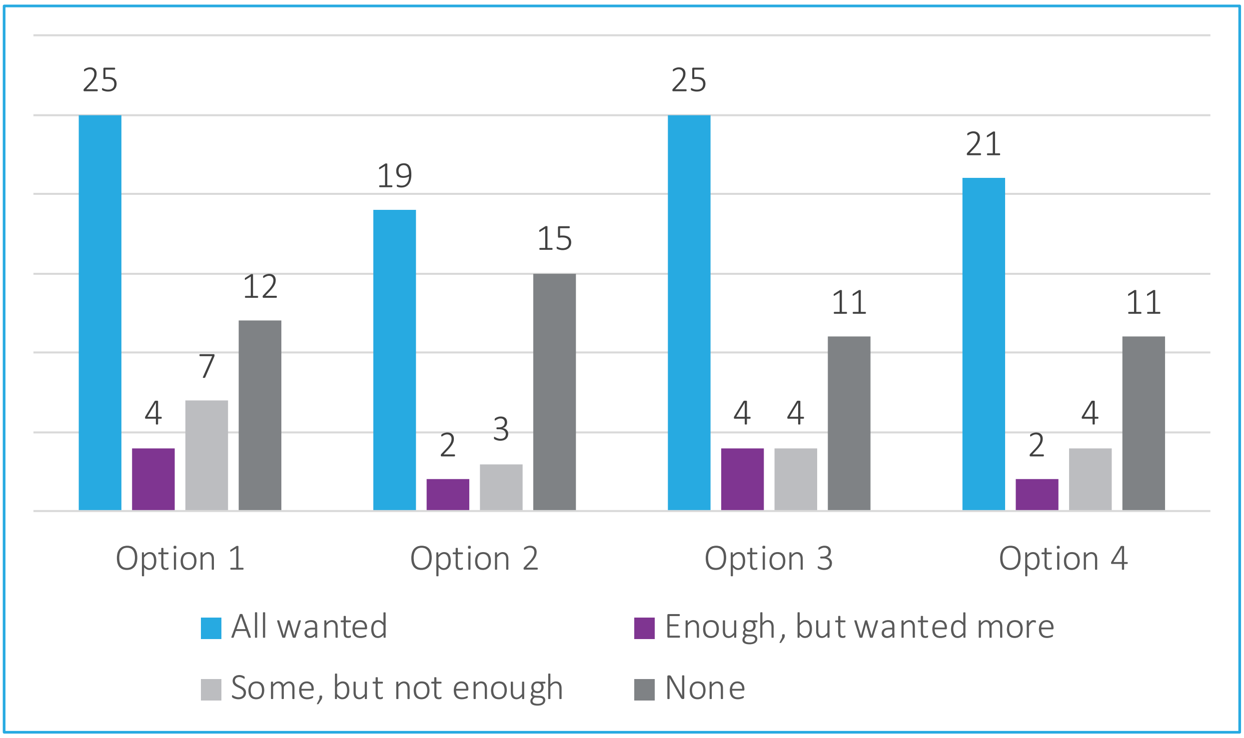
Option 1: 40% of respondents said that they received "some, but not enough" or no information, and 8% received "enough but wanted more".

Option 2: 46% of respondents reported that they had "some, but not enough" or no information, and 5% received "enough but wanted more".

Option 3: 34% of respondents said that they had "some, but not enough" or no information, and 9% received "enough but wanted more".

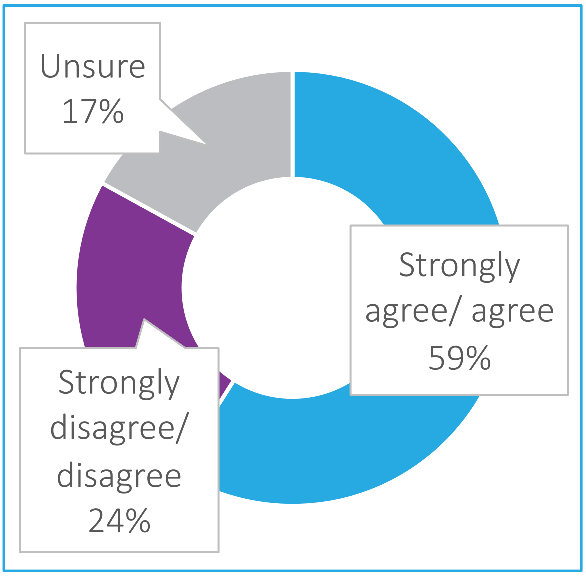
Option 4: 39% of respondents said they had received "some, but not enough" or no information, and 5% received "enough but wanted more".

Chart 10: Information received before discussing support (Survey)



We also asked survey respondents whether they felt prepared for their needs assessment. Of the 66 participants who answered the question, 39 (59%) strongly agreed or agreed, 16 (24%) disagreed or strongly disagreed, and 11 (17%) were unsure. While it is encouraging that nearly two-thirds of respondents in South Lanarkshire felt prepared for their assessment, it is concerning that nearly a quarter felt unprepared, with the remainder unsure.

Chart 11: “I felt prepared for my needs assessment” (Survey)



Most interviewees in South Lanarkshire had been fully informed about the options prior to their assessments, but others had not been told about all four options when they started the process of accessing SDS, with they said had made it harder to make informed decisions.

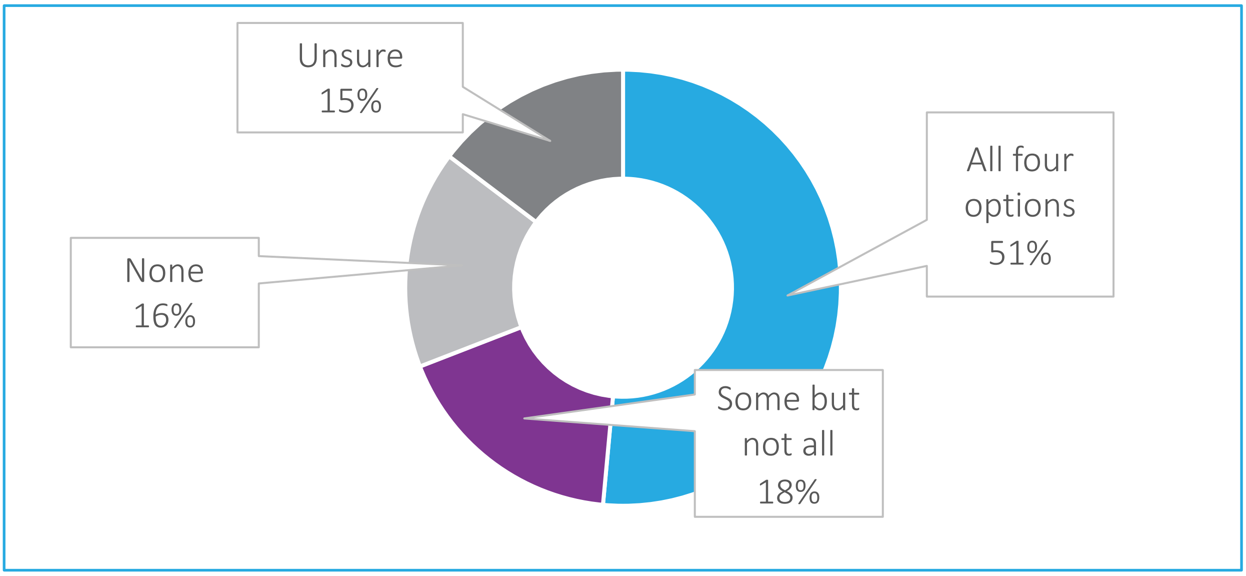
Information and Preparedness Before Assessments: The findings indicate both existing good practice in South Lanarkshire, and that improvements could be made to ensure everyone has adequate information in advance and feels prepared for a needs assessment. Comprehensive, high-quality information in a wide range of accessible formats should be proactively provided to people about the four SDS options – particularly about Option 2 – carers’ assessments and support plans, and what to expect of a needs assessment.

Information During Assessments

The pattern of variable information about the four SDS options continued into people’s needs assessments. We asked respondents whether all four SDS options were discussed with them when they met with a professional to discuss their support needs.

Of the 68 survey respondents, 35 (51%) stated that the professional discussed “all four options” with them, 12 (18%) that “some but not all” options were discussed, and 11 (16%) that “none” of the options were discussed. A further ten respondents (15%) indicated that they were “unsure” which options were discussed with them. This is a higher proportion of people who were able to discuss “all four options” than across Scotland more broadly, indicating good practice which could be usefully expanded to ensure that all four SDS options are outlined and discussed with all people accessing SDS during needs assessments and reviews.[30]

Chart 12: Discussing SDS options with professionals (Survey)

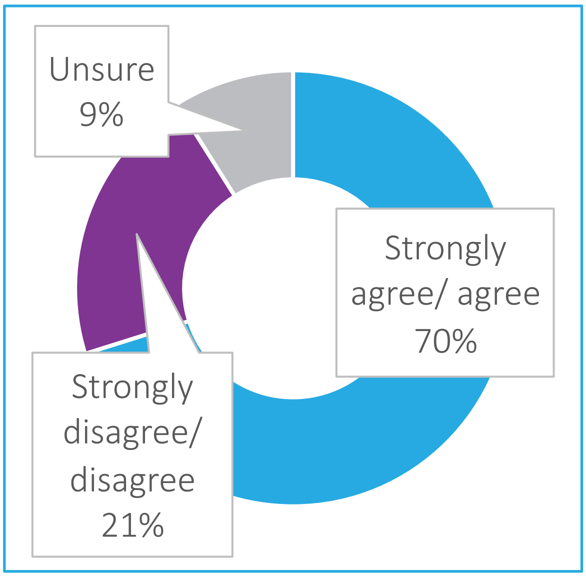


Most but not all interviewees had had all four options discussed with them during their needs assessments. One interviewee stated that they had not realised that there were four SDS options, having thought SDS was only available via direct payments. Interviewees highlighted the importance of access to information to make informed decisions, since they felt that their choices were linked to their social worker's knowledge of SDS, especially around Option 1.

One interviewee reflected favourably on the information given to them by a social work professional when during their initial needs assessment: "we got a [...] wee flip card that said 'this is your four options'. We weren't very sure ourselves what the options were." This information chart gave the interviewee information to go back to and read while they were deciding on their preferred support option.

