

A central graphic featuring a blue thought bubble containing the text 'My support my choice' in white. This bubble is surrounded by several other speech bubbles in various colors (orange, yellow, pink, purple) and sizes, all set against a solid orange background.

My
support
my
choice

My Support My Choice:

People with Learning Disabilities' Experiences of Self-directed Support and Social Care

Thematic Report, December 2020



Table of Contents

Acknowledgements and Dedication.....	4
About this Report.....	4
COVID-19.....	4
Executive Summary	5
Recommendations	8
Research Participants.....	12
Overall Experiences of SDS/ Social Care.....	18
Information About SDS	20
Informed Choice and Control	28
Communication and Relationships with Social Work.....	38
Impact of SDS on Family/Relationships	43
Care Staff Recruitment, Training and Quality	44
Independent Advocacy and Support.....	47
Endnotes	50
Glossary.....	52
About the Project Partners	56

List of Charts

Chart 1: Respondents' gender.....	13
Chart 2: Respondents' age.....	13
Chart 3: Client group/ disability/ long term condition in addition to “Learning Disabilities” (Survey).....	14
Chart 4: Survey respondents' religion	15
Chart 5: Survey respondents' sexual orientation.....	16
Chart 6: Survey respondents' housing arrangements.....	16
Chart 7: Survey respondents' annual household income.....	17
Chart 8: “SDS has improved my social care experience” (Survey).....	19
Chart 9: How did survey respondents first hear about SDS?.....	21
Chart 10: Information received before discussing support (Survey)	22
Chart 11: Discussing SDS options with professionals (Survey)	23
Chart 12: “The person I met explained things clearly to me” (Survey).....	24
Chart 13: “All my questions were answered” (Survey)	25
Chart 14: “Have you been told the amount of money you can spend on your support?” (Survey).....	27
Chart 15: Enough time to choose SDS option (Survey).....	28
Chart 16: “Waiting times, or waiting for responses, makes SDS more difficult for me” (Survey)	28
Chart 17: “I am fully involved in all decisions about my care and support” (Survey)	29
Chart 18: “I had a say in how my help, care or support was arranged” (Survey).....	30
Chart 19: Who chose support arrangements? (Survey)	30
Chart 20: Did you choose who manages your personal budget? (Survey).....	32
Chart 21: “Enough budget to meet my outcomes makes SDS easier for me” (Survey) ..	32
Chart 22: “Lack of flexibility in how I can use my personal budget makes SDS more difficult” (Survey).....	36
Chart 23: “How happy are you with the conversations you have had about your support with professionals?” (Survey)	38
Chart 24: “Lack of a regular PA makes SDS difficult for me” (Survey)	45
Chart 25: “Access to independent advocacy makes SDS easier for me” (Survey).....	47
Chart 26: “Access to independent information and support makes SDS easier for me” (Survey)	48

Acknowledgements and Dedication

This report is published with thanks to the people who shared their experiences and facilitated the research. 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] about people with learning disabilities^[2] who participated in “My Support, My Choice: User Experiences of Self-directed Support (SDS) 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.

This publication is part of a suite of MSMC reports. The national report sets out findings from all research participants and includes additional information about the overall project design and methodology, national context for SDS/ social care, and short reports about the experiences of older people and information about SDS, people with lived experience of homelessness, people living in rural areas, disabled parents, parent/ guardian carers, and LGBT+ people. Further thematic reports published separately explore the experiences of people with lived experience of mental health issues, Black and minority ethnic people,^[3] women as users of SDS/ social care, and blind and partially sighted people. A further suite of reports focus on people’s experiences in specific local authority areas; at the time of publishing this report, these had been interrupted by COVID-19.

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 their 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 in Scotland” (MSMC), a mixed-methods research project run by the Health and Social Care Alliance Scotland (the ALLIANCE) and Self Directed Support Scotland (SDSS), funded by the Scottish Government.

The aim of this research is to gain a better understanding of people’s experiences, 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 Self-directed Support (SDS)/ social care.

This document is part of a suite of MSMC reports and focuses on the experiences of people with learning disabilities who use SDS/ social care in Scotland. Between November 2018 and February 2020, MSMC heard about the experiences of 124 people with learning disabilities via a survey, interviews and focus groups. Research took place prior to the appearance COVID-19 in Scotland, and this report does not reflect people’s experiences during the pandemic.

Overall, people with learning disabilities reported that SDS had improved their social care experience, however there are some 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.

Poverty and SDS

An estimated 24% of Scottish households with a disabled person live in relative poverty after housing costs, and 63% of people with learning disabilities who provided income data for MSMC 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 with learning disabilities on low incomes who access or are trying to access social care, given that they can lead to people having to manage without support or share support, exclusion from community life, and unacceptable demands on family and friends to assume roles as unpaid carers.

Data Gathering and Analysis

There are concerning gaps in SDS data gathering and analysis – both generally and around the experiences of people with learning disabilities. Disaggregated data gathering 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

People with learning disabilities gave both positive and negative feedback when asked to summarise their experiences of SDS. However, they generally reported that SDS had improved their social care experience.

Information About SDS

People find out about SDS from a range of sources. Many report positive experiences, with a important minority highlighting difficulties in contacting social work departments, particularly when trying to obtain information about how to access SDS for the first time. They recommend 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. People with learning disabilities were less likely to feel that all their questions had been answered at their most recent meeting with social work professionals than was found in MSMC respondents as a whole.

Most people highlighted the value of face-to-face communication with social work and indicated they require more high-quality information at an earlier stage before deciding how their support would be arranged. Some had not been provided with accessible information or documentation, even after requesting such from social work departments.

Recommendations include ensuring that good access to high-quality information about SDS/ social care, in a range of accessible and tailored formats (e.g. Easy Read) is available at different points in a person's journey, e.g. finding out / first enquiry about SDS, pre-needs assessment, during needs assessment, after needs assessment, and once support is in place. People with learning disabilities 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.

Informed Choice and Control

Most people with learning disabilities were on their preferred SDS option and felt that they were fully involved in decisions about their care and support. Most people also stated that they had enough time to choose their SDS option and had been given details about their personal budget, as well as a choice over who manages it. People reported variable wait times for assessments and those who waited the longest generally report the highest levels of stress and difficulty in accessing SDS. Participants also called for greater clarity about expected wait times. People with learning disabilities were more likely to report that waiting times, or waiting for responses, made SDS more difficult for them than MSMC survey respondents more broadly. They were also less likely to have been able to choose their own support arrangements.

Recommendations include ensuring that social workers are trained in supported decision making to help reduce the number of cases of substitute decision making where they choose the SDS option and/ or who manages personal budgets instead of the service user. People with learning disabilities must be treated with dignity and respect in all interactions with health and social care professionals, and assessments and support must be adequate and tailored to their requirements and way of life, taking into account all clinical, dietary, religious, cultural, or any other considerations based on protected characteristics and other self-identities.

Communication and Relationships with Social Work

Participants highlighted that good, consistent, trusting relationships with social workers and clear lines of communication are all essential for

positive and effective experiences of SDS. Many interviewees reported positive and favourable experiences of assessments and reviews with professionals, while others outlined concerns around not receiving full answers to questions raised during assessments. Several people shared troubling stories of being treated with disrespect by social work or social care professionals.

People with learning disabilities require greater transparency about how decisions are made and by whom, alongside inclusive communication and easy access to information. People reported difficulty obtaining paperwork and documentation concerning their care arrangements, even after repeated requests to social work departments, and difficulty obtaining information about how to lodge formal complaints. Several people reported that health and social care professionals disregarded their preferences around social care arrangements, especially around housing.

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. Work to ensure positive conversations and meaningful, consistent relationships between social work professionals, service users, families and unpaid carers should continue, with ongoing planning to guarantee high quality practice for all people using SDS – especially around clear and accessible communication.

Impact of SDS on Family/ Relationships

People outlined a variety of ways that SDS has improved family life and relationships. However, they also

highlighted the importance of social workers not assuming that family members will provide unpaid care – or that the service user wishes to be reliant on family members and friends.

Social work professionals should ensure that all unpaid carers are offered carers' assessments and have their rights explained to them. 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.

Care Staff Recruitment, Training, and Quality

People report mixed experiences of support worker recruitment, training and quality, and several indicated difficulties finding and retaining personal assistants (PAs) and care workers that are suitable for their requirements as well as the positive impact of good support workers. Some people with learning disabilities indicated that they would welcome more support to arrange staff training and recruitment from the local authority or relevant support organisations. 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, which would help ensure a quality PA workforce.

Independent Advocacy and Support

People with learning disabilities value and benefit from the provision of independent advocacy, independent advice and peer support networks. These services need sustainable resources to continue their important role. Local authority staff should be given training about, and information from, local independent advice and support and independent advocacy organisations, so they can pro-actively refer people to these resources.

Recommendations

People with learning disabilities generally reported that SDS had improved their social care experience and shared examples of good practice from around Scotland. However, as this research highlights, there are key areas where improvements could be made to respond to people's concerns, build on existing good practice, and increase the effectiveness and reach of positive SDS experiences.

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 people with learning disabilities 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 SDS/ social care.

Information About SDS

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

4. A wider pool of professionals (health, education) should be educated about SDS and able to signpost people with learning disabilities to social work and appropriate resources. This includes professionals working in addiction, housing, and homelessness services.

5. More information should be available for people with learning disabilities 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.

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, their applicability for people with learning disabilities and how to support decision making.

9. People with learning disabilities should be informed about all four SDS options, rather than being given information about a more limited list of options.

10. People with learning disabilities should be supported to consider the advantages and disadvantages of each SDS option before making decisions.

11. Parent/guardian unpaid carers, who often need support with accessing and understanding information about SDS, should be encouraged to complete carers' assessments and support plans.
 12. Professionals should (be able to) spend more time reviewing case notes before meetings and reviews/assessments and getting to know the people they support.
 13. Professionals should proactively check back in with people after assessments to ensure any outstanding concerns are addressed.
 14. People with learning disabilities 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.
 15. People with learning disabilities should always have access to independent advocacy and support, including translators, for assessments and review meetings, if they desire.
 16. People with learning disabilities 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.
 17. Everyone must have access to information about the budget available to them and specific work may be required to ensure this extends to all population groups including people with learning disabilities.
 18. People with learning disabilities 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.
- ### Informed Choice and Control
19. People with learning disabilities should be given longer than a week to consider their SDS options.
 20. Systems could be improved to guarantee short waiting times – for a needs assessment, review, or for support to be put in place – to help people avoid unnecessary stress and anxiety, deteriorations in their physical and mental health and wellbeing, and from reaching crisis point and the potential for more serious and expensive intervention later on.
 21. People with learning disabilities have the right to expect a reasonable notice period for needs assessments or reviews.
 22. Professionals should be trained in supported decision making to help reduce the number of cases of substitute decision making where they choose the SDS option and/or who manages personal budgets instead of the service user.
 23. Targeted work is required to ensure people with learning disabilities are offered the four SDS options and that their support is person centred and rights based.

- 24.** Social workers should provide people with up to date lists of service providers in the local area, as well as contact details for other forms of support (e.g. housing assistance, occupational therapy). This list should be provided in accessible formats.
- 25.** People with learning disabilities must be treated with dignity and respect in all interactions with health and social care professionals and assessments and support must be adequate and tailored to people's requirements and way of life, taking into account all clinical, dietary, religious, cultural, or any other considerations based on protected characteristics and other self-identities.
- 26.** Health and social care staff should consider the possibility of mental health crisis if changing packages and eligibility criteria and be able to arrange reassessments and signpost support services where needed.
- 27.** No-one should feel or be pressured to share their support or move into residential care against their wishes – particularly not as a result of a desire to reduce funding for support via SDS. All resources should be maximised and options exhausted to provide person centre support and enable people to remain – with appropriate support – in their own homes for as long as possible if that is what they wish.
- 28.** People need flexible budgets and a focus on outcomes to enable them to live as independently as possible. Flexibility is required in a range of ways: from the flexibility to change SDS option, to being able to choose how and when to spend personal budgets,

with different amounts of spend and support at different times of year.

29. Flexible, regular access to respite should be strongly encouraged because it is an essential element of SDS that results in good personal outcomes for people who access social care, families and unpaid carers.

30. People with learning disabilities – particularly those living in rural areas – require more acknowledgement and accommodation of travel costs in their SDS budgets.

31. Many people could benefit from assistance from social workers and third sector organisations in navigating the bureaucratic processes to obtain mobility vehicles and travel passes.

32. Social work professionals should consider equality assessments in their processes – both for service users and their families.

Communication and Relationships with Social Work

33. Work to ensure positive conversations and meaningful, consistent relationships between social work professionals, service users, families and unpaid carers should continue, with ongoing planning to guarantee high quality practice for all people using SDS – especially around clear and accessible communication.

34. 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.

35. People with learning disabilities should be informed if their social worker changes and

have a right to request a new social worker if trust breaks down.

36. 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.

37. Appropriate training and ongoing support on equalities, human rights, intersectionality, conscious and unconscious bias and anger management should be provided to social work staff at regular intervals.

38. Professionals should pro-actively gather regular feedback – good and bad – from service users, families and unpaid carers as a way to support continuous improvement.

39. 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).

40. 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.

Impact of SDS on Family/ Relationships

41. Professionals should ensure that all unpaid carers are offered

carers' assessments and have their rights explained to them.

42. 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 supported to do so by social work professionals in a prompt manner, with appropriate future planning for contingencies.

43. Professionals should respect service users' preferences if they do not wish to be reliant on family members and friends for their care and support.

Care Staff, Recruitment, Training and Quality

44. Some people with learning disabilities need more help from local authorities to recruit and train care staff. Local authorities 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.

45. 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 in the local area.

46. Social care and social work professionals should be trained to support and acknowledge the concerns of people who have had traumatic or poor experiences with social care in the past. This is particularly important for the victims of crime.

Independent Advocacy and Support

47. Independent advocacy, independent advice and support services need sustainable resources to continue their important role.

48. Focused efforts are required to ensure people with learning disabilities are aware of – and can access – independent advocacy and support services.

49. Local authority and health and social care partnership staff should be given information and training on local independent advocacy, advice

and support organisations, so they can refer people to these resources.

50. Social work professionals should pro-actively provide people with information in accessible formats about independent support and independent advocacy organisations.