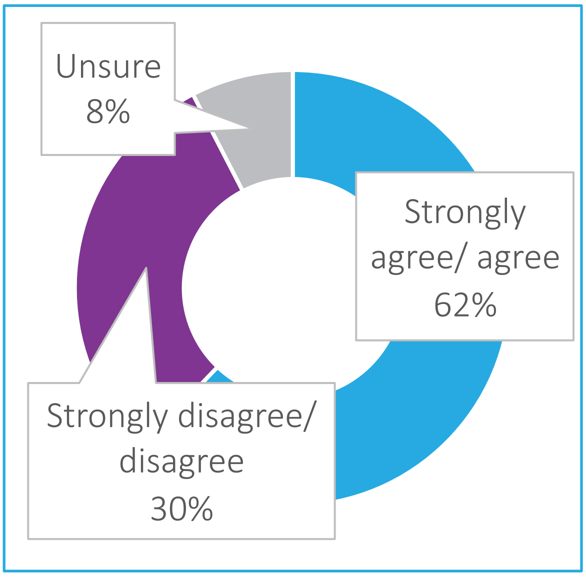
In the survey, we asked whether people agreed with the statement "The person I met with explained things clearly to me". Of the 67 respondents who answered this question, 47 (70%) strongly agreed or agreed, 14 (21%) disagreed or strongly disagreed, and six (9%) were unsure.

Chart 13: "The person I met explained things clearly to me" (Survey)



In the survey, we also asked people to respond to the statement "All my questions were answered", regarding their meeting with a professional. Of the 66 respondents, 41 (62%) strongly agreed or agreed, 20 (30%) strongly disagreed or disagreed and five (8%) said that they did not know. Interviewees indicated similar experiences. While work remains to be done to respond to those who had unanswered questions, these findings are encouraging, and higher than the national average in MSMC – where 52% of people reported that all their questions were answered, 36% had unanswered questions, and 12% were unsure.

Chart 14: "All my questions were answered" (Survey)



Several interviewees said that they had been able to ask questions during assessments and received satisfactory answers from social work professionals. One interviewee describing their social worker as empathetic about their complex care needs and ensuing questions; another stated that their social worker was "fantastic" about talking them through the process of accessing SDS.

A different interviewee stated that whenever they met their social worker, they felt that they "weren't getting the answers" to their questions, which mean that they "never felt satisfied at the end of any meetings." Another described the process of being assessed for SDS as follows:

> *"I'm always asking questions, but I never really feel that you get the right answer that you're expecting. It's a bit cloak and dagger honestly […] – even if you ask the question, they only tell you what they want you to know, so you can't get any further forward really. […] My experience over the years in different places and with different social workers is […] all the same. They feel happier when they are in control."*

One interviewee described their interactions with their social worker during their needs assessment as "strange from start to finish", because their social worker "didn't know" the answer to their questions about SDS, and how the process worked. The interviewee concluded that this interaction "wasn't easy, and we were already stressed enough as it was, doing what we were doing."

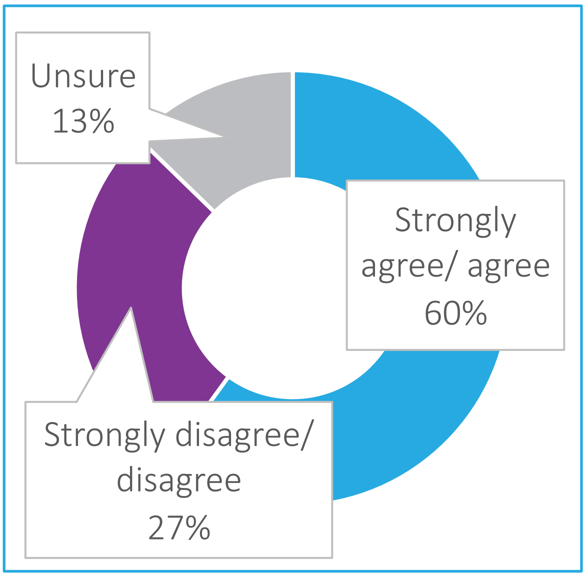
Overall, interviewees indicated that their questions to social work professionals covered a range of concerns, including how support package decision making processes worked, and how to become an employer of PAs.

Information During Assessments: Social work professionals play a significant role in informing and influencing decisions about social care, and they are often many people's first port of call for information about SDS, including eligibility criteria, wait times and available support. The research indicates that there are positive examples of good practice in South Lanarkshire. However, further work is needed to ensure that everyone is fully informed about all four SDS options during assessments, all questions are answered, and that decision-making processes are transparent.

Information About Budgets

We asked survey respondents if they had been told the amount of money they can spend on their support (sometimes called an estimated or a personal budget). Of the 55 respondents, 33 (60%) said yes, 15 (27%) said no, and seven (13%) said they did not know if they had been given a budget.

Chart 15: "Have you been told the amount of money you can spend on your support?" (Survey)



That most respondents in South Lanarkshire had received information about how much money was available to them is a positive finding. However, that nearly a third of respondents either had not received that information or were unsure indicates further work can be done in this area to expand existing good practice. It is vital for informed decision making that people are given full information about their personal budgets.

While many respondents had access to all the information they needed about their budgets, some interviewees expressed confusion about what costs were included in their allocated SDS budget. One interview described their perspective as follows:

> *"Let's say they're paying £40 equivalent a week, but the personal assistant is maybe only getting £30 a week with [the] correct hours and [the] correct rate of pay. So, is this £10 difference (just imaginary figures) going towards all this insurance and whatever? But nobody's said. It said on the thing I would get this money, the thing I signed, but nobody's actually said that money is included in the amount."*

Another interviewee, an unpaid carer, stated that they felt unsupported in seeking information about the person for whom they care's budget, and in finding solutions to the gap between the SDS budget and the actual cost of care:

> *"I was expecting to find out about the full budget available and the options for [Name's] care. In fact, because we wanted [Name] to attend day care, that was all that was supplied and there was no discussion as to how much of the budget day care services provided by the council cost, whether there was any shortfall or excess regarding the assessment of [Name's] actual care needs."*

Information About Budgets: In order to support and enable people to make informed decisions about their care, measures should be in place to ensure that everyone is provided with accessible information about the budget available to them, how it may interact with other income, and payment procedures (including wait times). Some people may want to take part in several conversations with well-informed professionals to support informed decision making about care charges, budgets and how they interact with other income like social security.

Outstanding Concerns and Appeals

In the survey we asked if people had any outstanding concerns that were not addressed during their last assessment. Of the 67 respondents, 37 (55%) had no concerns, 15 (22%) had outstanding issues, and 15 (22%) were unsure. While work remains to be done to respond to those who had unaddressed concerns, these findings are encouraging, and higher than the national average in MSMC – where 48% of people reported that they had no concerns, 29% had issues that they did not feel had been addressed, and 23% were unsure.

Of those respondents with outstanding concerns, the main issues were arranging adequate support, complicated application processes, difficulties communicating with social work professionals, and the slow introduction of care packages. One respondent stated that they received "no assistance in sourcing additional support when budget review did not increase, and [there is] still a gap in care needs versus [the] budget provided." A different participant stated that they found the "preparation form" challenging to complete – "like writing a thesis". They reflected that "it was designed for the council and completely inappropriate for disabled service users."

We also asked survey participants whether they were in the process of appealing the decision made in their last review or needs assessment. Of the 60 respondents, one person in South Lanarkshire indicated that they were in the process of appealing the outcome of their last social care assessment or review. They reported that they were being supported in their appeal by an independent advocate. Respondents highlighted that unresolved issues had direct and negative impacts upon their health and the health of the people for whom they care.

One interviewee also commented on their ongoing concerns about the limitations of the needs assessment process, and deficit approaches:

> *"The needs assessment is quite a big problem area, isn't it, because it's such a negative thing to always having to be saying the negative stuff. And in day-to-day life I'm always trying to feed the positive […], but for assessment obviously it's all the negative side. You have got to be truthful and say this is what it is, as such."*

Outstanding Concerns and Appeals: The research invites further work in South Lanarkshire to strengthen and embed existing good practice so that people are not left with unaddressed concerns following needs assessments and to prioritise asset-based assessment processes. People should be provided with alternative, accessible communication routes – like online chat functions, a freephone support line, and direct email addresses for professionals – that allow them to follow up and have questions answered later, if it is not possible during meetings. Social work professionals should proactively check in with people after assessments to identify and address any outstanding concerns and follow up on any questions or requests for additional information. They should also signpost and refer people to other sources of information, including independent advice organisations.

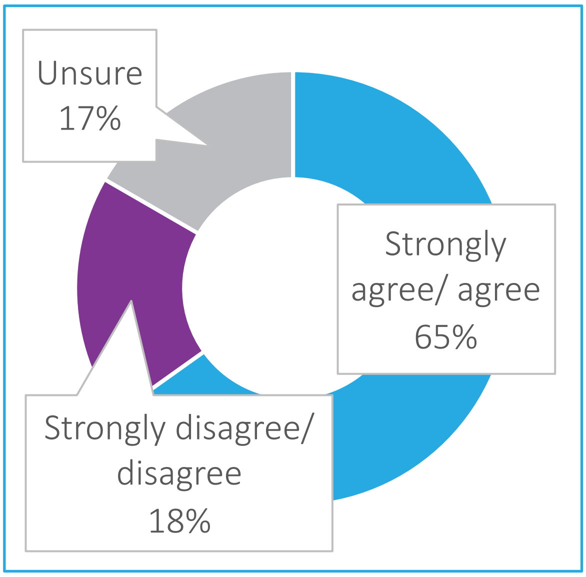
Informed Choice and Control

Time to Consider Options

In the survey, we asked if people agreed with the statement "I had enough time to choose the option of SDS that suited my needs." Of the 66 respondents, 43 (65%) agreed or strongly agreed, 12 (18%) disagreed or strongly disagreed, and 11 (17%) stated that they did not know. While it is encouraging that most respondents in South Lanarkshire had enough time to choose an SDS option, the findings suggest that work is required to improve the number of people who feel they have enough time to decide on the best SDS option for them.

Overall, most participants felt they had enough time to choose their preferred SDS option. However, nearly a fifth of people would have liked more time before deciding – a result that overlaps with those people who wanted more information about their options. Ten of the respondents who wanted more time to decide said that they had received either "some but not enough" or no information about SDS options at their needs assessment, while one reported that all four options were discussed with them, and one was unsure. Meanwhile, 74% of those who felt they had had enough time to choose had received information about "all four options" during their needs assessment. These results indicate a correlation between the provision of clear information and people feeling able to make prompt decisions about their support.