51. A free, independent and accessible national helpline and/or designated contact for any questions about SDS would be useful to people seeking/accessing support.

52. Local peer networks should be encouraged and supported.

Research Participants

The MSMC project heard about the SDS/ social care experiences of 124 people with learning disabilities. 98 people completed the survey, we interviewed ten people who spoke about their experiences and the experiences of other members of their household, and 16 people participated in focus groups. Throughout this report some participant details (e.g. age) have been changed slightly to preserve participant anonymity, while maintaining the most important information. Where changes have been made to interviewee quotations, those alterations are indicated via square brackets (e.g. “My advocate, [Name], has been great”).

According to figures published by the Scottish Commission for Learning Disabilities (SCLD), in 2019 an estimated 23,584 adults with learning disabilities were known to local authorities across Scotland (0.52% of all adults in the general population).^[4]

This figure does not include children and young people under 18 years old who have learning disabilities; but in 2011 the Scottish Census stated that there were 5,235 children with learning disabilities in Scotland (0.6% of all school-age children), according to local authority figures.^[5] Combining these figures and allowing for population growth, there are approximately 29,000 people with learning disabilities in Scotland (0.53% of the population).

Information Services Division (ISD) collects and analyses quantitative information about people using social care services in Scotland and where possible we have compared our participant data to ISD statistics.^[6]

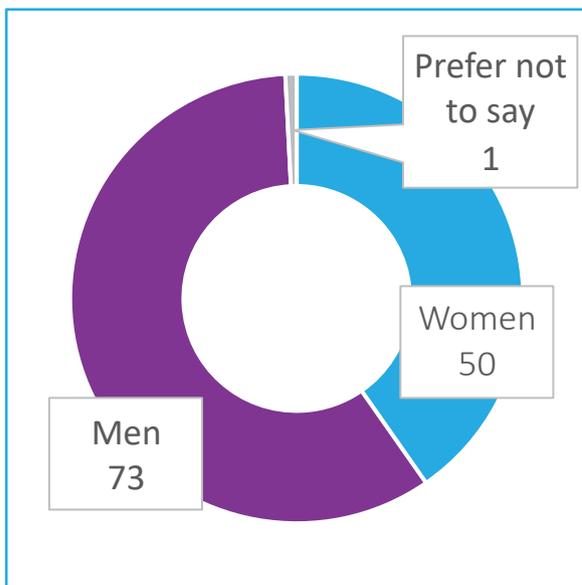
ISD estimate that 9,184 people with learning disabilities accessed SDS in 2017/2018. These figures indicate that approximately 10% of people in Scotland accessing SDS in 2018 were doing so based – at least in part – on

learning disabilities. ISD also record that there were 14,353 people with learning disabilities receiving broader social care services and support in Scotland (including the 9,184 people with learning disabilities accessing SDS). As such, an estimated 64% of the total number of people with learning disabilities accessing social care services in Scotland in 2017/2018 were using SDS.

Gender

Overall, 50 women and 73 men with learning disabilities participated in MSMC. One person preferred not to disclose their gender.

Chart 1: Respondents' gender



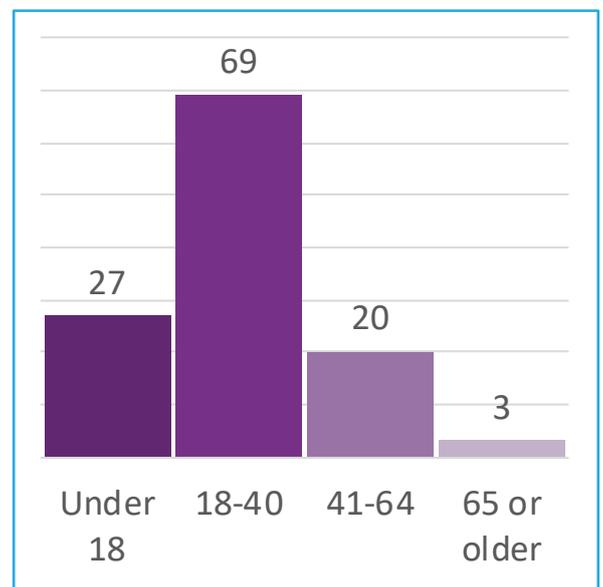
ISD figures are not available for women and men accessing SDS in 2017-18, however they do publish statistics on the number of women and men accessing social care support services more generally – of whom an estimated 45% access SDS – although not every local authority submitted gender disaggregated data. ISD report that in 2017-2018 62% of people accessing social care support were women and 38% were men.^[7] Gender disaggregated data of people with

learning disabilities who access SDS is not available on the ISD dashboard.

Age

We asked all participants to share their age. Of the participants who chose to answer the question, 27 people (22%) were under 18 years old, 69 (56%) were between 18 and 40 years old, 20 (16%) were between 41 and 64 years old, and three (5%) were 65 or older. Five people did not wish to share their age.

Chart 2: Respondents' age



ISD's SDS 'Client Group Profile Data' indicates that in 2017-18, 244 people aged 17 and under accessed SDS for support with learning disabilities, 7,875 people aged 18-64 years, 771 aged 65-74 years, 248 aged 75-84 years, and 45 aged 85 and older.^[8]

Ethnicity

96 people with learning disabilities who completed the survey described themselves as white, one person selected another group, and one person chose not to describe their ethnicity. Most interviewees and focus group participants did not disclose their ethnicity when self-describing themselves, and the majority of those

that did described themselves as “white”. The spread of respondents is less ethnically diverse than is typical for the overall population in Scotland.

The 2011 Scottish Census indicated that 92% of the population of Scotland identified as “White: Scottish” (84%) or “White: Other British” (8%), with a further 3.3% selecting “White: Irish”, “White: Polish”, “White: Gypsy/ Traveller” or “White: Other white”. The remaining 4.7% of the population identified as being part of minority ethnic groups: 3% of the population identified as “Asian”, “Scottish Asian”, or “British Asian”; 1% as “African, Caribbean, or Black”, 0.4% as “mixed or multiple ethnic groups”, and 0.3% as belonging to “other ethnic groups”.^[9]

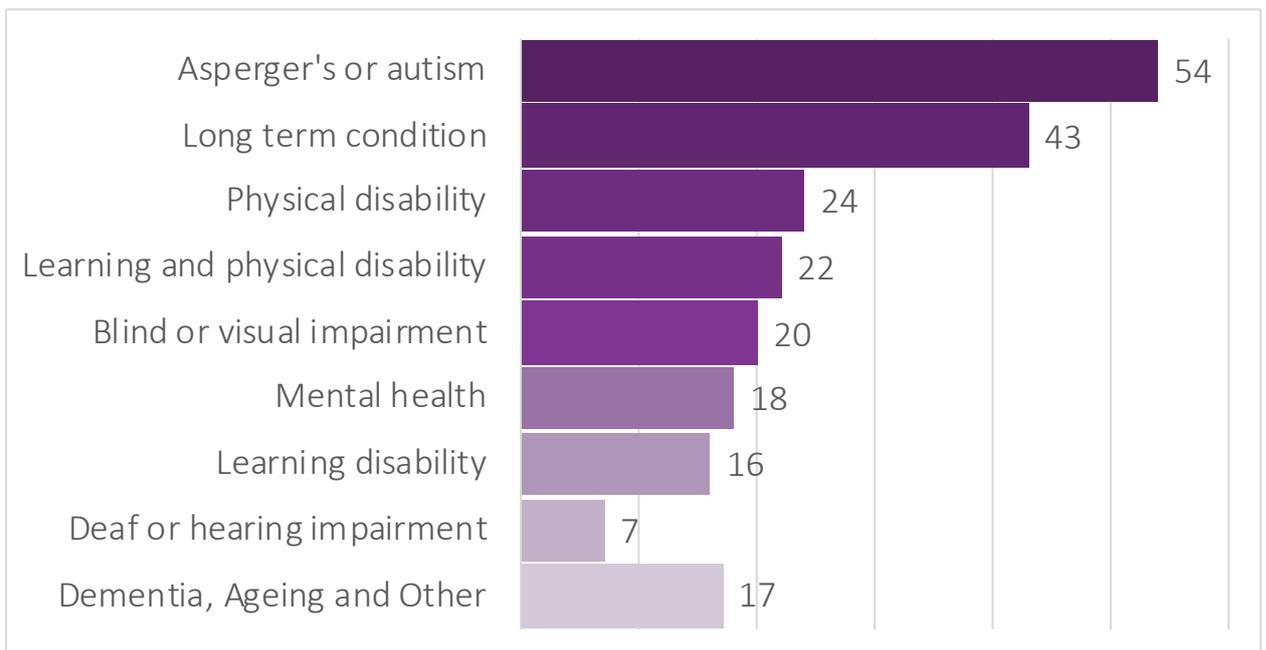
ISD do not provide a disaggregated breakdown of the ethnicity of people accessing SDS in 2017-18. They have some disaggregated data on the ethnicity of people receiving social care support services more generally (of whom an estimated 45% access SDS), using the limited categories of “White”, “Other”, and “Not provided/

Not known”.^[10] Not all local authorities submitted data on ethnicity to ISD. Of those local authorities that did submit information, ISD report that in 2017-2018, 71% of people accessing social care support were “White”, 28% were listed as ethnicity “not provided/not known”, and 1% categorised as “Other” (including “Caribbean or Black, African, Asian and Other Ethnic Groups”).^[11]

Client Group/ Disability/ Long Term Condition

MSMC survey respondents who self-identified as having learning disabilities live with a range of conditions, with the majority reporting that they live with multiple conditions. In addition to self-identifying as having learning disabilities, 54 people (55%) selected “Asperger’s Syndrome or autism”, 43 people (43%) reported that they live with a long term condition, and 24 people (24%) described themselves as physically disabled. Only 16 people selected “learning disability” and no other disability or long term condition.

Chart 3: Client group/ disability/ long term condition in addition to “Learning Disabilities” (Survey)



Interviewees and focus group participants also discussed their conditions, and – if they were unpaid carers – those of the people for whom they care. Of the 26 people with learning disabilities whose experiences of SDS we heard about during interviews and focus groups, the majority accessed SDS in part because of their learning disabilities but also due to additional conditions.

ISD list the following client groups for people accessing SDS in 2017-2018: frail/elderly, physical and sensory disability, learning disability, dementia, mental health, other, and not recorded.^[12] These broad categories do not directly align with those tracked in MSMC, and not all local authorities submitted data to ISD. As with MSMC, people could feature in more than one client group simultaneously. Overall, ISD estimate that 47% of people accessing SDS did so because they were “elderly/frail”, 35% due to a physical or sensory disability, 10%

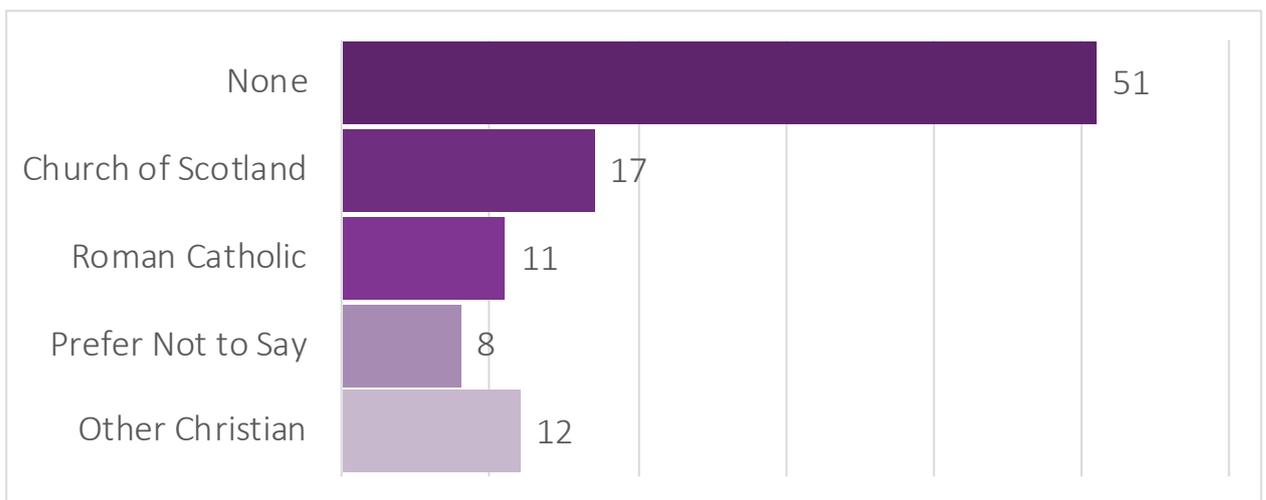
because of a learning disability, 8% due to dementia, 7% as a result of their mental health, and 17% for “other” reasons. A further 8% did not have their reason for accessing SDS recorded by the local authority (not including those that did not submit data).

Religion

When asked about their religion (if any), 51 (52%) people with learning disabilities stated “none”, 17 (17%) identified as belonging to the Church of Scotland, 11 (11%) identified as Roman Catholic, 12 (12%) described themselves as “other Christian”, and eight (8%) preferred not to answer. Only one of the interview / focus group participants with learning disabilities explicitly disclosed their religion when self-describing themselves. These results are less diverse than 2011 Scottish Census data for Scotland.

Data on people’s religion for 2017-18 is not available on the ISD dashboard.

Chart 4: Survey respondents’ religion



Sexual Orientation

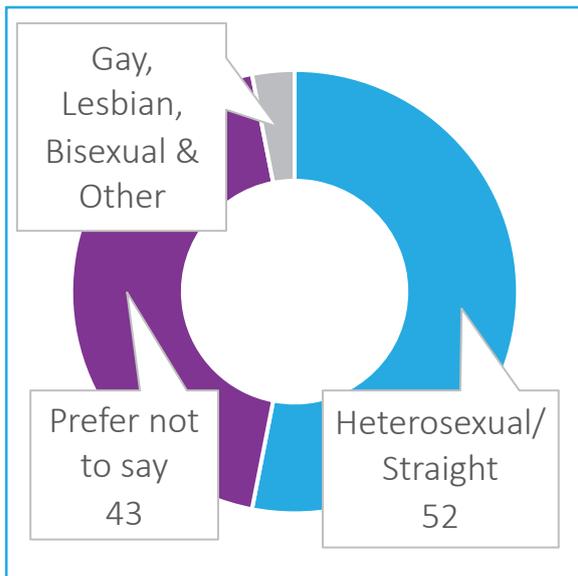
In the survey, 52 people with learning disabilities (53%) described their sexual orientation as heterosexual or straight, two people (2%) identified as gay or lesbian, and one selected

“other” (1%). 43 people preferred not to answer the question (44%). One interviewee stated that they are gay. None of the other interviewees or focus group participants explicitly disclosed their sexuality when self-describing themselves. The 2011

Scottish Census did not record data on sexual orientation at local authority level (although the 2021 Scottish Census will do so); as such, we do not have local statistics on sexual orientation available as a comparison.