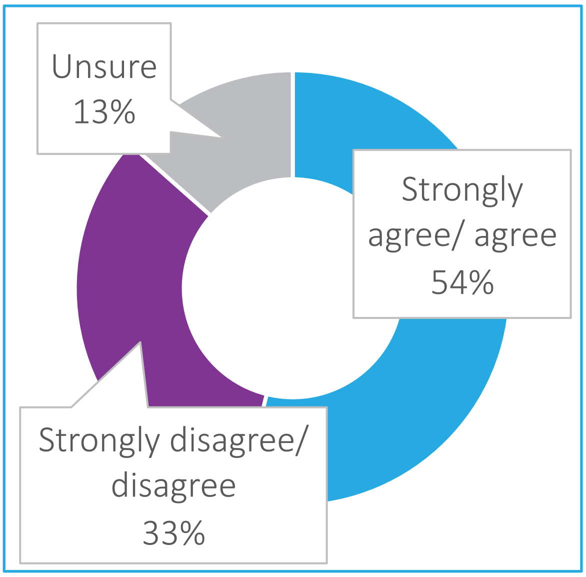
Chart 16: Enough time to choose SDS option (Survey)



Waiting Times

In the survey, we asked people to agree or disagree with the statement, "Waiting times, or waiting for responses, makes Self-directed Support more difficult for me." Of the 52 respondents, 28 (54%) strongly agreed or agreed, 17 (33%) disagreed or strongly disagreed, and seven (13%) stated that they were unsure.

Chart 17: “Waiting times, or waiting for responses, makes SDS more difficult for me” (Survey)



One survey respondent summarised the negative impact of a long waiting time between a needs assessment and a decision as follows:

> *“We were left at risk with no support; every time I chased assessment no-one got back. The support worker wasn’t given time to visit, always put on duty, [and] eight months since request for assistance the SDS forms are only now being done after a formal complaint that the service was not fit for purpose. We have been at crisis, in a critical situation throughout this time.”*

A different participant reflected on the negative impact of long waiting times:

> *“Eight months on SDS [is] not complete, months between [assessments] with no contact, numerous calls to social work unanswered, stress of process caused severe stress and humiliation. No timelines given, heading towards a welfare situation despite them knowing SDS support in place would solve the problems. Social worker pulled off SDS […] lack of experience to complete forms, no support to complete forms. Need to await a further three months to go to [decision-making panel]. Not fit for purpose!”*

Interviewees reported variable wait times for assessments and support to be put in place; some waited three or four months, and three people waited more than a year before the start of support provision. One summarised their experience of seeking information about SDS and requesting a needs assessment as follows:

> *“The hardest bit was applying for the social worker and waiting for a social worker to be allocated. It took over a year to get the social worker allocated. Once [Name] was allocated, [they were] fantastic.”*

A different interviewee spoke positively about the clarity of information across a four month wait between their request for a needs assessment and the implementation of support:

> *“We actually were quite lucky; we moved into the adult social work team [and] the social worker was brand new in the job, but not wholly new to the world of social care so filled in our needs assessment quite quickly. It only took maybe a few months. Probably about four months all in.”*

One interviewee commended their social worker’s quick response to put support in place at home prior to a hospital discharge and cited the timely provision of support as key to their positive experience of SDS.

A different interviewee had applied for SDS because they wanted a fast solution that would provide support for their child to have a good quality of life after finishing secondary school. The social worker was already known to the family because they had previously accessed short breaks via SDS; this continuity of staff contact was described as helpful, as was the speed of the response. A carers' SDS assessment was also carried out for the parents during this transitional period, which helped in planning appropriate care arrangements.

Interviewees uniformly appreciated short waiting times for a response or decision from social work. Those who waited the longest generally reported the highest levels of stress and difficulty in accessing SDS. Other respondents commented on additional waiting times that they did not expect, between initial phone contact with social work, assessments, decisions on packages and finances, and finally the eventual implementation of support. People indicated that more information about waiting times would have been useful in helping them manage expectations and plan accordingly.

Waiting Times: Short waiting times are greatly appreciated because when people have to wait too long – whether for a needs assessment, review, or for support to be put in place – it causes unnecessary stress and anxiety. Delays, compounded by barriers to accessible information and alternative support, must be avoided as they can lead to a deterioration in people's physical and mental health and wellbeing. Timely support can help people avoid reaching crisis point and the potential for more invasive and expensive intervention later. More publicly available information about waiting times would help increase people's understanding of what to expect of the process.

Choice over SDS Option and Support

We asked survey respondents in South Lanarkshire if they were on their preferred SDS option. Of the 55 participants who answered, 51 (93%) were on their preferred option, one (2%) was not on their preferred option, and three were unsure (5%). This is a higher proportion of people on their preferred option than across Scotland more broadly, indicating good practice which could be usefully expanded.[31]

A similar pattern was found with interviewees. Out of the 18 people's experiences of SDS we heard about via interviews, 14 were on their preferred SDS option, two were not on their preferred option, and two were unsure which SDS option they were on. The interviewees who were on their preferred option described how support arrangements enable them to live independently and engage with the local community:

> *"Yes [Name] is out and about and does quite a lot of good stuff. […] There's a […] café just down the road that they frequent quite a lot, where there's just a team and coffee and they play all the games."*

> *"Well, [my PA] does some personal care tasks and also instead of […] sitting and moping about doing nothing, we always go out somewhere for a bite to eat, a spot of lunch. You name it. My [partner] doesn't mind. They quite enjoy actually me going out because I'd be cooped up in the house with voluntary work, doing it from the house all the time. But now I'm out and about again, I've never looked back. I'm now called the chauffer because I'm able to drive."*

The proportion of respondents in South Lanarkshire indicating they are on their preferred SDS option is encouraging. These people described how support arrangements enable them to do a diverse range of activities. These included (but are not restricted to): personal care, assistance with household tasks and shopping, short breaks, access to educational facilities, and support with social activities.

However, not all experiences were positive. One interviewee stated that following a needs assessment they were informed that there were no suitable service providers in the area, limiting their options for support. The interviewee summarised their experience as follows:

> *"They've already told us they can't offer us anything for [Name]. They can't offer what [they] need in terms of these support packages that the draft guidelines outline when they come out to do [Name's] assessment. And they just don't seem able to provide that within South Lanarkshire Council. […] It's very much a lonely game."*

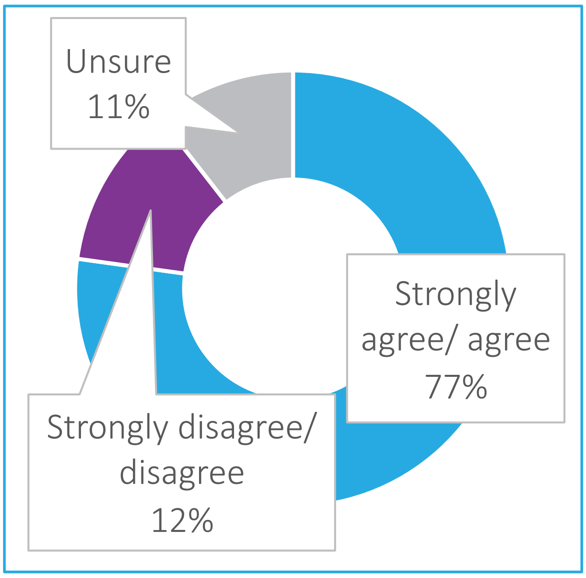
A different interviewee explained that they needed to employ a PA via Option 1 rather than an agency (Option 2) due to the low rates of pay available in their SDS budget, which was not sufficient to employ agency workers suitable for their care needs.

The single survey respondent who was not on their preferred option summarised their perspective as follows:

> *"[I am] not being facilitated to change options as 'needs' changed. Manipulated into remaining within the current option for the remainder of the assessed year."*

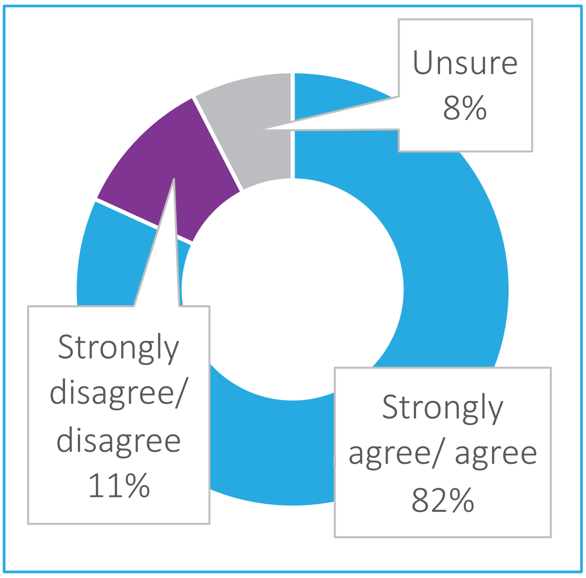
We also asked survey respondents to agree or disagree with the statement "I am fully involved in all decisions about my care and support". Of the 57 respondents, 44 (77%) strongly agreed or agreed, seven (12%) disagreed or strongly disagreed, and six (11%) stated that they did not know.

Chart 18: "I am fully involved in all decisions about my care and support" (Survey)



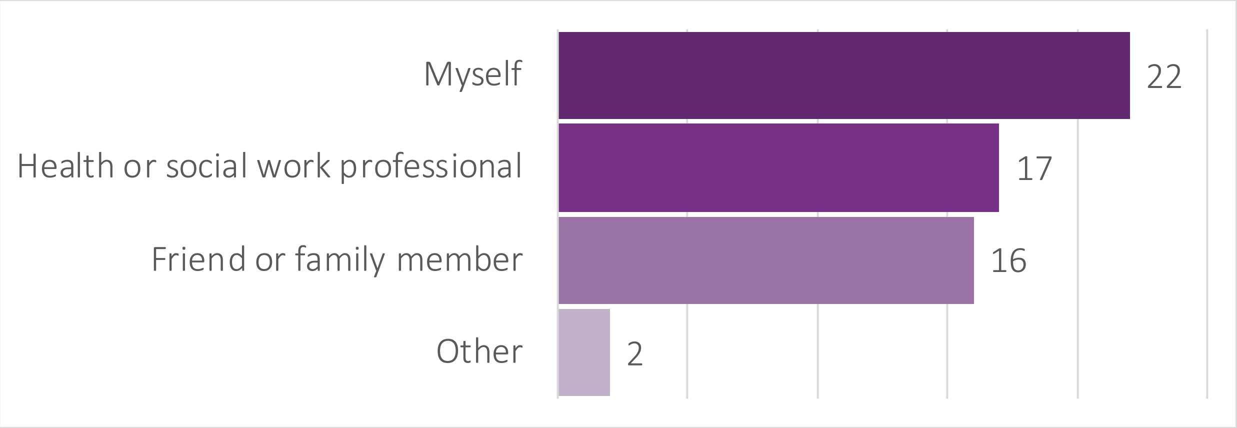
In the survey, we also asked people to respond to the statement "I had a say in how my help, care or support was arranged." Of the 66 respondents, 54 (82%) strongly agreed or agreed, seven (11%) disagreed or strongly disagreed, and five (8%) stated that they did not know. These findings are encouraging, and higher than the national average in MSMC – where 69% of people agreed that they had a say in their care arrangements, 22% disagreed, and 9% were unsure.

Chart 19: "I had a say in how my help, care or support was arranged" (Survey)



We also asked survey respondents who chose the way that their support is arranged now. Of the 58 respondents, 22 (38%) said that they chose the way their support was arranged. 17 (29%) said that a social work professional chose their support for them. A further 16 people (28%) stated that a friend or family member chose for them. Two people (3%) selected "other" – one stating that "support is still not in place". These findings invite further work to embed supported decision making (instead of substitute decision making) in SDS/ social work practice.

Chart 20: Who chose support arrangements? (Survey)

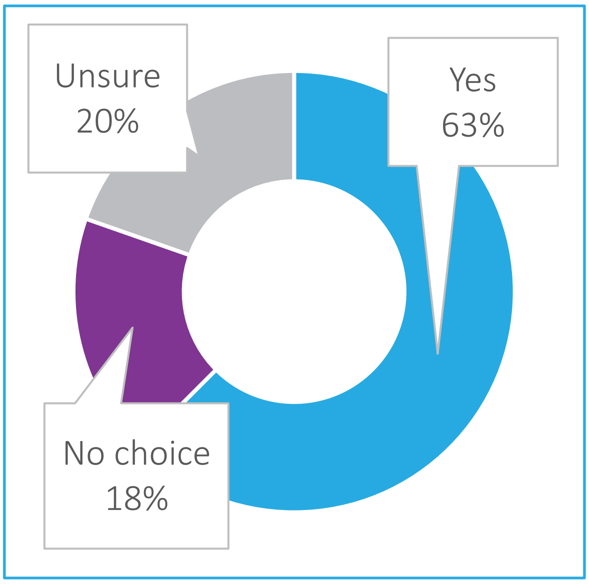


Choice Over SDS Options and Support: Although a substantial majority of respondents in South Lanarkshire indicated they were on their preferred SDS option, improvements could be made to information-sharing and decision making processes to ensure consistent practice is applied to SDS option choice. While professionals play an important role in helping people access appropriate services, that should not extend to making decisions on people's behalf – the principles of choice and control are clearly embedded in SDS legislation and policy. Staff could be given more training about how to support decision making rather than lead it, and on co-production methods more broadly. Professionals should also fully incorporate equality assessments into their processes for service users and families. People should also be able to choose care workers even when their support is organised by others – and this should be reflected in local commissioning processes.

Budget Management

We asked survey respondents whether they chose who manages their personal budget, and if so, who they chose to manage it. Of the 56 respondents, 35 (63%) said that they were free to choose who they wanted to manage their personal budget, ten (18%) said they were not given a choice, and 11 (20%) were unsure whether they had a choice.

Chart 21: Did you choose who manages your personal budget? (Survey)



Of the 35 people who were given free choice of who would manage their personal budget, ten (29%) selected the council, four (11%) chose a private sector provider, three (9%) opted for a third sector provider organisation, and three (9%) selected an independent support organisation. A further 13 people (37% of those who were free to choose) selected an individual person (this response could include themselves). Two people did not give further details of their choices.

Of the ten people who said that they were not given a choice, and the 11 who were unsure whether they had been offered a choice, none provided details of who manages their budget.

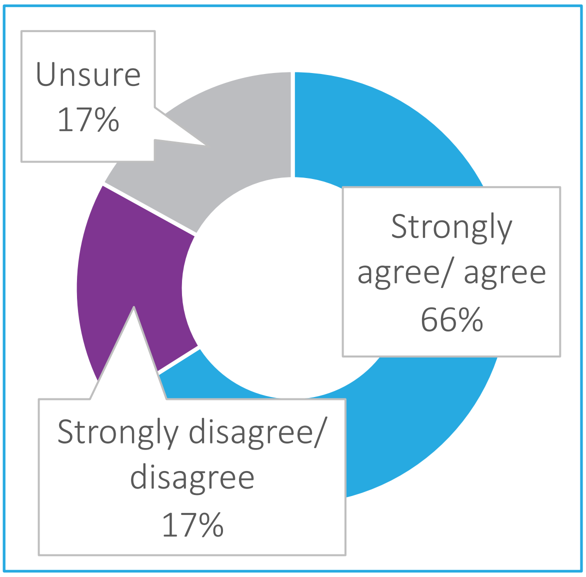
It is encouraging that nearly two thirds of respondents in South Lanarkshire were offered an unrestricted choice of who to manage their personal budget. However, it is concerning that over a third of respondents reported that they either had no choice or were unsure. This indicates that, amongst other things, these respondents were not fully offered all four SDS options (as that would necessitate discussion of who would manage their personal budget).

Budget Management: The findings indicate that further work is needed in South Lanarkshire to ensure everyone is offered a meaningful choice of all four SDS options and the opportunity to choose who will manage their personal budget.

Adequate Support

We asked survey participants to respond to the statement "Enough budget to meet my outcomes makes Self-directed Support easier for me". Of the 53 respondents, 35 (66%) strongly agreed or agreed, nine (17%) disagreed or strongly disagreed, and nine (17%) were unsure.

Chart 22: "Enough budget to meet my outcomes makes SDS easier for me" (Survey)



One survey respondent criticised the assessment process as designed to reduce their support package. They stated that their "assessment was toned down to imply more capability than there is, in order to lower the budget."

Some interviewees spoke in detail about the impact on their physical and mental health of substantial reductions to their SDS budgets and support. One interviewee provided unpaid care for an elderly person. After a short trip away, the interviewee returned to discover that a social work professional had visited the person for whom they care on short notice, without giving the person time to notify their support network or have anyone present to assist with communication. Without someone attending the review, the SDS user had struggled to understand and communicate with the social work professional – and their SDS package had been reduced:

> *"One of my children had something on and we actually went away for two nights with them. […] We have things in place and […] if [Name] presses the alert [care providers] go out. Because we're rural […] they'll let me know so I can just nip around because I can be there in two minutes, whereas they take half an hour to get there because they cover the whole of South Lanarkshire. So, that works really well and if [social work] are coming out, they're supposed to let me know they're coming out because [of the nature of the service user's impairment]. You know, they're supposed to let me know. So apparently, they'd phoned [Name] in the morning: 'We're coming out, see you in the afternoon.' And they had been out and cut [Name's] care. [Name] used to get three visits a day and they'd cut it to two."*

This account highlights two key areas of concern; firstly, the short notice given for a social work visit, with little time for the person accessing SDS to seek assistance (should they wish it) from family members, an independent advice or support organisation, or an independent advocate. Secondly, the interviewee reported confusion as to why service provision had been reduced when there had been no change in the individual's needs, outcomes, health, or disability. They stated that the reduced support would make it harder for the individual to meet their personal outcomes and require greater assistance from unpaid carers.

Another interviewee also reported that the person for whom they cared had struggled to get appropriate support arrangements in place via SDS because of assumptions about the availability of unpaid care. They stated that:

> *"If you consider the [...] years that I've done this for two people and what it would have cost if they had paid me to do that, it just does not make sense. [...] We're not valued at all. And because [Name] lives in the house it is even more frustrating for me because [social work] don't seem to worry, they can tick the box to say they are not at risk because we're in the house and can deal with their shower, their falling in the house, whatever, because there's somebody actually there [...] we're already going downhill and getting conditions."*

Several interviewees commented that people's social needs tended to be omitted from the allocated budget (particularly when budgets were cut), and that this affected SDS users' ability to meet their personal outcomes. One interviewee shared the experience of using their carers' SDS budget to enable an SDS user to participate in social activities:

> *"I would quite like [...] on a Sunday to take [Name] out and do something, [...] whatever [Name] wants to do. [...] If it came to it I could use the carers budget for that and just pay [...] I'm just trying to get the best for [Name]."*

As well as reporting on the negative impacts of cuts to social care support, some respondents described care arrangements that were not suitable. Given the concerns raised about effective communication of SDS options, it is reasonable to assume that some of these issues with individual care providers could be mitigated if – for example – individuals knew they had the freedom to move from Option 3 to Options 2 or 1 and receive support from different care providers or PAs.

Some interviewees reflected that part of the future planning of care depends on people realising that they need to hold conversations, including with their social worker, to put support provision in place for changed circumstances. One participant raised the overlaps between changing budgets and future planning as a key concern:

> *"There is no clear logic to how budgets are calculated, and the eligibility criteria is changing. As someone with a progressive condition, this is very anxiety provoking, giving no confidence about the future."*

A survey respondent stated that they had outstanding concerns about forward planning "for emergencies", if "anything happened to family carers". They summarised their perspective as follows:

> *"My wish to remain in own home with support was ignored and only residential support would be provided. Not suitable for a young [person] who has no wish to be put in an old people's home."*

Interviewees who were unpaid carers also voiced concerns about whether the local authority will provide adequate support for the people for whom they care if their health deteriorates, and they are no longer able to provide unpaid care. One summarised their concerns as follows:

> *"By the time my [partner] and I hit our seventies there is no doubt that [SDS user] will require a high level of support to be provided by South Lanarkshire Council in order to live independently, and there is no way around that. That is undoubtedly what is going to happen, because we know we will probably not be in a position health wise or age wise to be able to continue offering the level of care and support that we presently do. My feelings about the whole thing is that SDS is letting us down badly."*

People indicated that they would welcome more future planning in discussions about their care – both in terms of flexibility around contingencies, and in planning for futures where people might require more care (including scenarios where unpaid carers are no longer able to provide support).

Adequate Support: The research reinforces the need in South Lanarkshire for good quality, adequate support via SDS that acknowledges the importance of community engagement and social activities. This can be instrumental in ensuring good quality of life and plays an important role in helping people enjoy their right to independent living and equal participation in society. While most people in South Lanarkshire were happy with their care, we found that some people were not receiving adequate, person centred support. The impact of not providing rights based, person centred care can be devastating, resulting in isolation, loneliness and physical and mental ill-health. Any proposed reductions in SDS budgets/support should be communicated clearly and discussed with people well in advance of any changes being introduced. No-one should feel or be pressured to move or enter 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 to enable people to remain – with appropriate support – in their own homes for as long as possible, if that is what they want. Health and social care staff should consider the possibility of isolation or mental health crisis when changing packages and eligibility criteria and be able to arrange reassessments and signpost support services where needed. These recommendations are in keeping with the Care Inspectorate recommendation that the partnership "should evaluate the impact of changes to its eligibility criteria policy and how these might affect preventative and early intervention services."