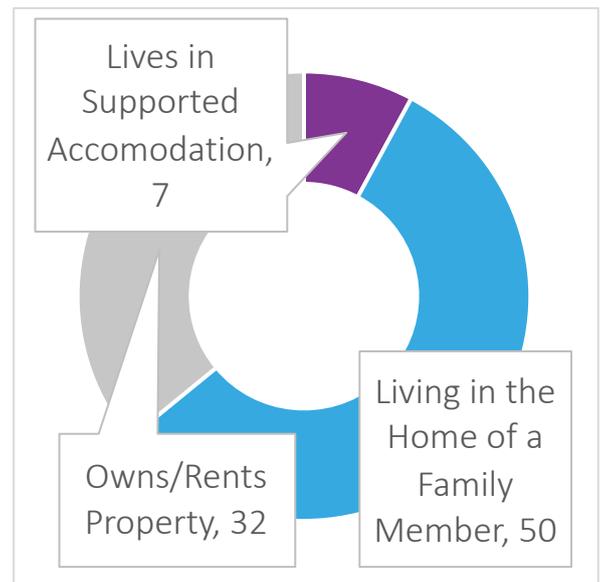
Data on people’s sexual orientation for 2017-18 is not available on the ISD dashboard.

Chart 5: Survey respondents’ sexual orientation



When discussing housing, several interviewees and focus group participants spoke about their current situations. Of those who discussed their housing arrangements, four people live independently in their own homes, and the remainder were evenly split between those who live with a family member and those who live in supported accommodation.

Chart 6: Survey respondents’ housing arrangements



Housing

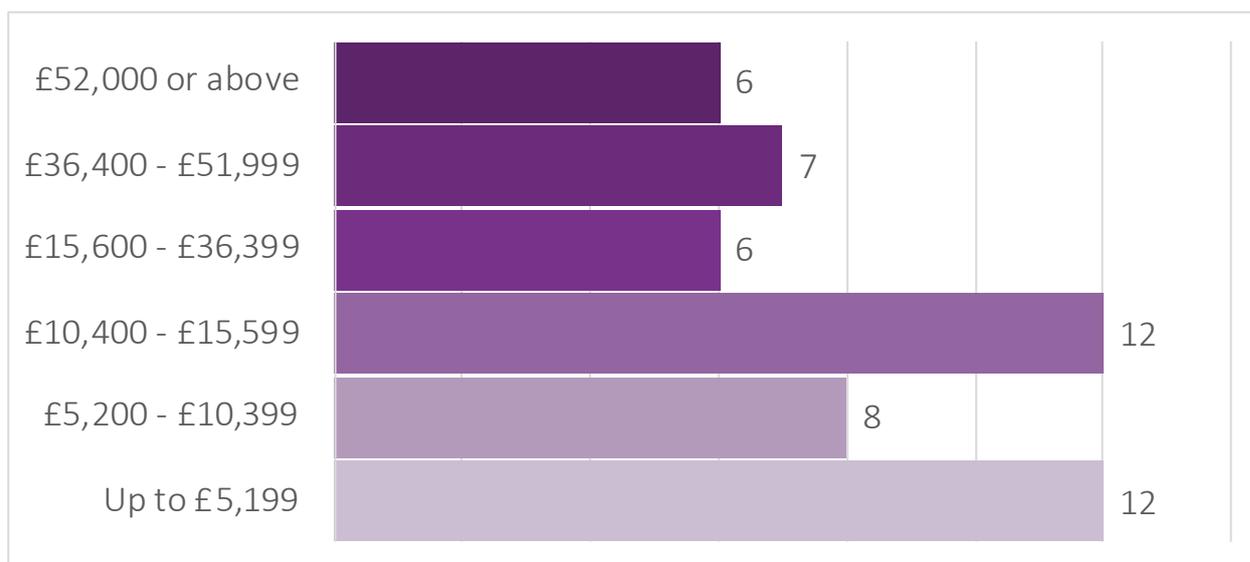
Among the people with learning disabilities who answered this question, 32 people either rent or own their own home, 50 people stated that they live in the home of a family member (including 36 people who lived with their parents), and seven lived in supported accommodation.

When adjusted to allow for respondents who are under 18 years old, these results are broadly in keeping with data from SCLD that 62% of adults with learning disabilities who are known to local authorities live in mainstream accommodation (including in the home of a family carer), 15% live in supported accommodation, 8% in a registered adult care home, and 4% in “other” accommodation.^[13]

Household Income

We asked survey respondents about their household income. We are interested in this information because within 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.^[14]

Chart 7: Survey respondents' annual household income



None of the interviewees or focus group participants 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.

According to Scottish Government data, the median household income in Scotland in 2015-2018, before housing costs, was £499 per week (£25,948 per annum).^[15] 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).^[16]

Based on this definition, 32 (63%) of respondents with learning disabilities who provided information about their household income are living below the poverty threshold.

Poverty and SDS: Reductions in SDS budgets and tightened eligibility criteria can pose serious risks to people with learning disabilities on low incomes who access or are trying to access social care. It can result in having to manage without support or share support, impact negatively on mental and physical health, lead to exclusion from community life, and place unacceptable demands on family and friends to assume roles as unpaid carers.

SDS Option

Of the MSMC survey participants with learning disabilities who shared which SDS option they used, 46 people (58%) indicated they use Option 1, five people (6%) use Option 2, 13 people (16%) use Option 3, and 11 people (14%) use Option 4. Four people stated that they did not know which SDS option they use.

Figures from ISD indicate that in 2017-2018 there were 8,390 people in Scotland using SDS Option 1, 7,435 people using Option 2, 78,054 people using Option 3, and 4,257 people using Option 4.^[17] In some instances, people were incorrectly logged as

being on two options simultaneously (e.g. Options 1 and 3) rather than Option 4, which skewed these figures. ISD do not publish data about which SDS options people with learning disabilities use across Scotland.

Data on the SDS options chosen by people with learning disabilities in 2017-18 is not available on the ISD dashboard.

Data Gathering and Analysis

As this chapter demonstrates, there are concerning gaps in SDS data gathering and analysis. Information Services Division (ISD) 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*.^[18] 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.^[19] Data gaps are also in part due to existing patterns

of data collation – leading, for example, to the ISD Social Care Information Dashboard tracking ethnicity via the limited and problematic categories of “White”, “Other”, and “Not provided/Not known”.^[20]

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, including people with learning disabilities, that follow 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 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 people with learning disabilities who answered this question, 57 (72%) stated that they “strongly agree” or “agree” with the statement “SDS would/has improve/d my social care experience”. 14 people (18%) disagreed with this statement. Eight

people (10%) indicated that they were unsure. Survey participants were also asked to share an overall summary of their experiences and any advice they might have for people considering SDS. Most people's statements were positive, such as:

“Do it!”

“It gives you greater options and choices.”

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

“It was the best option by miles for our circumstances.”

“It allows you to be flexible and in control of your own support.”

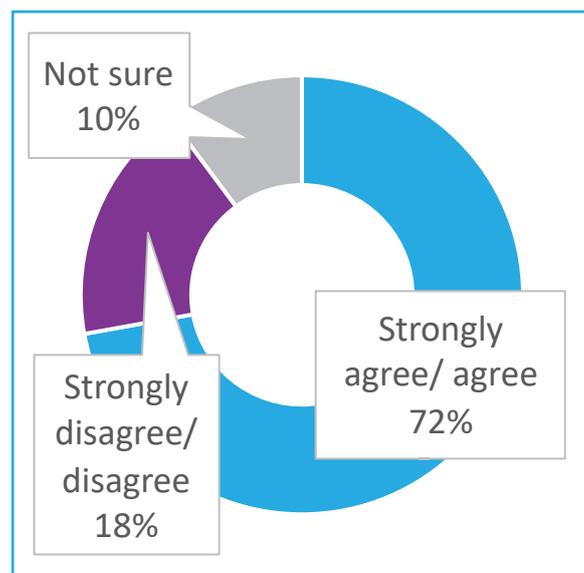
“It’s the way to go, because there is the option of having someone else to manage the budget. They are really helpful and know what they are doing.”

“Keep your eyes on the outcome that you are hoping to achieve. The assessment is time consuming and a bit overwhelming but tell the social worker everything relevant. Check the draft assessment and make sure that it is accurate. For us, Self-directed Support is the perfect solution.”

“When an accurate budget is put in places and the right services purchased SDS is a godsend that really works. My autistic son who also has learning disabilities is working with trained autism practitioners who are working on social skills and independent living skills to prepare him for when his parents are no longer around. This is done in a fun way that encourages the best from him.”

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

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



However, some people were more cautious or explicitly negative about SDS, particularly relating to difficulties with paperwork and assessment processes, and insufficient budgets:

“It’s like getting blood out of a stone.”

“Be prepared for a nightmare of paperwork.”

“We didn’t have any choice in the matter, as we were told it was happening and that was that. Try to make sure you are given as much information about choices as possible and sufficient to make your decision.”

“Don’t! Awful system, the stress I’ve had for over four years and to this day still don’t have a proper plan in place or enough of a budget or care package in place.”

“Don’t hold your breath. Process takes ages, too many long forms with stupid questions. Wait ages for SW [social worker]. Then pushed into PA option as its cheaper for local authority. That’s if you can meet criteria.”

“Very challenging, takes up a lot of time and isn’t the solution that it’s portrayed as. Very restrictive in terms of what SDS can and can’t be used for.”

“Don’t get beaten down by the ‘professionals’, and don’t accept that things can’t be done. They can, even if the council say no. (Our council like

to say a big fat ‘no’ to anything they didn’t think of first.)”

“Be focused on outcomes you want to achieve. Stand your ground on these outcomes as you know what’s best for your mental and physical wellbeing.”

“Be very sure of which option you want and stick to your guns if you feel that you are under pressure to change options.”

Information About SDS

Finding Out About SDS

We asked people how they first found out about SDS.

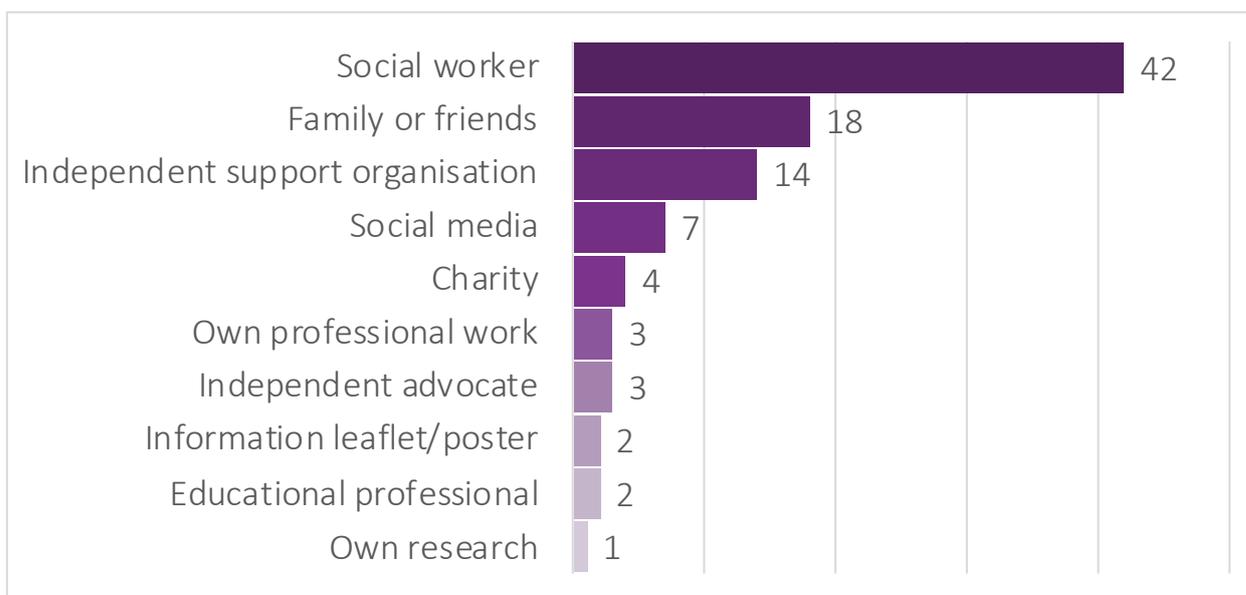
Of the people with learning disabilities who answered this question, 42 (43%) first heard about SDS from a social work professional or occupational therapist. 18 respondents (19%) heard from friends or family members, 14 from an independent support organisation, seven from social media, four from a charity, three from an independent advocate, two from an information leaflet or poster, two from an educational professional, one from the internet, and one from a community brokerage. Three people first heard about SDS through their own professional work (respectively, in education, care, and the NHS). Unlike other groups who participated in the MSMC research project, none of the survey participants with learning disabilities first heard about SDS through a medical or healthcare professional.

Among the interviewees and focus group participants, the most

common method through which people with learning disabilities first heard about SDS was from a social worker. This was followed by people hearing from friends or family, an independent support organisation, or a health professional.

Several interviewees and focus group participants stated that they didn’t understand or had “never heard of” SDS – even though they were receiving social care support, in ways that sounded identical to SDS. For example, one person discussed how their support was arranged on a day to day basis in some detail, but also stated that “I don’t actually know if I get Self-directed Support.” For some people with learning disabilities, this confusion was directly linked to conversations with social work where they were “told” how they support would be arranged – but did not have SDS explained to them in a way they could understand.