Inadequate support via SDS can also place unacceptable demands on some people to act as unpaid carers without any choice by themselves or the people they care for. Professionals should not assume that family members and friends are able or suitable to provide unpaid care, and future planning should be supported by professionals. These recommendations support the Care Inspectorate statement that "the partnership should engage with supported people and unpaid carers to find ways of ensuring they are involved and informed in the process for finalising of budgets".[33]

Flexibility

Many research participants commented on the value of and need for flexibility for the effective use of SDS – particularly around budgets. Interviewees talked about flexibility in a range of ways: from the flexibility to change SDS option, to being able to choose how and when to spend their personal budget, with different amounts of spend and support at different times of year. Some people spoke of positive examples of flexible funding and approaches to SDS that prioritised their choices and enabled individuals to make their own risk assessments when trying new activities. One interviewee mentioned that in their case, the budget is not viewed in terms of hours. They found that this helped with short-term and long-term flexibility since peoples' needs can change – stating that "nobody has ever mentioned hours to us, it's always just been a budget." One survey respondent also added that they "decided to change [from Option] 3 to Direct Payments [Option 1]", to ensure greater flexibility with their care arrangements.

While there were some examples of good practice with regard to flexible use of SDS in South Lanarkshire, one survey respondent outlined the need for greater flexibility in how they could access and use SDS. They stated that:

> *"SDS should allow option for 'home help' duties and shopping. I could live independently for much longer if some of my budget could be used for this."*

Another participant reflected that they were "discouraged regarding flexibility" by their social worker and that they were "repeatedly told [SDS] is only to be used to employ carers."

One interviewee discussed problems with finding a care provider that could be afforded within the hourly rate approved by social work, which severely limited their choice of providers:

> *"This is where the flexibility comes in too, because the budget they allocated didn't meet [my] needs. What I understand is that Self-directed Support should not restrict a service-user to taking a provider from the local community, it's to give the option of shopping around, and [...] the flexibility of a personal assistant, and then maybe a provider outwith the area. It should not be restricted and there's plenty of providers. [...] It's just a question of, again, the flexibility. I'm not expecting millions [...] – it's a budget – [...] but I need help and everyone in my situation [...] they need the help, they need to be able to take the time off and feel [...] safe. And that the people [care workers] going in there are compatible."*

Flexibility: The research suggests that there is good practice with regards to flexible approaches to SDS in South Lanarkshire, which positively impact's people's lives and those of the people for whom they care. However, some people in South Lanarkshire are not able to use SDS as flexibly as they should, which can negatively impact on quality of life and enjoyment of rights to independent living and equal participation in society. Ensuring universal access to flexible SDS will help reinforce the positive impact of support. This flexibility could be in how people are empowered and supported to use their SDS, or provide additional support during health crises, but also relates to people's ability to have ongoing conversations with social work professionals and adjust systems accordingly on a regular basis.

Access to Short Breaks

Short breaks were an important topic for many MSMC research participants in South Lanarkshire – for SDS users and unpaid carers alike.[34] People who used SDS budgets to access short breaks described them as an essential way that individuals and families could benefit by having time and space to themselves, doing activities that they enjoyed.

Short breaks were also mentioned by several interviewees as an important chance for people to have breaks and relax. One person described their experience as follows:

> *"It's been fantastic for us, with [Name's] respite, because we started to use [specific short break venue]. […] We were just supposed to send [Name] for like Friday to Tuesday but they have [a camp] that runs for 10-11 days, and they have it for adults and they have it for children, so we have used that. […] As far as we're concerned, [Name's] away on holiday, rock-clambering, away having a great time. And myself and the other members of our family once went [on holiday] for four nights [while the SDS user was accessing a short break facility which was paid for via SDS]. That was amazing."*

Some interviewees reflected on difficulties accessing short breaks, and the negative impact this had on their health and wellbeing. One interviewee discussed their challenges in accessing short breaks as part of SDS. They had been informed that short breaks were not part of the SDS budget and were not available, despite being listed on their personal outcome plan. Others recounted difficulties in getting short breaks approved as part of their budgets.

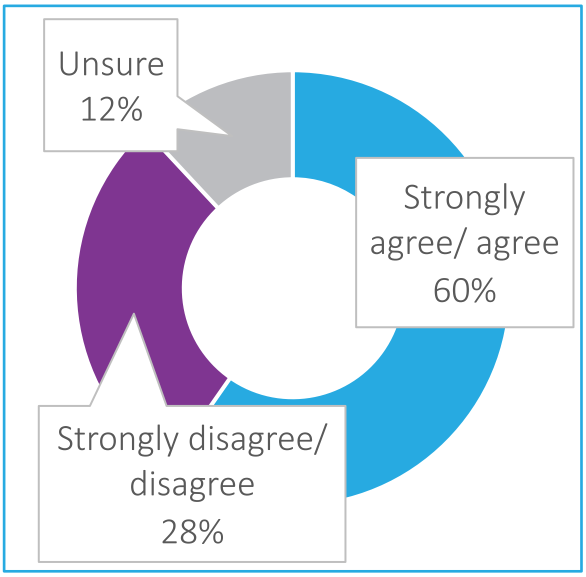
Access to Short Breaks: Flexible, regular access to short breaks should be strongly encouraged in South Lanarkshire because it is an essential element of SDS that results in good personal outcomes for people who access social care, families and unpaid carers.

Communication and Relationships with Social Work

Good Conversations and Consistent Relationships

The importance of productive conversations in arranging appropriate social care support was highlighted in the 2019 Care Inspectorate thematic review of SDS.[35] As such, we asked survey respondents to rate how happy they were with the conversations they had about their support with professionals (e.g. social workers/ social work assistants, occupational therapists).

Chart 23: "How happy are you with the conversations you have had about your support with professionals?" (Survey)



Of the 67 respondents, 40 (60%) were happy or very happy, 19 (28%) were very unhappy or unhappy, and eight (12%) didn't know. Survey respondents who were happy with their conversations with social work professionals highlighted the importance of social workers having a breadth and depth of knowledge about SDS and local services. They also praised the listening skills and empathy of their social workers as key to their positive interactions, along with social workers having the time to listen to them and become familiar with their needs:

> *"They listened to me and gave me time to say what I wanted."*
>
> *"Social worker was very understanding of my needs and put me at ease."*
>
> *"I felt I had a SW who understood SDS and was very professional. [They] listened and answered any questions I had."*
>
> *"Social worker listened carefully to my needs and explained all options available to meet my needs."*
>
> *"I was kept informed of all my options and was not pressured into choosing any particular one."*
>
> *"The relationship has improved over time between social worker and family. Relationships are very important and communication makes such a big difference. There has to be continuity with social workers."*
>
> *"My Social Worker was very friendly and helpful and tried patiently to make things clear to me. [They] helped to organise a care plan which is flexible and meets my needs."*
>
> *"Our social worker really took the time to get to know our family and spend time in our home. We never felt [they were] in a rush*

> *to get in and out or to just tick boxes. [They] had a really friendly, comfortable and confident manner and is always really available to us to answer questions."*

Interviewees highlighted that good conversations required effective communication, access to information, prompt decisions, and good future planning. People highlighted that they appreciated being able to both call and email their social worker and receive a prompt response – not just when they had questions about their support package, but about their wellbeing more generally. One described their social worker as a "good guy", who "gets back to you if you phone […] and leave messages", which the interviewee felt was very important.

A different interviewee reflected on the positive impact of building a trusting relationship with their social worker:

> *"I think I found it daunting as well though, just because we never ever wanted social work in our life and that was the big thing. […] I think a lot of [people] are very much like that, they don't want social work in their life, but actually the social worker has been fantastic. […] [Name] been on our side, yes, as opposed to, I always thought it was something that we might have to fight against."*

People repeatedly referenced prompt communication, time for full explanations and discussion, and easy access to information as key to smooth communication with social work and effective SDS provision.

Good Conversations and Consistent Relationships: The research demonstrates that most people in South Lanarkshire feel that they have good conversations with their social workers. This positive finding supports the vital importance of good conversations and communication between service users and social work professionals – and there are many different elements and examples of this in the experiences shared by participants. It is important that social workers have a good breadth and depth of knowledge about SDS and local services, can demonstrate good listening skills and empathy, and take time to listen to people and become familiar with their requirements. These findings also highlight the benefits of consistent and trusting relationships with social workers, including having direct and varied lines of prompt communication available.
Overall, we would recommend that work to ensure positive conversations and relationships should continue, with ongoing planning to guarantee high quality practice for all people using SDS.

Poor Communication and Relationships

A minority of participants described less positive experiences of communication and relationships with social work professionals in South Lanarkshire. Of the 67 people who answered the survey questions about how happy they are with the conversations they have had about their support with professionals, 19 (28%) indicated they were either very unhappy or unhappy, and eight (12%) were unsure. Some stated that their social worker did not have enough time or knowledge to meet with them and discuss their needs and questions properly. Others indicated more fraught relationships.

The most common reasons for dissatisfaction were that people did not feel “listened to”, reported that that their needs assessments were rushed, and/or felt they had received inadequate information about SDS. Key comments from people who were unhappy with their conversations and relationships with social work professionals are as follows:

> *“My social worker wasn’t listening to the people that knew me.”*

> *“I asked for information regarding the agreement, the criteria using family members and the flexibility regarding how the funding can be used. No information given. Told family members can’t be considered [as PAs].”*

> *“Not aware of what support was available, no information was given. Took a year to get place at day centre one day a week. Felt they had no urgency as in a staff environment.”*

> *“Bad – no minutes/notes, no agreed goals or timescales. This caused confusion resulting in not being able to change the payment option.”*

> *“Social worker omits many necessary facts from the assessment including key phrases like ‘with support’.”*

> *“Communications completely broke down because nothing was being done about progressing SDS.”*

> *“No social work engagement post assessment outcome. [Third party] has had to chase updates. A new social worker was introduced approx. four months after outcome.”*

> *“Forced to change carers because of the new system. I was happy with existing care provision, no consideration.”*

> *“Dedicated worker has no time to complete application. The service has been unethical and I’ve had to go to humiliating lengths to get them even to get in contact.”*

Poor Communication and Relationships: Examples of poor communication raise clear concerns about decision making and autonomy; if information about SDS is not provided, then people cannot be said to control or choose their support. The findings invite further work to expand existing good practice in South Lanarkshire to ensure that people’s experiences of conversations and relationships with social work are consistently good. All processes and paperwork should be transparent and shared in an accessible format with service users. Social work staff should proactively gather regular feedback – good and bad – from service users, families and unpaid carers as a way to support continuous improvement. People should be proactively informed 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).