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



Finding Out About SDS: The research indicates that work is needed to better inform people with learning disabilities about SDS. It would be helpful to widen the pool of professionals who are informed about SDS and can encourage people with learning disabilities to access it. Making more use of health and education professionals would be particularly valuable, as well as building on the existing expertise of social workers, independent advice and support organisations. Greater use of health professionals in the process would also help to strengthen the integration of health and social care.

Information and Preparedness Before Assessments

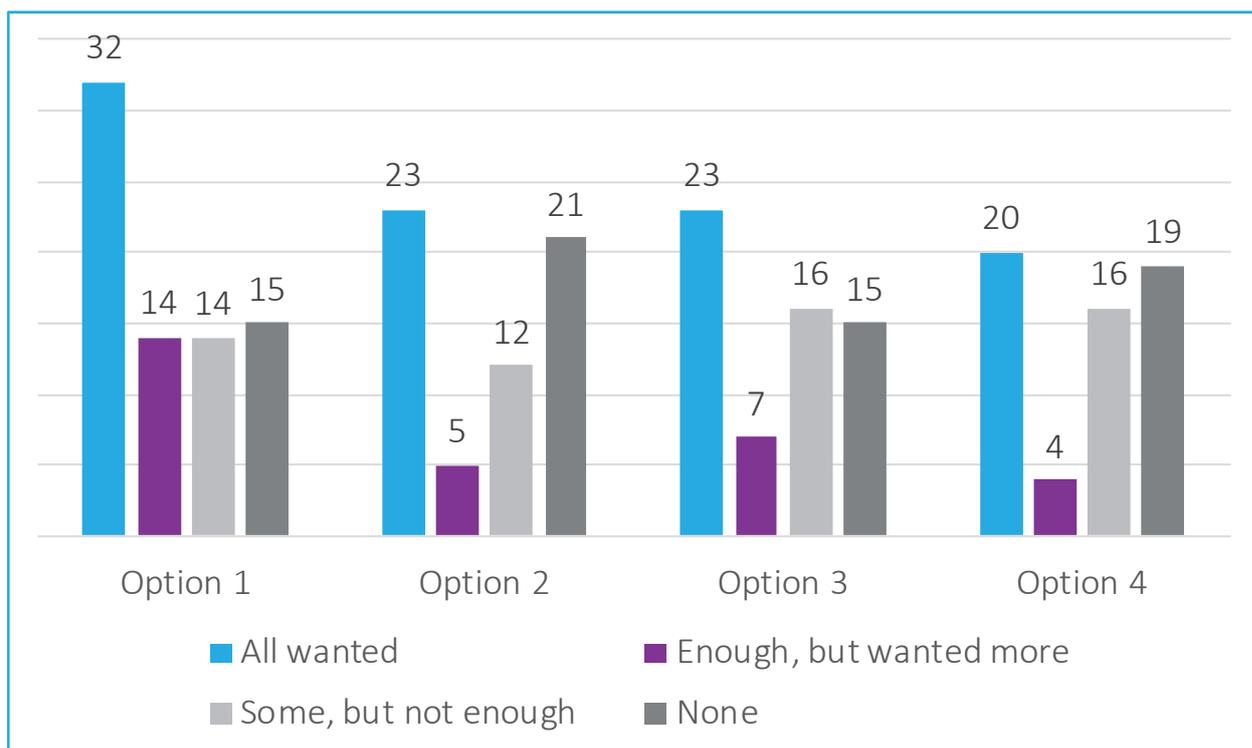
We asked survey respondents how much information they received on each of the SDS options before meeting with a professional to discuss their support, and whether it was enough information for their needs.

Of the people with learning disabilities who answered this question, across

all four options, a minority of people received “all the information [they] wanted” (43% (Option 1), 38% (Option 2), 38% (Option 3) and 34% (Option 4)). It is concerning that the majority of people across all options either had no information or were left wanting more in advance of their needs assessment.

Of the people who answered this question who felt they needed more information before meeting with a professional to discuss their support, 39% stated that they either received “some, but not enough” or no information at all about Option 1, while a further 19% of respondents said they had received “enough” information “but wanted more”. With Option 2, 54% of respondents reported that they had either “some, but not enough” or no information, with 8% receiving “enough, but wanted more”. For Option 3, 51% of respondents said that they had either “some, but not enough” or no information, and 11% of had “enough, but wanted more”. Finally, 59% of respondents said they had received either “some, but not enough” or no information about Option 4, while 7% received “enough, but wanted more” (the lowest satisfaction rate across the options).

Chart 10: Information received before discussing support (Survey)



Some interviewees and focus group participants felt fully informed about the options prior to their assessments, but many had not been told about all four options when they started the process of accessing SDS, which made it harder to make informed decisions. Those that felt well prepared for their initial assessment usually credited an independent support and advice organisation for providing them with appropriate information (several were mentioned by different participants).

Several people with learning disabilities reported that they struggled to access large print or Braille versions of documents and information leaflets – even when social work professionals knew that they required documents in accessible formats. One respondent suggested that an information and support line would be useful in preparing people to access SDS:

“There should be a phone number [...]. If people knew, if anybody did know about it [could] phone and find out if they would be entitled to [...] and they could sort of ask questions and give people a guide. ‘You should

apply for it’, ‘you should be entitled to it’, or ‘you should apply and you might get it’ – if they questioned them over the phone, if they knew what they were talking about with the person at the other end.”

Information and Preparedness Before Assessments:

The findings indicate that people with learning disabilities require better advance information and support to feel prepared for their needs assessments. Comprehensive, high-quality information in a wide range of accessible formats should be pro-actively provided to people about the four SDS options, carers’ assessments and support plans. Overall satisfaction with advance information about all SDS options could be improved, particularly Options 2 and 4. The benefits of earlier high-quality information include: early intervention before people reach crisis point, and reduced demands on staff time because people are better prepared for discussion and assessments.

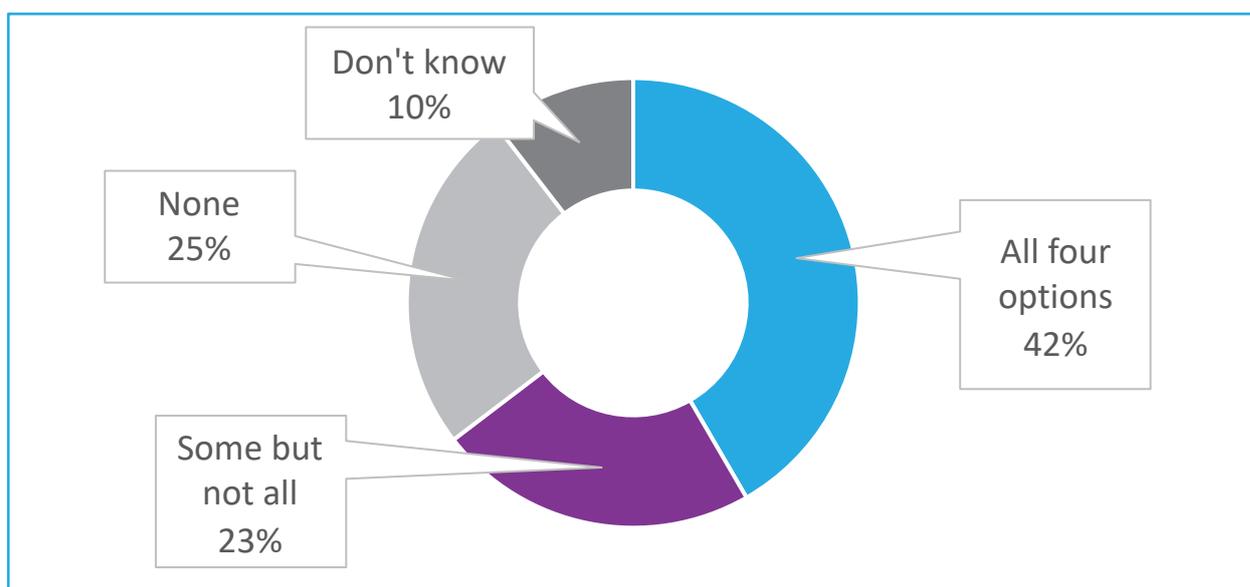
Information During Assessments

This pattern of variable information 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 (e.g. a social worker/social work assistant or an occupational therapist).

Of the 96 people with learning disabilities who answered this question, 40 (42%) stated that the professional discussed "all four

options" with them. However, 22 (23%) also reported that "some but not all" options were discussed with them, and 24 (25%) stated that "none" of the options were discussed. A further 10 respondents (10%) stated that they were "unsure" which options were discussed with them during that meeting. These findings indicate that more work needs to be done to fully outline and discuss the four SDS options with people with learning disabilities during their needs assessments and reviews.

Chart 11: Discussing SDS options with professionals (Survey)



Some interviewees and focus group participants reflected on positive experiences during their needs assessments. One participant related that their local authority SDS team has recently changed the way it arranges SDS, and service users are all being reviewed again. They recounted that this was a positive experience for them:

"I have to say it has been really, really good, it's been proper reviews for the first time in a long time and people are getting a proper review."

However, the majority of people with learning disabilities recounted more mixed experiences with their needs assessments or review. Several reported that they felt that the conversations they had with social work professionals during their needs assessments were rushed, and many people stated that social workers did not explain the process around SDS properly to them in a way they could understand.

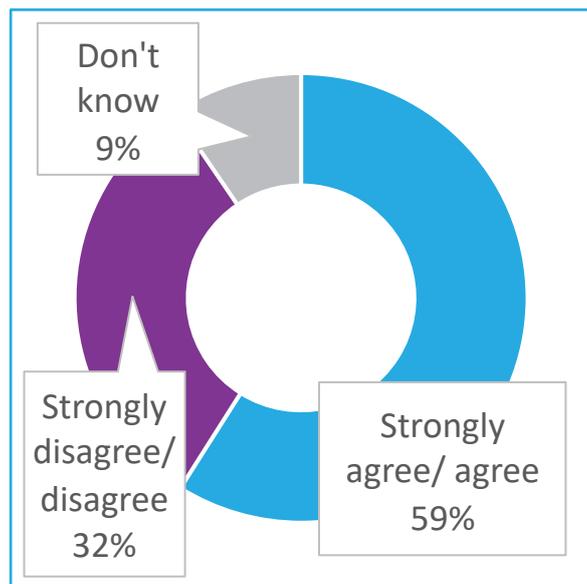
One person outlined that they did not feel that social workers in their area were equipped with enough information about the

different SDS options – and so struggled to share information with service users. They summarised their perspective as follows:

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

We asked survey respondents whether they agreed with the statement “The person I met with explained things clearly to me”. Of the people with learning disabilities who answered this question, 56 (59%) either “strongly agreed” or “agreed” with the statement, 30 (32%) disagreed or strongly disagreed, and nine people were unsure.

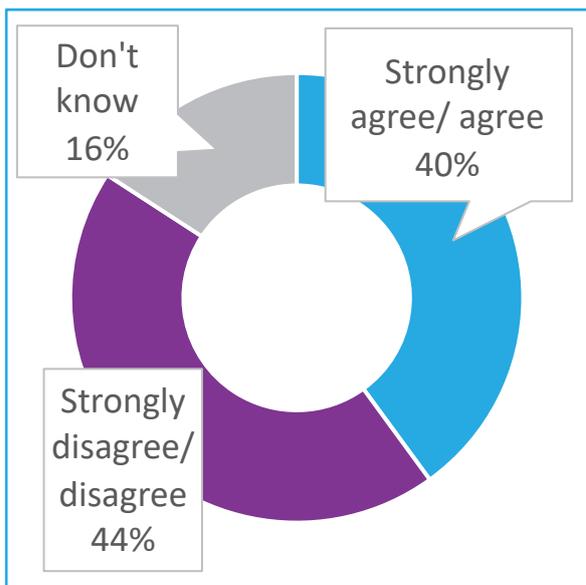
Chart 12: “The person I met explained things clearly to me” (Survey)



In the survey, we also asked respondents whether they had any questions during their needs assessments or review with a social work professional, and to respond to the statement “All my questions were answered”.

Of the 96 people with learning disabilities who answered this question, 38 (40%) “strongly agreed” or “agreed”, while 42 (44%) “strongly disagreed” or “disagreed”. A further 15 people (16%) said that they did not know. Compared to all MSMC survey respondents overall, people with learning disabilities were less likely to feel that all their questions had been answered. Interviewees and focus group participants with learning disabilities indicated similar experiences.

Chart 13: “All my questions were answered” (Survey)



From the survey responses, around half of people felt that social work professionals provided good information and answered all their questions – even if a proportion of people also wanted more information. These findings indicate constructive interactions between people who need social care support and social work professionals. The large minority who disagreed with these statements invites further work to improve services to ensure consistently good experiences in this area.

Information During Assessments: Social workers and other professionals play an important role in informing, influencing and implementing decisions about social care, and they are often many people’s first port of call for information about SDS, including eligibility criteria, waiting times and available support. The research indicates that further work is needed to ensure that people with learning disabilities are fully informed about the four SDS options during assessments, given the opportunity to consider them, and to make sure their questions are answered. For some people, information is best provided face-to-face, more than one conversation may be needed, and people should have access to independent advocacy and support during these meetings if they want. People should have access to information in a range of accessible and inclusive communication formats in advance of and during meetings. Options for assisting this work could include further training for professionals in supported decision making and the SDS options, and ensuring more time is allocated to assessments/review meetings.

Outstanding Concerns and Appeals

We asked survey respondents whether they have any concerns that were not addressed during their last assessment. Of the 97 respondents with learning disabilities who answered this question, 41 (42%) had outstanding issues that were not addressed by social work, 39 (40%) had no concerns, and 17 (18%) were unsure.

Of those respondents with unaddressed concerns, budgets, delays in implementing care, and

a lack of information about SDS were the main issues – with people highlighting that these issues had direct and negative impacts upon their health and the health of the people for whom they care.

Survey respondents with learning disabilities offered some comments on their outstanding concerns:

“[I had] concerns about how I would retain my specialist care given my budget has been cut.”

“[I] didn’t feel I got enough time to think about what options really met our needs. Does feel rushed decision to get it to panel. Also, very little options available.”

“I was not given enough information about how much of a budget I would receive, which made it difficult to know if my needs were going to be met.”

“Exactly what constitutes permitted expenditure; how calculations are made to determine amount; what factors are used in calculations.”