Transparency

As indicated throughout this report, research participants commented on the importance of transparency in a variety of ways, centred around the need for clear information about what to expect from SDS and social workers, the process of accessing support, expected wait times, and how to challenge decisions.

Several respondents touched upon the lack of transparency during the needs assessment and that they lacked access to the calculation of need carried out by social work. One interviewee stated that:

> *"Apparently it goes to a board or something to decide what support you get. I asked for a copy and was never given a copy of how they worked it out or anything. I was just told [we would] get three hours support, enough to get three hours of somebody coming a week. But I wasn't told how they worked that out, how they came about that figure, anything. I got a report about it, but they didn't say how they then took that report to be quantifiable as anything. […] It just was somebody on high has decided."*

The interviewee went on to comment that clearer explanation of process would be helpful, and social work professionals should ensure that service users understand and agree with everything that they sign off on in the assessment process. They stated that:

> *"I've felt that that is where the biggest bit of influencing, if you can put it that way, […] is filling in that needs assessment, because I don't think it gets explained properly. And at the end, some things they'll just sort of say, 'Well now that we've finished that […] I've got enough information from what you're telling me, I'll go back to the office and fill that out'. And you don't know what's filled out. You don't what generates the budget – but they do, so you're influenced at that juncture as well, and at the end of it they sort of give you, 'right, that's the assessment I'll send it out, I'll fetch this out, now I just need you to sign that off.' And the important bits to us are really belittled by them to get it all through and on a place that they really want it to be."*

Several respondents also reported that they would like access to copies of all documentation concerning their social care provision, including copies of their agreed budget and personal outcome plans, but struggled to obtain these documents from social work – which in some cases prompted distrust in the system, and in one instance conflict with social work professionals. Greater transparency and better communication may have reduced these points of conflict with the local authority.

Transparency: The research indicates that while there are good examples of transparent process in South Lanarkshire, this is not consistent across all areas and more work is needed to ensure systematic good practice and complete transparency across several elements of SDS/ social care. This includes publicly available information about participation in decision making and how to challenge decisions. Further information on document publication dates, webpage timestamps, details of Equality Impact Assessments, and the role of people who use support, carers, and partner organisations in decision making, is encouraged. These conclusions are in keeping with the Care Inspectorate Review for South Lanarkshire, and particularly their recommendations that the partnership should "ensure that people have copies of their assessment and support plans".[36]

Care Staff Recruitment, Training and Quality

Throughout MSMC, care staff – PAs, support workers, and agency staff alike – were mentioned as a key element of people's experiences of SDS and social care.

Several interviewees outlined how SDS has provided them with person centred support that benefits their entire household. One interviewee commended SDS for giving them increasing control over care providers. They pointed out that working relationships, especially those involving intimate and personal tasks, require a sense of trust between all parties in order for service users and staff to feel safe and comfortable. They explained that having the power to choose who carries out their care enables SDS users to enjoy a more relaxed atmosphere in their own homes.

Participants liked the flexibility that SDS can provide in terms of staff working patterns and ability to carry out unplanned activities. When people had good relationships with care workers, they described them as key to their ability to live independently, and interviewees highlighted improvements to their quality of life when high quality support was available.

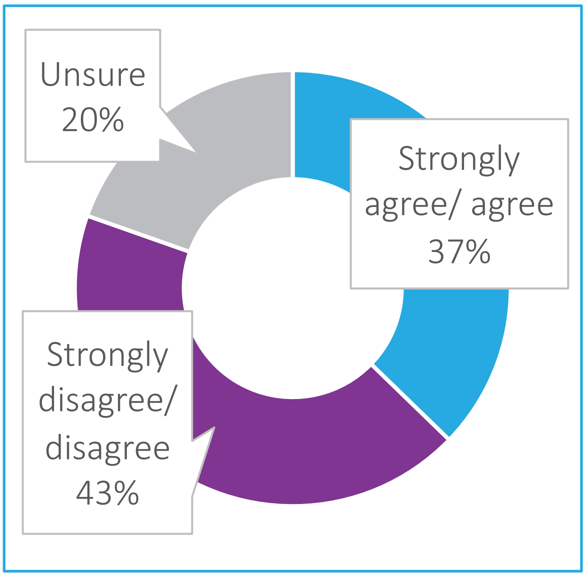
Some respondents also reported that they would like to have more choice over which care workers provide their care when receiving support from third party organisations via Option 2 and Option 3. As discussed earlier in this report, people should be able to choose care workers even when their support is organised by others – and this should be reflected in local commissioning processes.

Staff Recruitment, Retention and Turnover

In the survey, we asked people to respond to the statement "Lack of a regular personal assistant makes SDS difficult for me". Of the 51 respondents in South Lanarkshire, 19 (37%) strongly agreed or agreed, 22

(43%) disagreed or strongly disagreed, and ten (20%) were unsure.

Chart 24: "Lack of a regular personal assistant (PA) makes SDS difficult for me" (Survey)



These findings are supported by comments by interviewees about the importance of, and difficulties finding and retaining, care workers who are appropriate to their requirements. Some interviewees commented on concerns with PA recruitment, specifically linked to their experiences using Option 1 in South Lanarkshire, and their responsibilities as employers. Interviewees discussed difficulties with recruitment, the volume of forms they were required to process, the complexities of employing PAs, and their uncertainty about legally binding contracts.

Some interviewees also recounted that unless they topped up budgets with their own finances or carers' SDS budgets, it was difficult to recruit or retain their preferred staff – both PAs and agency staff. This led to SDS users using personal contributions to supplement rates of pay. Several interviewees highlighted that the amount granted towards wages for PAs or care workers tended to compel a choice of the cheapest care provider.

Interviewees argued that instead of costing labour at the lowest common denominator, the best value for money should be viewed in terms of quality of life for service users and care workers.

Some people also commented on the need for care workers to receive appropriate specialist training. Some respondents suggested they would welcome more support from South Lanarkshire Council regarding PA recruitment, training and continued professional development.

Care Staff Recruitment, Training and Quality: Some people would welcome more support with PA recruitment, training and continued professional development. South Lanarkshire Council should work with people who access SDS and unpaid carers to improve systems and processes related to care staff recruitment, training and quality. People would also welcome the ability to choose their care workers even when their support is organised by others – and this should be reflected in local commissioning processes. It is also evident that some people would welcome improved access to suitably trained and high calibre care workers. While some people are comfortable with the role of employer and have experienced good, long term, working relationships with their support workers, this experience is not universal. This suggests that staff in South Lanarkshire should continue to work with people accessing SDS/ social care to find ways to improve systems and processes – particularly around difficulties with recruitment, training, and staff retention within the wider social care sector.

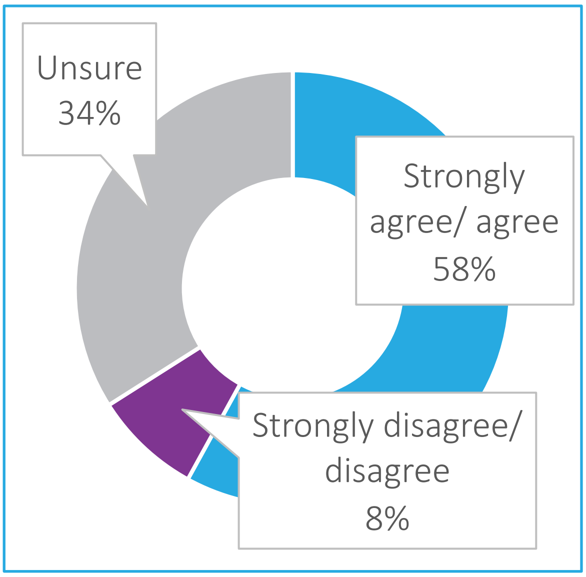
Independent Advocacy and Support

Respondents in South Lanarkshire accessed independent advice and advocacy services for a range of different reasons. These included access to information, assistance to develop a support plan, exploring flexibility with SDS budgets, mediation with social workers, support to appeal a decision, access to legal aid, and advice on payroll and other PA employer related issues. Participants spoke positively of the benefits of independent advocacy and independent advice and support organisations in South Lanarkshire (including several mentions of Take Control South Lanarkshire).

Independent Advocacy

We asked survey participants to respond to the statement "access to independent advocacy makes SDS easier for me". Of the 50 respondents, 29 (58%) strongly agreed or agreed, four (8%) disagreed or strongly disagreed, and 17 (34%) were unsure.

Chart 25: "Access to independent advocacy makes SDS easier for me" (Survey)



Some survey respondents provided additional comments on the value of independent advocacy when accessing SDS. Key comments are as follows:

> *"I would suggest seeking advice from an organisation such as Take Control or an advocacy group to ensure you are prepared and understand as much as you can about SDS."*

> *"Take an external advocate [to meetings with social work], even if you feel 'able', to cause scrutiny and better conduct from social work."*

Interviewees also commented on the value of independent advocacy and having a range of independent support in accessing SDS. One interviewee commented that, "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."

One theme for interviewees in South Lanarkshire was the relationship between people accessing SDS, social workers, and independent advocates. When good relationships were established, collaboration led to effective support planning and implementation of SDS options. One interviewee described the positive outcome of a meeting between their social worker, the interviewee, and an independent advocate, despite initial apprehension from the social worker:

> *"But I still felt that they were ticking boxes along the line of, "well for my job I've got to cover this, this, this and this." Which [...]*

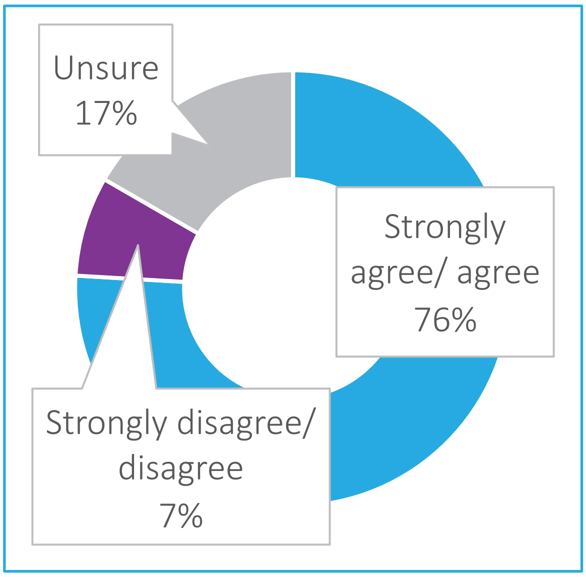
> *that's what [social worker's name] is employed to do as such, but it does come over as a different kind of experience. But we did have a meeting here with social work and […] advocacy when we were getting more into the detail of things. So, [the social worker] was open and [they] did come to that and […] it was a good meeting. I think [Name] was apprehensive when [they] arrived but at the end [they] actually did say, 'this has turned out to be a really good meeting', because it gave [Name] a better idea of what we wanted."*

This positive account of the involvement of independent advocates in the development of support plans is an excellent example of all parties benefiting from their involvement, with productive outcomes for the person in need of support and social work professionals.

Independent Advice and Support

When asked whether access to independent information and support made SDS easier for them, people responded in a positive fashion. Of the 54 respondents, 41 (76%) strongly agreed or agreed, four (7%) disagreed or strongly disagreed, and nine (17%) were unsure.

Chart 26: "Access to independent information and support makes SDS easier for me" (Survey)



Survey respondents and interviewees commented on the value of independent advice and support in accessing SDS. Several people highlighted that they had benefited from the involvement of independent advice and support services during their needs assessment and reviews, and received support from them in challenging decisions about SDS. Several people recommended that people should seek independent advice and support as follows:

> *"Ensure you seek support and information from an independent organisation."*
>
> *"Link with SDS organisations like Take Control, they are brilliant!"*
>
> *"Look into everything and try and get help from other agencies."*

Another said that local independent advice and support organisation Take Control was the key to "unlocking Self-directed Support […] and I can't thank them enough for that."

One interviewee outlined that a local user-led service organisation has assisted them, particularly with the recruitment process of PAs. They explained that the organisation had helped with everything from advertising to interview venue:

> *"The adverts, setting up the interviews, […] it's just you don't know the calibre of person that's coming through the door. […] You don't want them coming to the house."*

Another interviewee praised their social worker for taking the time to consult with a local organisation who provide independent information and advice on SDS. They reported that:

> *"The social worker wasn't too sure […] after the assessment so I know what [social worker] did [...] I know [they have] spoken to Take Control 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, Take Control, and myself."*

Peer Support

Several people in South Lanarkshire highlighted the value of peer support and encouraged the promotion or establishment of local peer networks. One interviewee pointed out that peer support can improve relationships between families and their social workers, since social worker involvement can carry negative connotations for some people – and reassurance via peer support can help counter those concerns.

Independent Advocacy and Support: People clearly value and benefit from independent advocacy, advice and support, and these services play an important role in SDS/ social care. As well as ensuring that these services continue to be sufficiently resourced to carry out their vital work, we recommend that social work and healthcare professionals be given more training and information about local independent advice, support and advocacy organisations so they can routinely refer people and recognise the value they bring to their own work. Focused efforts are required to ensure all people are aware of – and can access – independent services. Local peer support networks and groups should also be encouraged and supported.

Response from South Lanarkshire Health and Social Care Partnership

South Lanarkshire Health and Social Care Partnership welcomes the report and its recommendations.

SLHCP and its principal partners South Lanarkshire Council and NHS Lanarkshire acknowledge the experience of people accessing support and the individual journeys and experiences that have been recorded. We have worked hard with our national and local partners to ensure good outcomes for the people of South Lanarkshire.

The report rightly highlights the importance of access to good quality information about the process and how SDS is being delivered. We acknowledge the strong support from our independent information service Take Control South Lanarkshire as well as our advocacy partners The Advocacy Project, Speak Out Advocacy and People First, together with a host of third sector support organisations.

We recognise the responsibility to take on board the less favourable comments about our approach and the consequences for individuals. Whilst the sample size is relatively small in comparison to our overall activity, nevertheless there are lessons to be learned and these will feature in our refresh of the current approach.

It is recognised that SDS does not sit on its own and many individuals face challenges in other parts of their lives. Recognising these challenges and adopting a solution focussed approach is at the heart of where we want to be. Equality, fairness, and consistency is the benchmark that should apply.

Some of the narrative in respect of workers knowledge, approach and attitude does give some concern. We will be proactive in addressing these issues to ensure, as far as is reasonably practical, that our staff are fully up to date and have the tools at their disposal to make good conversations the norm and that this is applied consistently across our workforce.

We have already embarked on a refresh of our assessment which we anticipate will be going live in the immediate future together with a new Adult Carer Support Plan. In addition, we are reviewing our authorisation protocols to ensure key decision makers are at a locality level and reduce the occasions where things need to be escalated.

We will work to improve our management information so that the impact of SDS is more readily evident at both a local and national level.

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For all enquiries relating to social work services please visit **https://www.southlanarkshire.gov.uk/info/200146/social_care_and_health/815/contacting_social_work_services**

Key numbers:

Social Work enquiries during office hours **0303 123 1008**

Social Work Emergency Service outwith office hours for urgent enquiries only **0303 123 1008** or email: **esws@southlanarkshire.gov.uk**

Endnotes

1 To support readability, the 'N' number is not reported for all survey question responses. Due to the relatively small number of interviewees being discussed in this report (12 interviews, spanning 18 people's experiences of SDS), we use "some" or "several" to refer to between four and seven interviewees, "many" to refer to eight or nine interviewees, and "the majority" to refer to ten or more interviewees.

2 Information and documents related to project design and methodology can be found in the national report, available at: https://www.alliance-scotland.org.uk/blog/resources/my-support-my-choice-peoples-experiences-of-self-directed-support-and-social-care-in-scotland-reports/. All MSMC reports are also published on the Self Directed Support Scotland website, available at: https://www.sdsscotland.org.uk/mysupportmychoice/.

3 Health and Social Care Alliance Scotland and Self Directed Support Scotland, *My Support My Choice – People's Experiences of Self-directed Support and Social Care in Scotland – National Report* (Oct 2020); *Women's Experiences of Self-directed Support and Social Care in Scotland – Thematic Report* (Dec 2020); *People with Mental Health Problems' Experiences of Self-directed Support and Social Care in Scotland – Thematic Report* (Dec 2020); *People with Learning Disabilities' Experiences of Self-directed Support and Social Care in Scotland – Thematic Report* (Dec 2020); *Blind and Partially Sighted Peoples' Experiences of Self-directed Support and Social Care in Scotland – Thematic Report* (Dec 2020); *Black and Minority Ethnic Peoples' Experiences of Self-directed Support and Social Care in Scotland – Thematic Report* (Dec 2020). These reports, and an Easy Read version of the national report, are available at: https://www.alliance-scotland.org.uk/blog/resources/my-support-my-choice-peoples-experiences-of-self-directed-support-and-social-care-in-scotland-reports/.

4 As well as the work of the Care Inspectorate and Audit Scotland noted in the MSMC national report, we note the recent Independent Review of Adult Social Care. See https://www.gov.scot/groups/independent-review-of-adult-social-care/ and https://www.alliance-scotland.org.uk/blog/resources/independent-review-of-adult-social-care-in-scotland-engagement-report/.

5 Health and Social Care Alliance Scotland and Self Directed Support Scotland, *My Support My Choice – People's Experiences of Self-directed Support and Social Care in Scotland – National Report* (Oct 2020); *Women's Experiences of Self-directed Support and Social Care in Scotland – Thematic Report* (Dec 2020); *People with Mental Health Problems' Experiences of Self-directed Support and Social Care in Scotland – Thematic Report* (Dec 2020); *People with Learning Disabilities' Experiences of Self-directed Support and Social Care in Scotland – Thematic Report* (Dec 2020); *Blind and Partially Sighted Peoples' Experiences of Self-directed Support and Social Care in Scotland – Thematic Report* (Dec 2020); *Black and Minority Ethnic Peoples' Experiences of Self-directed Support and Social Care in Scotland – Thematic Report* (Dec 2020). These reports are available at: https://www.alliance-scotland.org.uk/blog/resources/my-support-my-choice-peoples-experiences-of-self-directed-support-and-social-care-in-scotland-reports/.

6 Scottish Government, *Self-directed Support: A National Strategy for Scotland* (2010). Available at: http://www.gov.scot/Resource/Doc/329971/0106962.pdf.

7 Health and Social Care Alliance Scotland and Self Directed Support Scotland, *My Support My Choice – People's Experiences of Self-directed Support and Social Care in Scotland – National Report* (Oct 2020). Available at: https://www.alliance-scotland.org.uk/blog/resources/my-support-my-choice-peoples-experiences-of-self-directed-support-and-social-care-in-scotland-reports/.

8 NRS Scotland, "South Lanarkshire Council Profile". Available at: https://www.nrscotland.gov.uk/files//statistics/council-area-data-sheets/south-lanarkshire-council-profile.html.

9 South Lanarkshire Council, "Social care and health". Available at: https://www.southlanarkshire.gov.uk/info/200146/social_care_and_health.

10 South Lanarkshire Council, "Information from other agencies". Available at: https://www.southlanarkshire.gov.uk/info/200221/children_and_families/985/self-directed_support/4.

11 South Lanarkshire HSCP, ***Strategic Commissioning Plan: 2019-22,*** p. 26. Available at: https://www.southlanarkshire.gov.uk/slhscp/download/downloads/id/194/sl_hscp_strategic_commissioning_plan_2019-2022.pdf.

12 *Ibid.*

13 South Lanarkshire Council, "Eligibility". Available at: https://www.southlanarkshire.gov.uk/info/200221/children_and_families/985/self-directed_support/3.

14 Public Health Scotland, Social Care Information Dashboard: https://scotland.shinyapps.io/nhs-social-care/.

15 While it is common practice to exclude response groups of less than five or ten for statistical and anonymity purposes, in this report we have not done so, while maintaining anonymity. To do otherwise would be to exclude some respondents, which would be problematic. Throughout this report, we indicate the number of respondents to each question to underline that recommendations are based on the experiences reported.

16 NRS Scotland, "South Lanarkshire Council Area Profile". Available at: https://www.nrscotland.gov.uk/files/statistics/council-area-data-sheets/south-lanarkshire-council-profile.html.

17 Public Health Scotland, Social Care Information Dashboard: https://scotland.shinyapps.io/nhs-social-care/.

18 Scotland's Census (2011), "Ethnicity, Identity, Language and Religion". Available at: https://www.scotlandscensus.gov.uk/.

19 Public Health Scotland, Social Care Information Dashboard: https://scotland.shinyapps.io/nhs-social-care/.

20 This was a multiple choice question and some respondents chose more than one option.

21 Scotland's Census (2011), "Ethnicity, identity, Language and Religion". Available at: https://www.scotlandscensus.gov.uk/.

22 Scottish Government, ***Poverty and income inequality in Scotland: 2015-2018*** (2018), p. 10. Available at: https://www.gov.scot/publications/poverty-income-inequalityscotland-2015-18/pages/10/.