“Many questions unanswered. No written information provided – not even of the agreement. Discouraged re: flexibility. Repeatedly told it’s only to be used to employ carers.”

“Whether I would receive money, how long the process took.”

Some interviewees and focus group participants also highlighted key outstanding concerns about their support, specifically around transparency of process, accessible information, budgets, and waiting times.

We asked survey participants whether they were in the process of appealing the decision made in their last review or needs assessment. Of the 361 MSMC survey respondents who answered the question, 25 people (7%) indicated that they are in the process of appealing the outcome of their last social care assessment or review, including seven people with learning disabilities.

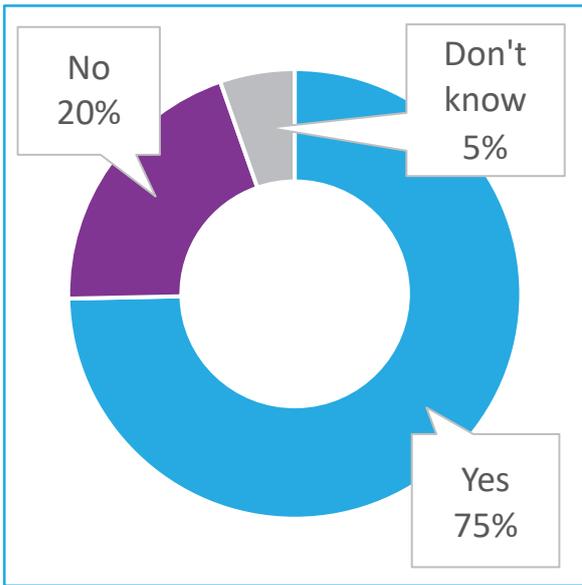
Outstanding Concerns and Appeals:

The research invites further work to strengthen and embed existing good practice to ensure that people with learning disabilities are not left with unaddressed concerns following needs assessments. People should be provided with alternative, accessible communication routes – like online chat functions, a freephone support line, and providing direct email addresses – that would allow them to follow up and have questions answered at a later date if it is not possible during meetings. Social work professionals should proactively check in with people after assessments to address any outstanding concerns.

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 75 people with learning disabilities who answered the question, 56 (75%) said they had been told how much money they could spend, 15 (20%) said they had not been told how much money was available to them, and four people (5%) stated that they did not know if they had been given a budget. That most people had received information about how much money was available to them is a positive finding. However, it is concerning that a quarter of people had either not received that information or were unsure.

Chart 14: “Have you been told the amount of money you can spend on your support?” (Survey)



Overall, people were clear that they required consistent and accurate information about the budgets in order to effectively plan support, and to make decisions about their care.

Information About Budgets:

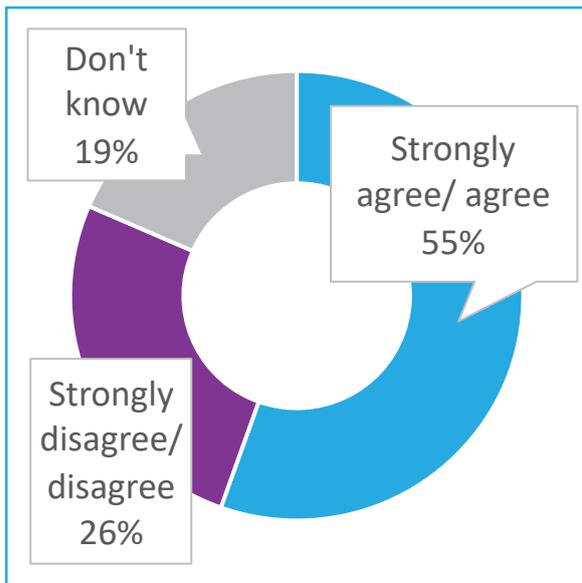
In order to support and enable people to make informed decisions about their care, everyone must be provided with accessible information about the budget available to them. People may want to take part in several conversations to support informed decision making about care charges, budgets and how they interact with other income like social security. Measures should be in place to ensure that all population groups, including people with learning disabilities, are given full information about their personal budgets.

Informed Choice and Control

Time to Consider Options

We asked survey respondents whether they agreed with the statement “I had enough time to choose the option of SDS that suited my needs.” Of the 94 respondents with learning disabilities who answered this question, 51 (55%) either “agreed” or “strongly agreed”, 24 (26%) either “disagreed” or “strongly disagreed”. 17 people stated that they did not know.

Chart 15: Enough time to choose SDS option (Survey)



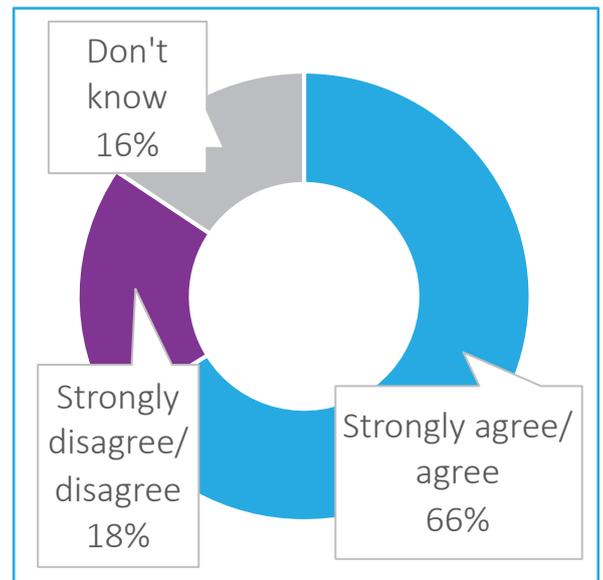
Time to Consider Options: The research suggests that there is a correlation between the time people with learning disabilities are given and the need for clear, prompt and accessible information so that they are able to make informed and appropriate decisions about their support.

Waiting Times

We asked survey respondents to agree or disagree with the statement, “Waiting times, or waiting for responses, makes Self-directed Support more difficult for me.”

Of the 77 people with learning disabilities who answered, 51 (66%) either “strongly agreed” or “agreed” with that statement, 14 (18%) “disagreed” or “strongly disagreed” and 12 (16%) stated that they were unsure. Compared to all MSMC survey respondents overall, people with learning disabilities were more likely to report that waiting times, or waiting for responses, made SDS more difficult for them.

Chart 16: “Waiting times, or waiting for responses, makes SDS more difficult for me” (Survey)



Interviewees and focus group participants with learning disabilities also appreciated short waiting times for a response or decision from social work. Many interviewees and focus group participants had

waited longer than six months for a needs assessment or review, following a request for support, and many had waited over a year.

Waiting Times: Short waiting times are greatly appreciated because when people with learning disabilities 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 also 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 serious and expensive intervention later on.

Choice Over SDS Options and Support

We asked survey respondents if they were on their preferred SDS option. Of the 78 people with learning disabilities who answered, 69 (88%) were on their preferred option, with the remaining respondents either unsure (six people) or not on their preferred option (three people).

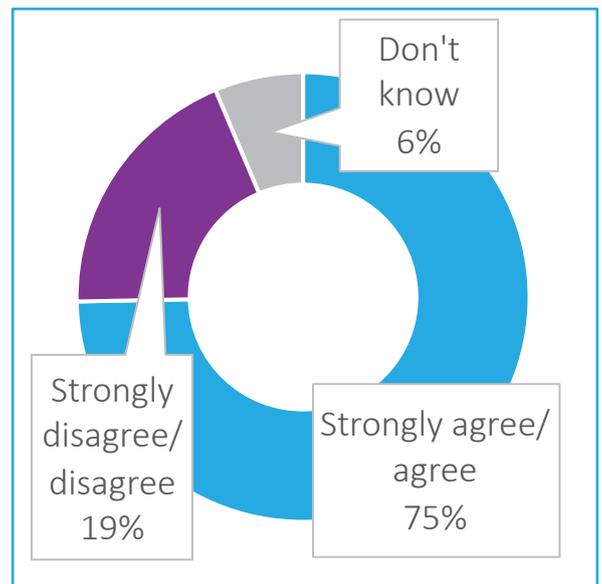
The people who were on their preferred option described how support arrangements enable them to do a diverse range of activities. These include (but are not restricted to): personal care, assistance with household tasks and shopping, respite breaks, access to educational facilities, and support with social activities.

Several interviewees and focus group participants reported that their social workers had informed them that SDS was not suitable or accessible for

people with learning disabilities. One participant stated that “my social worker, she turned around and said to me, ‘SDS isn’t suitable for people with learning disabilities.’” Others reported that they had not had any choice about how their support was arranged and were instead simply informed about their care arrangements.

One respondent outlined that they requested Option 2 rather than Option 3 when they were first assessed and received considerable pushback from their social worker. They related that their social worker said that they didn’t think that the service user “would be capable” of using Option 2 – a statement which the interviewee “couldn’t believe”, because they are “more than able” of expressing a preference about who provides their care.

Chart 17: “I am fully involved in all decisions about my care and support” (Survey)

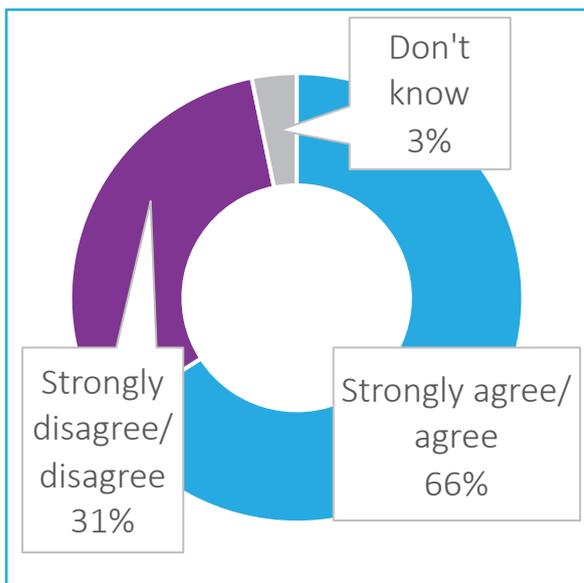


We also asked survey respondents to agree or disagree with the statement “I am fully involved in all decisions about my care and support”. Of the 79 people with learning disabilities who responded, 59 (75%) strongly agreed or agreed with that statement, 15 (19%)

disagreed or strongly disagreed, and five (6%) stated that they did not know.

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 94 people with learning disabilities who responded, 62 (66%) either “strongly agreed” or “agreed” with that statement, 29 (31%) “disagreed” or “strongly disagreed”, and three people stated (3%) that they did not know.

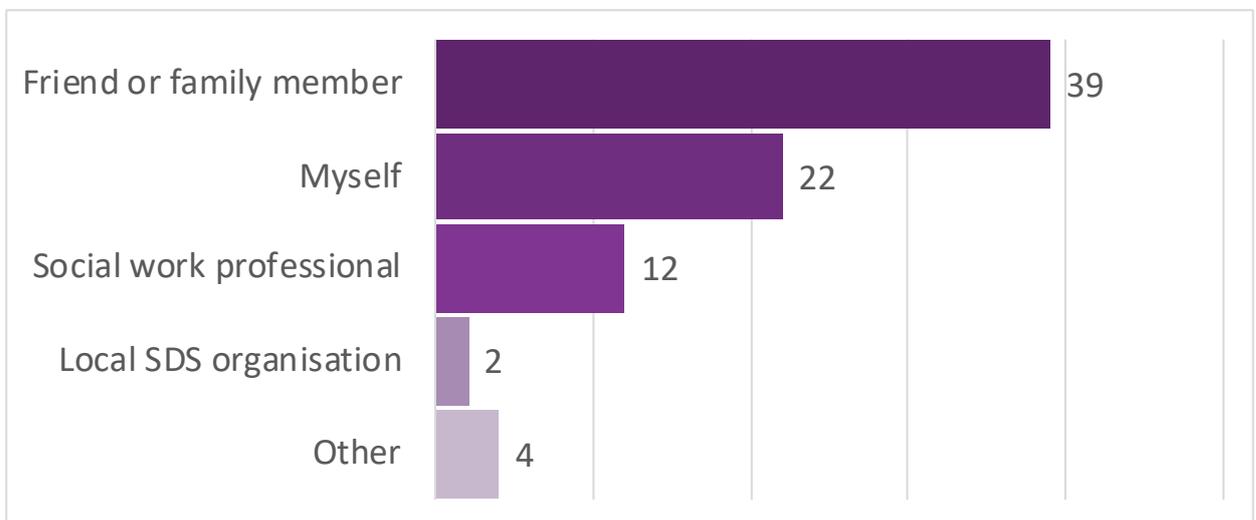
Chart 18: “I had a say in how my help, care or support was arranged” (Survey)



We asked survey respondents who chose the way that their support is arranged now. Of the 79 people with learning disabilities who answered this question, 22 (28%) said that they chose the way their support was arranged, 39 (49%) stated that a friend or family member chose the way their support was arranged, 12 (15%) said that a social worker chose for them. A further four people selected “other”; and of those who provided further details, one respondent stated that the decision was shared between themselves and their family, and one person stated that they chose “with strong lead from social work”. Two people said that a local SDS-related organisation chose for them.

These findings indicate that just over a quarter of people with learning disabilities were free to choose their own support arrangements, and just under half of people had their care and support chosen by friends or family members. While the former results are welcome, the fact that 15% of people state that social work professionals chose for them invites further work in supported (rather than substitute) decision making.

Chart 19: Who chose support arrangements? (Survey)



A similar pattern was found with interviewees and focus group participants' support arrangements. Out of the 26 people with learning disabilities who spoke to the research team, the majority were unsure which SDS option they were on, and many felt that they had not been offered any meaningful choice. One participant summarised their experience as follows, to wide-spread agreement from other focus group participants:

"I'm not being funny – I never got the choice of who I wanted to support me, if you know what I mean." Another person stated that "I don't get any option at all. I get told I have to have my support [...] they tell me what I have to do." Overall, interviewees and focus group participants with learning disabilities were more likely to report that they did not choose their support arrangements than people within the wider MSMC project as whole.

Choice Over SDS Options and Support: The research suggests that more work could be done to build on good practice that ensures people with learning disabilities are offered a meaningful choice between all four SDS options and are fully involved in all decision making about their care and support. While health and social care professionals, and family members, 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, and extend to all population groups, including people with learning disabilities. Staff could be given more training about SDS and its appropriateness for people with learning disabilities, how to support decision making rather than lead it, and on co-production methods more broadly.

Budget Management

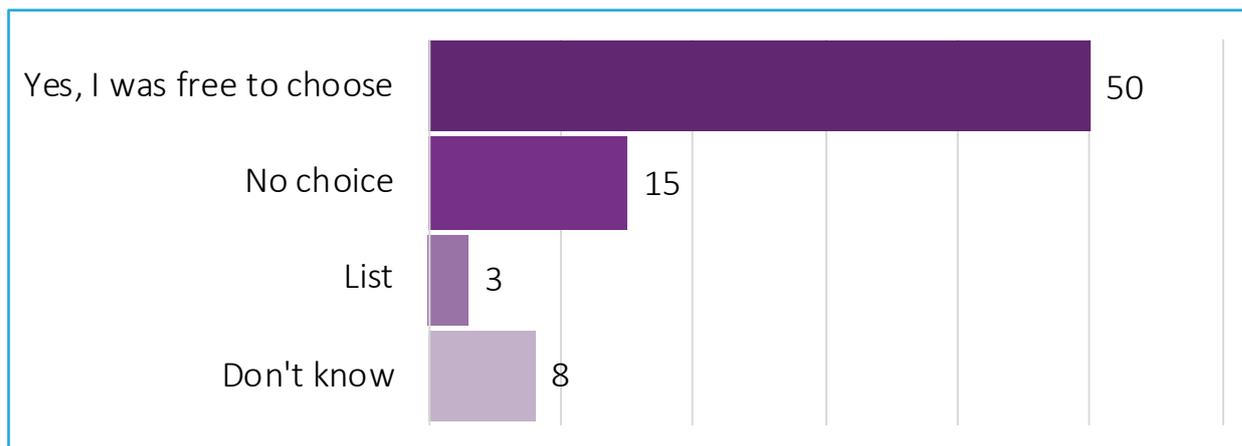
We asked survey respondents whether they chose who manages their personal budget, and if so, who they chose to manage it. Of the 76 people with learning disabilities who answered this question, 50 (66%) said that they were free to choose whom they wanted to manage their personal budget. Three people were able to choose from a set list of providers given to them by a social work professional. 15 people (20%) stated that they were not given a choice. Finally, eight people (11%) were unsure of whether they had a choice.

Of the 50 people who were given free choice of who would manage their personal budget, eight people chose a third sector provider organisation, five selected the local authority, four chose a private care agency, two

chose an individual broker, and one selected an independent support organisation. A further 30 people (60% of those who were free to choose) selected an individual person (this response could include themselves).

Of the three people who chose from a list, two selected the local authority and one chose a third sector provider organisation. Of the 15 people who said that they were not given a choice and the eight who were unsure, none provided details of who manages their budget.

Chart 20: Did you choose who manages your personal budget? (Survey)

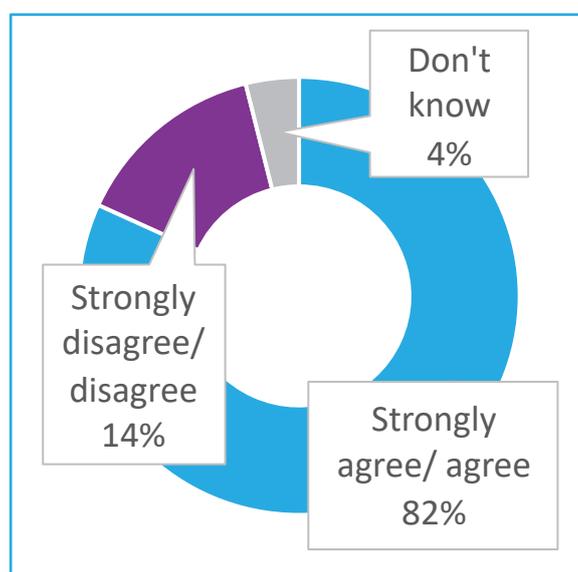


Budget Management: These findings reinforce earlier recommendations that further work is needed to ensure that people are offered a meaningful choice of all four SDS options.

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 77 people with learning disabilities who responded, 63 (82%) either “strongly agreed” or “agreed”, while 11 people (14%) “disagreed” or “strongly disagreed”. A further three people (4%) were unsure.

Chart 21: “Enough budget to meet my outcomes makes SDS easier for me” (Survey)



Several people with learning disabilities spoke in detail about the impact on their physical and mental health of substantial reductions to their SDS budgets and support. One person stated that they had an initial SDS package. Following a reassessment within the first year, the individual’s budget was cut entirely:

“They ask if you are getting on with it OK, and then the answer was ‘yes’. And then they heard, [...] they were asking how was [support worker] getting on with, was I needing help with this, you can do that yourself?’ And then

'nope, nope, you're not needing it anymore. You could do this and all that, you're not needing it. You're capable of doing shopping yourself. You can do all this, you can do that, so you are not needing your help.' [...] I didn't get a choice in it. They said, 'you're not needing it now', so it got stopped."

The respondent reported that the abrupt end of support caused substantial difficulties for them and praised the work of a local third sector organisation that provided alternative support instead of the local authority.

Other respondents recounted similar experiences, especially around reductions to support with social activities or home help – which generally led to corresponding reductions in their ability to engage with their local communities. Another person highlighted that the abrupt reduction in their support had coincided with their transition from children and young adult's services to adult social work services. They stated that "there was no transition, no nothing", and that "the minute I turned 18 everything got stripped".

Another person spoke of problems with having their choices respected during discussions with social work. They had previously had a comprehensive SDS package that covered time for social engagement as well as personal care, which enabled them to be active in the community, attend religious services with their support worker, and have a good quality of life. However, following a reassessment by a new social worker their package was cut substantially – despite no changes to their needs or stated outcomes – with social support removed. The person pointed out that this would mean that they could no longer attend religious services

on a weekly basis, as before, and explicitly said that they needed social support two hours a week to attend services, as part of their faith. Their social worker did not accept this as necessary to that person's life, and "reduced [their] hours" anyway. The person is no longer able to attend religious services, as a direct result of reductions to their SDS package. Such a decision does not seem to respect either the individual choices and outcomes of the person involved, nor their right to religious freedom.

A further troubling pattern was raised by some people with learning disabilities during a focus group, who reported that they were being asked to share their support (typically for social activities or completing tasks such as weekly shopping) with another person with learning disabilities – who they did not necessarily know, or have any desire to socialise with.

One person stated that they like the additional company "sometimes", but that they "don't like it all the time, because sometimes you want your own space". They agreed with another focus group participant who asked if they would prefer to have their own support worker, without having to share them with another service user. The first person noted that this enforced sharing of support workers was "because of the cutbacks" across their local authority. Another respondent recounted how they also share support – for personal and home care – with someone else in their household, following reductions to their SDS package.

In both cases, while the participants indicated that in some instances they were not averse to sharing support with others, neither felt that this had been offered to them as a choice – and both commented that it restricted their choice of activities. People with

learning disabilities who took part in other focus groups (e.g. people living in rural areas, people with lived experience of mental health problems)

also reported similar practices around having to share support against their wishes and preferences.

Adequate Support: The research suggests that some people with learning disabilities are not receiving adequate person centred support. Good quality, adequate support via SDS can be instrumental in improving people's quality of life and plays an important role in ensuring they enjoy their rights to independent living and equal participation in society. The impact of not providing rights based, person centred care can be devastating, resulting in severe isolation and loneliness and mental ill-health. It is therefore vital that people are treated with dignity and respect in all interactions with health and social care professionals and that assessments and support are adequate and tailored to people's requirements and way of life, taking into account all clinical, dietary, religious, cultural, or any other considerations based on protected characteristics and other self-identities. Health and social care staff should consider the possibility of mental health crisis when changing packages and eligibility criteria and be able to arrange reassessments and signpost support services where needed. Targeted work is needed to ensure person centred, rights based support continues in the transition from child to adult social care, and to ensure people with learning disabilities are given a free, meaningful and active role in decision making about whether to share their support or not.

Residential Care and Independent Living

The MSMC research team heard from several people with learning disabilities across Scotland who felt that their local authority and social workers had pressured them to consider residential care rather than remain in their own home with support via SDS. One person summarised their experience at their most recent review as follows:

"I was reduced to a sum of money; I was no longer a person. My needs were not met and [social work] were not interested in the problems faced with my family having to do half of my 24-hour care. They offered me residential care which I would not be able to cope with [...]. My needs are successfully catered for by my present personal care assistant and I am very happy

living in my own home and don't want to go into care."

Another person outlined that their social worker was able to ensure that they were provided with safe accommodation in a residential unit after they were made homeless (which they appreciated) – but that since then they had not been able to arrange housing as they want. They stated that they did not want to remain in residential care ("I don't want to be there, but they made me stay there"), but would prefer to stay in their "own house to go in what time I want, in and out whatever time".

One person discussed how their request to move into supported accommodation was accepted, but that when the time came to move the flat was unsuitable for a wheelchair user, and they had to move again (with corresponding upheaval). Another

participant detailed how they were previously in residential care, and following a discussion with social work they moved to a flat with very little notice (“two days apart”) – and although they are now happy with their living arrangements and support, more explanation and preparation time would have helped their transition.

A different respondent stated that they currently live at home with family (who provide some unpaid care alongside the participant’s SDS package), but that they would prefer to be in their “own home or living somewhere else [...] with carers or something” – although the participant did also state that they wouldn’t want to be on their own, as “I wouldn’t ken how to cook”.

Another respondent also linked their concerns about residential care to a lack of future-proofing for a time when they would no longer be able to receive support from family members as unpaid carers. They stated that “forward planning [was] ignored for emergencies”, and went on to state that:

“My wish to remain in own home with support was ignored and only residential support would be provided. Not suitable for a young man who has no wish to be put in an old people’s home.”

One interviewee stated that their adult child’s care had been arranged through SDS, but that they were now being pressured to move their child into residential care. They stated that they were happy to continue a combination of unpaid care and paid care workers to support their child, but summarised the response of their social worker as follows:

“Social work [...] they’re trying to take control, they’re

refusing to let me have Self-directed Support, they want to put him into [residential care home]. [...] It’s totally unfair.”

Another survey respondent concluded that they “will never be able to live independently”, because when they asked about options for longer term care and support services, their social worker agreed to “find out what the options may be for independent living”, but has since not provided any assistance or information.

Several unpaid carers also raised concerns about whether their adult children (who have learning disabilities) would continue to be supported via SDS once they were no longer able to provide unpaid care – and were particularly worried about the idea of local authorities defaulting to residential care for their adult children. One interviewee stated that this concern means that they “will not rest” until they feel confident that their child is supported within a community setting.

Residential Care and Independent Living:

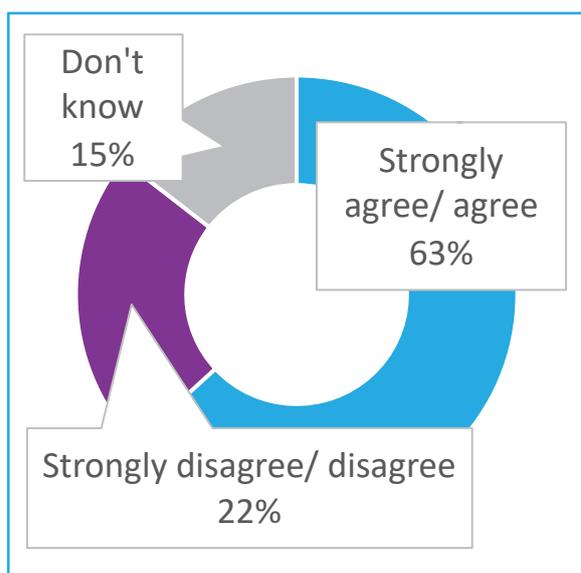
No-one should feel or be pressured to move into residential care against their wishes – particularly not as a result of a desire to reduce funding for support via SDS. All resources should be maximised and options exhausted to enable people with learning disabilities to remain – with appropriate support – in their own homes for as long as possible, if that is what they wish.

Flexibility

Many people with learning disabilities commented on the value of and need for flexibility for the effective use of SDS – particularly around budgets.

We asked survey respondents to respond to the statement “Lack of flexibility in how I can use my personal budget makes Self-directed Support more difficult for me”. Of the 76 people with learning disabilities who responded, 48 (63%) “strongly agreed” or “agreed” with that statement, while 17 (22%) “disagreed” or “strongly disagreed”. A further 11 people (15%) stated that they were unsure. Compared to all MSMC survey respondents overall, people with learning disabilities are more likely to feel that inflexibility in how they can use their budgets makes SDS more difficult for them.

Chart 22: “Lack of flexibility in how I can use my personal budget makes SDS more difficult” (Survey)



Interviewees and focus group participants expanded on this theme, with some reporting troublingly practice across Scotland, indicating the negative impact that inflexible SDS practices had on their quality of life. One interviewee, who had experienced less flexibility in the way their SDS was arranged after moving to a different local authority, called for more choice to be available to service users:

“[We need] flexibility. [...] Allow money to leave [specific LA] to go to [neighbouring LA] if you’re not able [...] to provide a service that would be beneficial to somebody both mentally and physically.”

However, one focus group participant’s experiences indicate that it is possible to reduce SDS well, as long as it is done in a flexible and supported way. This individual had originally moved into independent accommodation, and had overnight care seven days a week, plus support in the day. As they became accustomed to living on their own, this support was gradually reduced, following regular consultations between the service user and their social worker. The person stated that the gradual nature of the change was key, taking place “over time until I could live independently”, with discussions that were about testing reductions rather than completely cutting a budget. They reported that now they could “never go back to having seven sleepovers – being told to come in at half past ten every night!” and that they were happy with their reduced SDS package and increased level of independence. Other participants in the focus group commented positively on the flexibility of this person’s experience, and the careful supported decision making process that prioritised the individual’s input, ideal outcomes, and consent.

Flexibility: The research suggests that many people with learning disabilities 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. Improving 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, 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 Respite

Respite was a major topic for many research participants – for SDS users and unpaid carers alike. People who used SDS budgets to access respite described it as an essential way that individuals and families could benefit by having time and space to themselves, doing activities that they enjoyed.