23 *Ibid., p. 1.*

24 *Ibid., p. 12.*

25 Public Health Scotland, Social Care Information Dashboard: https://scotland.shinyapps.io/nhs-social-care/.

26 Information Services Division (now Public Health Scotland), ***Insights into Social Care in Scotland: Support provided or funded by health and social care partnerships in Scotland 2017/2018*** (11 June 2019). Available at: https://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/Publications/index.asp?#2399/.

27 Information Services Division (now Public Health Scotland), ***Insights into Social Care in Scotland: Support provided or funded by health and social care partnerships in Scotland 2017/2018*** (11 June 2019), pp. 6, 48-60. Available at: https://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/Publications/index.asp?#2399/.

28 Public Health Scotland, Social Care Information Dashboard: https://scotland.shinyapps.io/nhs-social-care/.

29 Care Inspectorate, ***Thematic review of self-directed support in Scotland South Lanarkshire local partnership report*** (June 2019), p. 24. Available at: https://www.careinspectorate.com/images/documents/5136/Self-directed%20support%20in%20South%20Lanarkshire%20June%202019.pdf.

30 In the national MSMC report, 42% of survey respondents agreed that a social work professional discussed "all four options" with them, while 20% reported that "some but not all" options were discussed, 21% stated that "none" of the options were outlined, and 17% were unsure.

31 In the national MSMC report, 84% of survey respondents agreed that they felt prepared for their needs assessment, while 9% were unsure and 7% disagreed.

32 Care Inspectorate, ***Thematic review of self-directed support in Scotland South Lanarkshire local partnership report***, p. 12. Available at: https://www.careinspectorate.com/images/documents/5136/Self-directed%20support%20in%20South%20Lanarkshire%20June%202019.pdf.

33 ***Ibid., p. 18.***

34 As a term that is still widely used, some MSMC respondents referred to "respite". We use "short breaks" in place of "respite" in this report, following discussion elsewhere by unpaid carers and carer organisations about the unhelpful definition of respite as "a short period of rest from something unpleasant". For example: www.collinsdictionary.com/dictionary/english/respite.

35 Care Inspectorate, ***Thematic review of self-directed support in Scotland: Transforming lives (2019).*** Available at: https://hub.careinspectorate.com/media/3676/thematic-review-of-self-directed-support-in-scotland-transforming-lives.pdf.

36 Care Inspectorate, ***Thematic review of self-directed support in Scotland: South Lanarkshire local partnership report,*** p. 18. Available at: https://www.careinspectorate.com/images/documents/5136/Self-directed%20support%20in%20South%20Lanarkshire%20June%202019.pdf.

Glossary

Budget / Hours / Package

The agreed support provision for an individual from the local authority or health and social care partnership.

Charging Policy

Local authorities decide on a charging policy for their services. Charging policy sits within a framework designed by COSLA that aims to maintain local accountability and discretion while encouraging local authorities to demonstrate that in arriving at charges, they have followed best practice.

COSLA

The Convention of Scottish Local Authorities (COSLA) represents local government in Scotland and the 32 local authorities. They work with councils to improve local services and processes.

Direct Payment

See “Option 1”.

Disability

The loss or limitation of opportunities to take part in society on an equal level with others due to social and environmental barriers. A disabled person is a person who experiences disability. Disability is the result of negative interactions that take place between a disabled person and her or his social environment.

Eligibility Criteria

Scotland’s National Eligibility Framework uses four ‘risk’ criteria to assess an individual’s requirement for SDS/ social care, categorised as critical, substantial, moderate, and low.

Guardian

An Attorney or Guardian Person can consent on behalf of someone if they lack decision making capacity. The local authority would have to conclude, in its assessment, that the person with assessed need has, after every attempt to support them, no capacity to decide to receive SDS.

Health and Social Care Partnership / HSCP

There are 31 health and social care partnerships in Scotland. They work towards a set of national health and wellbeing outcomes and are responsible for adult social care, adult primary health care and unscheduled adult hospital care. Some are also responsible for children’s services, homelessness and criminal justice social work.

Independent Advocacy Service/ Independent Advocate

Independent advocacy is a way to help people have a stronger voice and to have as much control as possible over their own lives. Independent advocacy organisations are separate from organisations that provide other types of services or support. An independent advocate will not make decisions on behalf of the person/group they are supporting. The independent advocate helps the person/group to get the information they need to make real choices about their circumstances and supports the person/group to put their choices across to others. An independent advocate may speak on behalf of people who are unable to do so for themselves.

Independent Living

Independent living means all disabled people and people living with long term conditions having the same freedom, dignity, choice and control as other citizens at home, at work and in the community. It does not mean living by yourself or fending for yourself. It means rights to practical assistance and support to participate in society and live an ordinary life.

Independent Living Fund / ILF

A Scottish Government fund available to certain people to enable them to live at home.

Independent Support Organisation

An organisation that provides independent, impartial information and support for people, for example on social care choices, e.g. a centre for independent living.

Integration Joint Board / IJB

Legislation in Scotland requires local authorities and NHS Boards to jointly plan and lead health and social care services. Two ways of doing this were provided – the ‘body corporate’ model (IJB) and the ‘lead agency’ model. 30 areas have adopted the IJB model (Clackmannanshire and Stirling formed a joint IJB, and Highland adopted the ‘lead agency’ model).

Impairment

An injury, illness, or congenital condition that causes or is likely to cause a loss or difference of physiological or psychological function.

Local Authority / LA

Local council (32 across Scotland).

Needs Assessment

Review of individual’s support provision or plan by local authority staff.

Option 1 (also called “direct payment”)

After a support plan is agreed the money to fund it is paid directly to the individual, into a bank account managed separately from any other accounts they have. They can manage the money themselves, or with assistance from others. A record must be kept of how the money is spent. People may choose to use their direct payment to employ their own staff, purchase services (from agencies or local authorities), and/or purchase equipment.

Option 2

If individuals do not wish to manage their support directly, then local authorities can arrange to pay for support. People will still choose what support they want and how it will be provided, but the local authority (or another nominated organisation) will manage it for them.

Option 3

People can ask for their support to be arranged for them by the local authority and provided either directly by local authority staff or by someone else on behalf of the local authority.

Option 4

A combination of the other options – for example, it allows people to let the local authority manage some parts of their support package, while giving the individual direct control of other elements of their support. The money to fund the parts of the support which individuals will manage will be paid into a bank account in the same way as described in the direct payments option.

Occupational Therapist / OT

Occupational therapists provide support to people whose health prevents them doing the activities that matter to them.

Personal Assistant / PA / Support Worker

Someone who is paid to provide people with social care and support. They can be employed directly by the person or they can be arranged through an agency.

Personalisation

SDS is often described as the personalisation of health and social care. Personalisation means that people are actively involved in shaping and selecting the services they receive. However, services can be personalised without people using SDS to get them.

Physical Impairment / Physical Disability

SDSS and the ALLIANCE endorse the use of the phrase “physical impairment” in preference to “physical disability”, in order to highlight that it is society that disables people with impairments, rather than that people possess intrinsic “disabilities” (this is the basis of the social model of disability). In this report, however, the more traditional terms, which are still in standard use by government agencies and more common in public discourse, are used. This choice was made for practical reasons, to maximise understanding of the survey language among the people surveyed and to allow comparisons to be made with other available data.

Reablement

A short-term social care rehabilitation service to assist people to become or remain independent in doing everyday tasks (typically after hospital discharge).

Self-directed Support / SDS

Self-directed Support is about how a support plan is put into action so that people receive the help they need to meet agreed personal outcomes. It means that people have choices in how their care and support is managed. By choosing one of four options people can choose how best to manage their support based on their individual needs.

Short Breaks

A pause from routine care arrangements (also referred to as “respite”). Could include holidays or short breaks for the person who receives support (with or without their PA/carers), and/or a pause from caring responsibilities for carers. May also include day activities.

Sleepovers

The provision of care and support services overnight.

Social Care

Social care includes all forms of personal and practical support for people who need extra support. It describes services and other types of help, including residential care homes, care at home, and community alarms/telecare systems, and systems designed to support unpaid carers in their caring role/s.

Support Plan

A support plan says how people will spend their budget to get the life they want, agreed between the individuals involved and the local authority.

Support Worker

See Personal Assistant / PA.

Unpaid Carer

Anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support.

About the Project Partners

ALLIANCE
HEALTH AND SOCIAL CARE
ALLIANCE SCOTLAND
people at the centre

About the ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for a range of health and social care organisations. We have a growing membership of over 3,000 national and local third sector organisations, associates in the statutory and private sectors, disabled people, people living with long term conditions and unpaid carers. Many NHS Boards, Health and Social Care Partnerships, Medical Practices, Third Sector Interfaces, Libraries and Access Panels are also members.

The ALLIANCE is a strategic partner of the Scottish Government and has close working relationships, several of which are underpinned by Memorandum of Understanding, with many national NHS Boards, academic institutions and key organisations spanning health, social care, housing and digital technology.

Our vision is for a Scotland where people of all ages who are disabled or living with long term conditions, and unpaid carers, have a strong voice and enjoy their right to live well, as equal and active citizens, free from discrimination, with support and services that put them at the centre.

The ALLIANCE has three core aims; we seek to:

- Ensure people are at the centre, that their voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.
- Support transformational change, towards approaches that work with indi-vidual and community assets, helping people to stay well, supporting human rights, self management, co-production and independent living.
- Champion and support the third sector as a vital strategic and delivery part-ner and foster better cross-sector understanding and partnership.

Self Directed Support Scotland
the organisation of choice

About Self Directed Support Scotland

Self Directed Support Scotland is a national partner organisation that supports the implementation of SDS across all of Scotland. We do this by having other organisations join us so that we can work together at both a local and national level, to influence the implementation of SDS. SDS Scotland has a wide range of members organisations covering every Local Authority area in Scotland. We are particularly keen to support the development of organisations run by and for disabled people. Our members support over 31,000 people across Scotland with their social care choices. Together we work to ensure that SDS is implemented successfully so that people have full choice and control over their lives. We do this by:

- Supporting our members in the delivery of their services to provide local independent information, advice and support to those at each stage of their social care journey.
- Signposting individuals at each stage of their social care journey to appropriate organisations that can support them.
- Representing our members nationally to discuss SDS implementation.
- Showcasing good practice from those involved with SDS.
- Providing health and social care professionals, other voluntary organisations and educational institutions with the resources they need to champion SDS.
- Conducting research which recognises the power of lived experience.
- Developing and delivering training on a range of key topics relevant to SDS.

The ALLIANCE

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Health and Social Care Alliance Scotland is a company registered by guarantee.

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