Using SDS for respite services was also mentioned by several people with learning disabilities as an important chance for people to have breaks and relax. One interviewee explained that respite enabled long-distance visits to the SDS users' relatives without needing to stay at their houses, allowing the SDS user to both see their family and have privacy and support for their personal care.

Another person described their experience as follows:

“It's been fantastic for us, with [Name's] respite, because we started to use [respite 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-climbing, away having a great time. And myself and the other members of our family once went to [location] for four nights [...]. That was amazing.”

People also reported that some local authorities specified designated centres for respite provision, rather than allowing people to choose which arrangements suited them best, and refused to fund respite outwith those providers. This caused problems in terms of respecting people's choices, but also prompted longer waiting lists for spaces at those designated centres – particularly around typical holiday periods. Respondents highlighted the need for people to be able to use their respite budget flexibly, as long as they could demonstrate activities met their personal outcomes and were within budget.

Access to Respite: Flexible, regular access to respite should be strongly encouraged because it is an essential element of SDS that results in good personal outcomes for people with learning disabilities who access social care, families and unpaid carers.

Travel Costs

Travel costs – for respondents, personal assistants and care staff – were also repeatedly mentioned as a key concern, especially for people with learning disabilities living in rural areas. This was not always linked directly to people's SDS packages,

but where people employed personal assistants, the time to travel by public transport to carry out activities was not always acknowledged in care plans. People with learning disabilities also indicated that they would welcome more assistance from social work in accessing appropriate mobility passes and in dealing with transport problems. Even in cases where decisions lie with the Department for Work and Pensions rather than local authorities, most people tended to reflect on transport issues and SDS without clearly

delineating between the two parts of their experience of social support.

Travel Costs: People with learning disabilities – particularly those living in rural areas – require more acknowledgement and accommodation of travel costs in their SDS budgets. Many would also welcome assistance from social workers and third sector organisations in navigating the bureaucratic processes to obtain mobility vehicles and travel passes.

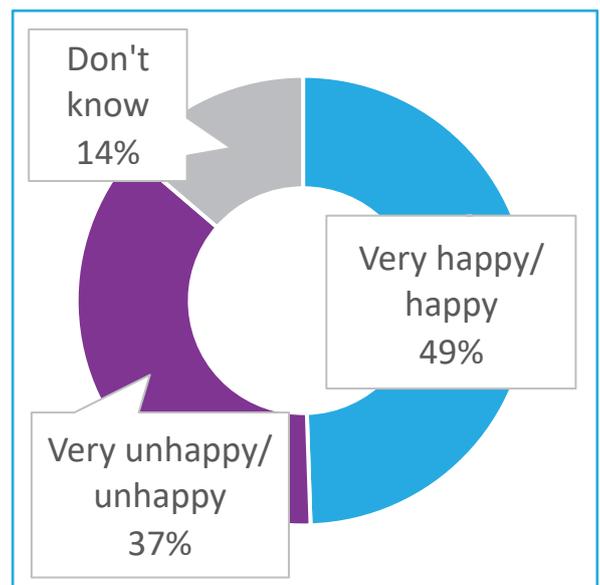
Communication and Relationships with Social Work

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.^[21] As such, we asked survey respondents to rate how happy they were with the conversations they had about their support with the professionals with whom they spoke (e.g. social workers/social work assistants, occupational therapists), on a scale of one to five.

Of the 95 people with learning disabilities who answered this question, 47 (49%) were either “happy” or “very happy” with their conversations with social work professionals, 13 respondents (14%) didn’t know, and 35 people (37%) were either “very unhappy” or “unhappy”.

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



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. Some key examples of people's positive experiences of conversations with social workers are as follows:

"They listened to me and gave me time to say what I wanted."

"We have an excellent social worker who knows our circumstances really well."

"Very good social worker who I was able to engage easily with. She was very knowledgeable and a really good communicator."

"The professionals involved took the time to listen and understand our personal circumstances."

"Lots of listening, note taking, recapping, offers of feedback to questions unanswerable at meetings, etc."

"A social worker who really wants me to have a happy life and sees value in what I choose to do. She works hard to secure my budget for me."

"We actually got listened to by the social worker. She encouraged us to think outside the box for things like respite and what we could do with the support."

"Supportive tone of the professional helped to feel comfortable discussing my care needs."

"I was kept informed of all my options and was not pressured into choosing any particular one."

"I felt I had a social worker who understood SDS and was very professional. She listened and answered any questions I had."

"She listened to me and put my care forward when I moved next door to my parents."

"I was initially worried about being responsible for budget and for paying PA wages etc., however after speaking with social worker she put my mind at ease."

Interviewees with learning disabilities also highlighted that good conversations require effective communication, access to information, prompt decisions, and good future planning. One person related examples of good practice in terms of their needs assessment and conversations with their current social worker. They had not felt supported by their first social worker, who did not take the time to explain the needs assessment process to them. On changing to a new social worker, they reflected on the difference that individual had made to their experience of needs assessments – particularly in prompting the respondent to consider all elements of their day to day routine, and what level of support they would need at each stage:

"The second one, I just felt like she was a lot honest with me [...] she was kind of prompting me in saying, 'have you thought about your wash?' and things like that – but if I said to her it was an hour then that's what got put [...]. And I felt more supported and she kept me fully up to date with everything that was going on. She called me as soon as she came out of the meeting on Monday and told me how it went and she had went to the meeting and had asked for

30 hours which was what I had kind of agreed and then when she had said to her line manager like she had a breakdown of what

those thirty hours was spent on. [...] I felt a lot more supported by her and I felt like she was a lot more honest with me."

Good Conversations and Consistent Relationships: The research demonstrates the vital importance of good conversations and communication between service users and social work professionals, and there were many different elements and examples of this in the experiences shared by people with learning disabilities. 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. The research also highlights the benefits of consistent relationships with social workers, including direct and varied lines of prompt communication available. Overall, we recommend that work to ensure positive conversations and meaningful, consistent engagement with people should continue, with ongoing planning to guarantee high quality practice for people with learning disabilities who access SDS – especially around clear and accessible communication.

Poor Communication and Relationships

Some people with learning disabilities described less positive experiences of communication and relationships with social work professionals. Of the people who answered the survey questions about how happy they are with the conversations they have had about their support with professionals, 35 (37%) were either "very unhappy" or "unhappy". Some people 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.

Key comments from people with learning disabilities who were unhappy with their conversations with social work professionals are as follows:

"Initial assessment still focussed on LA services with little thought about me as an individual. No real discussion took place around choices [...] in my opinion didn't provide quality information."

"Bad – rushed due to time. Social worker is stretched too far to spend time on the case."

"Always feels rushed. Feels like we need to fit the boxes rather than what works well."

"The bad points of the conversation – not truly listening by the professional throughout the assessment/review, the professional's views of spends from the budget was final, no authorisation of [...] choice/wishes would be given."

"Social work have no wish to provide adequate quality support, only cheap support to reduce budgets. Autism and learning disabilities do not disappear year on year so why are assessments forced on us every year causing illness from stress?"

"Her lack of knowledge having just started the job. Unable to answer basic questions. Giving wrong information, e.g. you can start your carers now as your money will come through within

two weeks (the money took six weeks, and thankfully I got accurate advice via a friend)."

"We were patronised, not listened to. Poor and slow response. No named person has been in touch since money was awarded three years ago! We currently don't have a named social worker."

"Social worker didn't listen to me. I wanted to make my support individual to me, but this didn't happen."

"Social worker omits many necessary facts from the assessment – including key phrases like 'with support.'"

"Lack of continuity support (no meeting in four years) and acknowledgment of changes to care needs."

"I was never told my options, I was never told about SDS, I only found out about it on YouTube. I started challenging once I learnt my rights but they shut the door on me. They told me they have no money but that's not my problem. The social worker treated me like an idiot. When I spoke to a social worker last year I said I wanted to leave the support group [...] they told me I can't. Then they told me to get a PA but they won't support me with that."

One person with learning disabilities related difficulties communicating effectively with their social worker during their needs assessment. They felt that their social worker gave them sufficient information about SDS and the different options, but was poor at listening:

"She put words into my mouth. She thought I wasn't capable to

choose what I wanted [to choose] and what outcomes I wanted. And I said, 'No, I can choose what I want, I've got a voice. Why are you putting things into my mouth?' So, that was the difficult part of it."

When asked what is needed to stop this practice, the interviewee outlined the importance of allowing plenty of time for discussion and supported decision making (rather than social workers making decisions for people):

"Just be with the person and go through the complete assessment. If people struggle then yes, I can understand that [social workers guiding a decision]. But if you are capable of saying what you want to do with that budget and what outcomes you need, then that is completely different – you can do that! I was really shocked with her."

Interviewees highlighted the problems that communication difficulties and misinformation from social work professionals can cause, and the negative impact on their lives. Some noted that although they had constructive conversations with their social worker, decisions about SDS budgets fall to a social worker team manager – who can reduce the agreed support package.

Poor Communication and Relationships: Examples of poor communication raise clear concerns about decision making and autonomy; if people's opinions (spoken or written) are not recorded and acknowledged during assessments, then they cannot be said to control or choose their support. The findings invite further work to continue existing good practice and ensure that people with learning disabilities' experiences of conversations with social work improve. Cumulatively, the research findings highlight the importance not only of good communication with social workers during needs assessments, but the need for transparency, sustained and trusting relationships, and depth of knowledge about SDS.

Transparency

Research participants with learning disabilities commented on the importance of transparency in a variety of ways, centred around the need for clear information about what to expect from SDS, social work professionals, the process of accessing support, and how to challenge decisions. Some people with learning disabilities spoke warmly of their social workers and the transparency of process, saying "there was no problem", they had copies of all agreements and paperwork, and that when they queried sections of the plan their social worker "was quite happy to agree to some changes".

One key theme around transparency was the need for greater clarity on eligibility criteria for accessing SDS. While some local authorities share eligibility criteria publicly (either in information leaflets or via local authority websites), this is not the case across Scotland.

For many MSMC research participants, particularly people with learning disabilities, concerns about transparency of process were often synonymous with issues with accessible information and sharing of documentation. Respondents summarised their difficulties with opaque processes as follows:

"Many questions unanswered. No written information provided – not even of the agreement. Discouraged re: flexibility. Repeatedly told it's only to be used to employ carers."

"I find it challenging when the communication is not clear, and when written communication is unclear. I like things written down. And the lack of transparency, those would be the main challenges."

One respondent, who uses SDS alongside another member of their household, said that they have trouble even trying to contact their social worker by phone:

"When I phone my social worker [they] are not pleased – and I'm only phoning to find out what is happening. [...] Once I spoke to the social worker about [arranging carers], my social worker came in on the Wednesday very angry because I didn't tell her. I had to do it because I wasn't able to look after a 16-stone man. She says, 'you shouldn't have done it that way'. [...] Every time I phone my social worker and ask what is going on [...] I never get an answer. It's so annoying because I so want [Name] to go somewhere new to chat to people because [...] he is so bored, and it is not fair. I just want better for him; that's all I want."

Another interviewee highlighted similar difficulties contacting their social worker for support on changing the way their care was arranged. They requested a change, with support from the company currently providing care, but did not receive a response. Eventually, the respondent “ended up having to put in a complaint to social work” – after which they were assigned a social worker who reassessed the respondent and arranged for them to move to a different option.

Transparency: The research indicates that while there are some good examples, this is not consistent across all areas and more work needs to be done to ensure systematic good practice and complete 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.

Impact of SDS on Family/Relationships

People with learning disabilities identified a range of ways that SDS has enhanced their lives, including a beneficial impact upon family relationships. Several interviewees emphasised the positive aspects of SDS for the whole household. In multi-person interviews, the friends and family of SDS users mentioned that they could enjoy retirement or doing activities associated with their own interests, knowing that the SDS user had suitable support.

Interviewees also emphasised that access to SDS has provided a person centred approach towards the provision of support. Discussing their disabled young adult children, one interviewee stated that with SDS their children “feel like they can do things without us always being attached to them, so they’re quite happy.” Another interviewee outlined how empowering their child (now a young adult) found it that with SDS they could do what they liked, when they liked:

“[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.”

Another respondent, the parent of a young adult with learning disabilities, summarised the impact of SDS on their family life as follows:

“It’s really helped her, it’s given her a new lease of life, she can go and she can work and she doesn’t need to have her mother there all the time [...] and she’s got things

to tell her mum about when she comes back. And also, [personal assistant's name] is brilliant because she can get [service user's name] to do things that I can't get her to do, you know? 'It's mum, so I'll no do it.' Whereas [personal assistant's name] gets her to do it. She isn't mum! And they have a good laugh – it's been one of the best things we've ever done for [service user's name]."

However, not all respondents were positive about the impact of SDS on

family life. Those that highlighted problems tended to centre these concerns around budget cuts, which led to increased care responsibilities for friends and family as unpaid carers. Several people shared the negative impacts of when there was not enough support in place to meet the needs of a SDS user. These issues were particularly acute when social workers assumed that family members would be able to provide unpaid care without properly assessing whether that was feasible or desirable for the people involved.

Impact of SDS on Family/Relationships: Adequate person centred support via SDS can be instrumental in improving people's family life and relationships, however serious problems can arise if support is insufficient. It is essential that social work professionals do not assume that family members will be able to provide unpaid care – or that the service users wish to be supported by friends and family. It is also important for professionals to consider conscious and unconscious gender bias when assessing people's right to access support, and receive regular access to diversity and equality training.

Care Staff Recruitment, Training and Quality

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

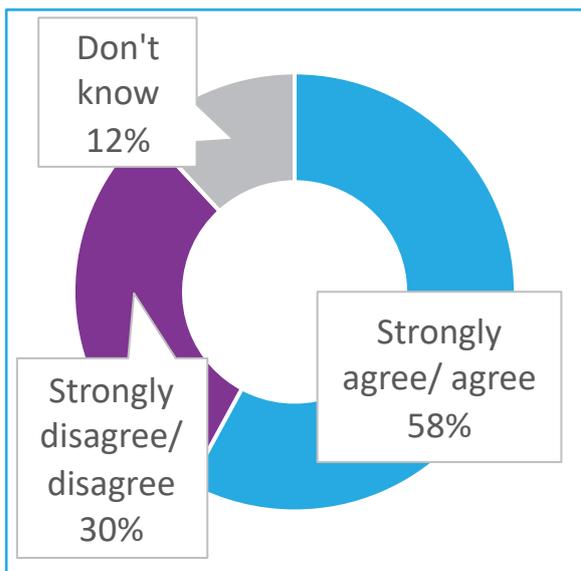
Staff Recruitment, Retention and Turnover

Within the survey, we asked participants to respond to the statement "Lack of a regular personal assistant makes SDS difficult for me". Of the 76 people with learning disabilities

who answered this question, 44 people (58%) either "strongly agreed" or "agreed", while 23 people (30%) disagreed or strongly disagreed. A further nine people (12%) were unsure.

These findings are supported by comments by interviewees and focus group participants about the importance of, and difficulties finding and retaining, PAs who are appropriate to their requirements.

Chart 24: “Lack of a regular PA makes SDS difficult for me” (Survey)



One person reflected on their initial difficulties with recruitment – and particularly the overlap between care work and state entitlements for some workers. They recounted that rules on working hours could compound recruitment difficulties – for example, if someone had a SDS package for 15 or 16 hours a week but this clashed with Universal Credit working requirements, preventing otherwise good PA candidates from taking up post.

Several interviewees who lived in rural areas of Scotland also highlighted that recruiting and retaining staff was easier when budgets included mileage for support workers to travel to and from their place of work. This consideration was particularly key when travel time was extensive (e.g. in situations where the nearest town or settlement to the service user could be over an hour away by public transport, or not reachable by any means other than a private car).

Important Characteristics of Care Workers

Many people commented on their priorities regarding care staff.

One interviewee summarised the following important characteristics in a support worker:

“I’m not really interested in someone with [...] an impressive CV. I’m more interested in someone I can meet, get along with, trust. And that might be someone who’s never had a job, but if I feel I can trust them, if I feel they’re going to be reliable then I’m more interested in that person than someone who just went and done a degree.”

Another interviewee expressed their satisfaction with the range of activities – including work and social activities – that they were able to access with support from their care worker and a local third sector organisation. The care worker also added to the discussion; a family friend, they stated that the service user’s parent asked them to work part-time as a PA:

“And I said, ‘I don’t have any qualifications, I can’t look after [Name]!’

[They said,] ‘You’ve known him since he was [age], and you can communicate with him, so that’s all you need.’”

In this situation, both interviewees agreed that trust, familiarity, and the ability to communicate effectively were key to the success of the support arrangement – and worked better than having a rotating group of strangers providing care and support.

Care Workers and Risk

Several people commented on their consciousness of the potential risks of being reliant on care workers – even those who currently had good working relationships with trusted people.

One person discussed their feelings of vulnerability around support staff who provide personal care on a one-to-one basis – and vice versa:

“Even to the support staff who come in, we can be vulnerable to them. Even though we know them, we’ve known them for five years, but even at that we can still be vulnerable to them. And likewise, they can be vulnerable to us.”

The interviewee went on to state that sometimes support workers can build up good, trusting relationships with service users, but that this can create different problems with boundaries – even with good intentions:

“And staff forget. And how I say that is because one of them has offered to give me a cuddle. And I’m thinking, ‘in your professional

role that is not allowed because I’m not allowed to touch you.’ [...] I did say to my support staff, ‘the only person that gets to do that is my mum.’ And she went, ‘that’s the best cuddle that you can ever receive.’”

While the interviewee appropriately diffused this situation, they recounted this experience within a wider context – and particularly of being aware of other people’s discomfort at their sexual orientation. It was evident that while the interviewee had a team of social care workers with whom they were comfortable, they found that trust was particularly important for them, having experienced discriminatory attitudes elsewhere in their community. It is worth noting that they stated that their social worker was excellent in providing additional support in this area.

Care Staff Recruitment, Training and Quality: Some people with learning disabilities would welcome more support from their local authority to arrange PA recruitment, training and continued professional development. 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 local authorities 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. This support and acknowledgement of variable practice is particularly important when social care and social work professionals are discussing care arrangements with people who have had poor experiences in the past – whether that be difficulties with individual care workers, or as the victims of crime. People have the right to feel safe – particularly in their own homes – and social care workers and professionals across the sector should do all they can to support service users to feel safe, secure, and independent.

Independent Advocacy and Support

People with learning disabilities accessed independent advice and advocacy services for a range of different reasons. These included access to information, access to needs assessment criteria, assistance to develop a support plan, exploring flexibility with SDS budgets, mediation with social work professionals, support to appeal a decision, and advice on payroll and other PA employer-related issues.

Survey respondents spoke warmly of the benefits of independent advocacy and independent advice and support organisations. People recommended getting in touch with independent advocacy and independent support and advice organisations as early as possible. Some of their key comments are as follows:

“Get advocacy support and know what you’re entitled to as council will not be forthcoming with support.”

“There is little flexibility with the package now, I would definitely access advocacy services to know all the facts.”

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

“Get independent advice and speak to other people who have it. We always get told ‘you can’t have that’ and then meet someone else who has it!”

“Seek support and information from an independent organisation.”

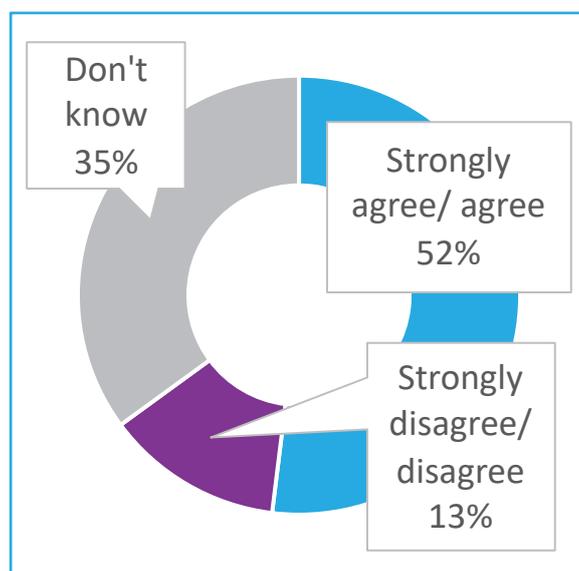
“I would suggest seeking advice from an organisation such as [independent advice and support organisation] or an advocacy group to ensure you are prepared and understand as much as you can about SDS.”

“Get independent information and raise concerns if too many ‘limitations’ are put on the direct payment.”

Independent Advocacy

We asked survey participants with learning disabilities to respond to the statement “access to independent advocacy makes SDS easier for me”. Of the 77 people with learning disabilities who answered the question, 40 (52%) “strongly agreed” or “agreed” with that statement, and ten people (13%) “disagreed” or “strongly disagreed”. A further 27 people (35%) said that they were unsure.

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

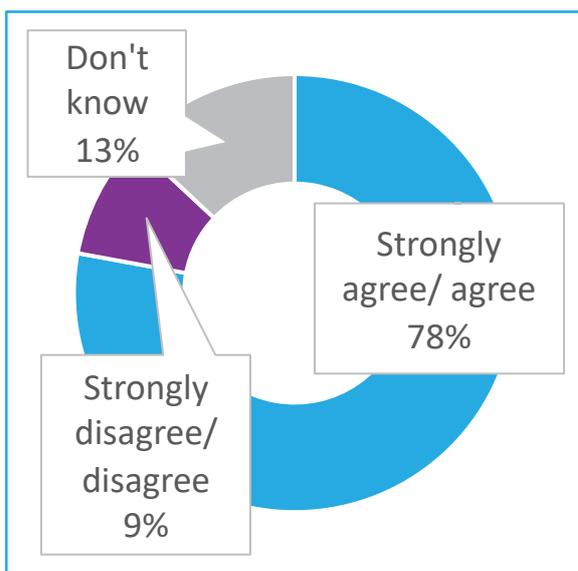


Survey respondents and focus group participants noted that confidentiality and time to build up trust was important to the success of independent advocacy. Several people highlighted that they had benefited from the involvement of independent advocacy services during their needs assessments and reviews. Various forms of advocacy were mentioned, including local user-led service organisations, independent advocacy, solicitors, national legal aid organisations and carers' centres.

Independent Advice and Support

When asked whether access to independent information and support made SDS easier for them, survey respondents with learning disabilities responded in a positive fashion. 60 people (78%) "strongly agreed" or "agreed" with that statement, and seven people (9%) "disagreed" or "strongly disagreed". A further ten people (13%) said that they were unsure.

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



Survey respondents, focus group participants, and interviewees

all commented on the value of independent advice and support in accessing SDS. Several people with learning disabilities highlighted that they had benefited from the involvement of independent advice and support services during their needs assessment and reviews.

Interviewees were highly complementary about third sector organisations, who provide independent advice, and support services in assisting them with SDS. One person summarised their experience of support from a third sector organisation as follows:

“And any problems that we’ve had [...] have been ironed out, so we’ve got no problems at all; [local third sector organisation] are very, very good.”

This interviewee went on to outline that the local authority had planned to cut the budget for the local independent support and advice organisation, and require people to access alternative services at a considerable distance away, elsewhere in the geographically large local authority. The interviewee recounted that the outcry from local service users was so great that the local authority changed their mind. The organisation had still had to work out alternative revenue streams to compensate for a reduced budget in order to continue operations. The interviewee summarised the experience and local service as follows:

“And we’ve fought hard [...]. So yeah, it needs to be kept open and more people are going to it now – it’s absolutely brilliant.”

Peer Support

Several people with learning disabilities also highlighted the value of peer support and encouraged the promotion or establishment of local peer networks. According to interviewees and focus group participants, peer support helps to sound out ideas around how support should be arranged, facilitates access to information, combats isolation, and prompts some people to be SDS ambassadors.

One interviewee summarised their experience of peer support as follows:

“It’s nice to have others you can talk to, people that are in the same situation as you, and maybe have a bit more experience with things like Self-directed [Support], or other, housing, or whatever issues. And you can, I don’t know, sort of help each other out. That peer support is huge, because being a disabled person, you’re often really isolated. So the peer support gives you a lot more sort of freedom, and opportunities, and things. And it can be little things like meeting up in your own time to go for a coffee, or go to the cinema, or pub, or whatever – things that, [...] I never would have thought of doing a year ago.”

Independent Advocacy and Support: People with learning disabilities clearly value and benefit from independent advocacy, independent 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 local authority staff be given more training and information about local independent support and advocacy organisations, so they can more routinely refer people to these resources as part of assessment processes, and recognise the value these services can bring to their own work. Focused efforts are required to ensure people with learning disabilities are aware of – and can access – independent advocacy and support services. Local peer support networks should also be encouraged and supported.

Endnotes

- 1 To support readability, the 'N' number is not reported for all survey question responses.
- 2 SDSS and the ALLIANCE endorse the use of the term “learning difficulty” in preference to “learning 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 term, which are still in standard use by public bodies and more common in public discourse, is 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.
- 3 Throughout MSMC we have used “Black and minority ethnic people”. While the project partners are aware that this is a potentially contested term, the interviewees and focus group participants contributing to the research project most commonly self-described their ethnicity as “white”, “Black”, “minority ethnic” or “Black or minority ethnic”; as such, we have followed their preferred terminology. Where participants refer to the experiences of specific groups, we have kept those references unique.
- 4 Scottish Commission for Learning Disability, Learning Disability Statistics Scotland, 2019: A National Statistics Publication for Scotland (17 December 2019), p. 2. Available at: <https://www.sclد.org.uk/wp-content/uploads/2019/12/Learning-Disability-Statistics-Scotland-2019.pdf>.
- 5 National Records of Scotland, Scotland’s Census 2011 (2011). Available at: <http://www.scotlandscensus.gov.uk/>.
- 6 ISD 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://beta.isdscotland.org/find-publications-and-data/health-and-social-care/social-and-community-care/insights-in-social-care-statistics-for-scotland/>.
- 7 ISD National Services Scotland, Social Care Information Dashboard. Available at: <https://scotland.shinyapps.io/nhs-social-care/> ('ISD dashboard').
- 8 Ibid.
- 9 2011 Scottish Census, 'Ethnicity, Identity, Language and Religion' (2011). Available at: <https://www.scotlandscensus.gov.uk/ethnicity-identity-language-and-religion>.
- 10 <https://scotland.shinyapps.io/nhs-social-care/>
- 11 Ibid.
- 12 ISD dashboard, <https://scotland.shinyapps.io/nhs-social-care/>.
- 13 Scottish Commission for Learning Disability, 'Learning Disability Statistics Scotland, 2019: A National Statistics Publication for Scotland' (17 December 2019), pp. 19, 23.
- 14 Scottish Government, Poverty and income inequality in Scotland: 2015-2018 (2018), p. 10. Available at: <https://www.gov.scot/publications/poverty-income-inequality-scotland-2015-18/pages/10/>.
- 15 Scottish Government, Poverty and income inequality in Scotland: 2015-2018 (2018), p. 1. Available at: <https://www.gov.scot/publications/poverty-income-inequality-scotland-2015-18/pages/1/>.
- 16 Ibid., p. 12.

- 17 ISD Scotland, 'Social Care Information Dashboard'. Available at: <https://scotland.shinyapps.io/nhs-social-care/>.
- 18 ISD 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://beta.isdscotland.org/find-publications-and-data/health-and-social-care/social-and-community-care/insights-in-social-care-statistics-for-scotland/>.
- 19 Ibid, pp. 6, 48-60.
- 20 ISD dashboard.
- 21 Care Inspectorate, Thematic review of self-directed support in Scotland: Transforming lives (2019). Available at: <https://www.careinspectorate.com/images/documents/5139/Thematic%20review%20of%20self-directed%20support%20in%20Scotland%20June%202019.pdf>.

Glossary

Budget / Hours / Package

The agreed support provision for an individual from the local authority/ 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

social care/SDS, 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). Key local authorities likely to be mentioned in MSMC interviews are Dumfries and Galloway, Fife, Glasgow City, Highland, Moray, North Lanarkshire, Scottish Borders, South Lanarkshire and Stirling.

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).

Respite

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

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.

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



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 nearly 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 individual 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 partner and foster better cross-sector understanding and partnership.



About Self Directed Support Scotland

Self Directed Support Scotland represents 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.
- 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.

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