My Support My Choice:

Women's Experiences of Self-directed Support and Social Care

Thematic Report, December 2020

Self Directed Support Scotland
the organisation of choice

ALLIANCE
HEALTH AND SOCIAL CARE
ALLIANCE SCOTLAND
people at the centre

Table of Contents

List of Charts

Acknowledgements and Dedication

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

About this Report

This report uses data[1] about women who participated in “My Support, My Choice: User Experiences of Self-directed Support 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 Self-Directed Support (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 learning disabilities,[2] Black and minority ethnic people,[3] people with lived experience of mental health problems, 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 women’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 women’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 women’s experiences.

Executive Summary

This thematic report uses data about women who participated in "My Support, My Choice: User Experiences of Self-directed Support 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.

The aim of the 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 women's experiences of using SDS/ social care in Scotland. Between November 2018 and February 2020, MSMC heard about the experiences of 321 women who received SDS (or had been assessed in the previous 12 months) via a survey, interviews and focus groups. Research took place prior to the appearance of COVID-19 in Scotland, and this report does not reflect women's experiences during the pandemic. However, as the largest direct consultation of its kind to date, MSMC provides vital evidence, analysis and recommendations for improvement to SDS/social care in the aftermath of the pandemic, based on people's experiences.

Women who participated in the research acknowledged SDS as important to achieving a higher quality of life and independent living. However, there are some key improvements that would respond to women'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 women 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 women on low incomes who access or are trying to access social care, given that they can lead to women having to manage without support, deteriorating physical and mental health, and demands on family and friends to assume roles as unpaid carers.

Data Gathering and Analysis

There are concerning gaps in SDS data gathering and analysis – both generally and around women's experiences. 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

Women 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

Women find out about SDS from a range of sources. Many report positive experiences, with an 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.

Women reported lower satisfaction levels than men with the information they received about SDS and were also less likely than men to have had all four SDS options discussed with them during their needs assessment. They were also less likely than men to feel that all their questions had been answered at their most recent meeting with social work professionals.

Most women 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 dismantling barriers to women's access to information about SDS/social care, and ensuring that a wider pool of professionals (e.g. educational professionals, GPs and community health practitioners) are aware of SDS and able to signpost women to social work and appropriate resources.

Informed Choice and Control

Most women were on their preferred SDS option and felt that they were fully involved in decisions about their care and support. Most women also stated that they had enough time to choose their SDS option. However, women were less likely to report that they had had enough time to choose an SDS option than men. Similarly, while most women stated that they had a say in how their support was arranged – and this finding is to be welcomed – women were more likely than men to have had decisions about their support made by a social work professional. Disabled women who are parents also reported difficulties in having care workers and social work professionals respect their parenting choices.

Most women had been given details about their personal budget, however they were less likely than men to have been given that information. They were also less likely than men to have been given free choice over who manages their budget. Women reported variable wait times for assessments and those who waited the longest generally report the highest levels of stress and difficulty in accessing SDS. Women called for greater clarity about expected wait times.

Recommendations include targeted efforts to ensure that women, particularly those who are homeless and/or living in deprived areas, enjoy equal decision making about their SDS option and support, and that women with learning disabilities are offered the four SDS options and that their support is person centred and rights based.

Conversations and Relationships with Social Work

Women consistently highlight that good, consistent, trusting relationships with social workers and clear lines of communication are all essential for positive and effective experiences of SDS. Many women who were interviewed reported positive and favourable experiences of assessments and reviews with professionals, while others outlined concerns about not receiving full answers to questions raised during assessments. Some women shared deeply concerning stories of discrimination, intimidation and bullying by social work or social care professionals.

Many women require greater transparency about how care decisions are made and by whom, alongside inclusive communication and easy access to information. Participants reported difficulty obtaining paperwork and documentation concerning their care arrangements, even after repeated requests to social work departments, as well as difficulty obtaining information about how to lodge formal complaints. Several women reported that health and social care professionals disregarded their preferences for social care arrangements.

Recommendations include ensuring that appropriate training and ongoing support on equalities, human rights, intersectionality, conscious and unconscious bias and anger management is provided to social work staff at regular intervals. Social work professionals should also 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).

Impact of SDS on Family/ Relationships

Women 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. Recommendations include social work professionals ensuring that disabled mothers are properly supported through SDS, and their decisions and parental rights are respected by social care workers.

SDS and Mental Health

Women were clear in stating that high quality support via SDS is beneficial to their mental health. However, they were also explicit in outlining how inadequate assessment processes and reductions in support have a negative impact on their mental health. Social work professionals and decision makers should consider the impact on women's mental health of any reductions or changes to support arrangements – particularly substantial reductions in budgets.

Care Staff Recruitment, Training, and Quality

Women report mixed experiences of support worker recruitment, training and quality, and several indicated difficulties finding and retaining personal assistants and care workers that are suitable for their requirements as well as the positive impact of good support workers. Women suggested that they would welcome more support to arrange staff training and recruitment from the local authority or relevant support organisations.

Independent Advocacy and Support

Women value and benefit from the provision of independent advocacy, advice and support. These services – and the organisations that run them – need sustainable resources to continue their important role. Local peer support networks should also be encouraged and supported.

Recommendations

Women generally reported that SDS had improved their social care experience and have 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 women'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 the physical and mental health of women 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. This should include gender disaggregated data, which distinguishes between the experiences of women as users of SDS, and women who are unpaid carers for friends and family members who use SDS (as important but distinct experiences).

Information About SDS

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

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

5. Work should be done to dismantle communication barriers faced by Black and minority ethnic people and older people – particularly in communities where women are more likely than men to have limited fluency in English.

6. Women's socioeconomic status should help inform tailored communications.

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

8. Women 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.

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

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

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

12. Women should be supported to consider the advantages and disadvantages of each SDS option before making decisions.

13. If emergency support is put in place following hospital discharge, women should receive follow-up information and conversations to ensure that the original arrangements continue to suit their needs and preferences.

14. Professionals should (be able to) spend more time reviewing case notes before meetings and reviews/assessments and getting to know the people they support.

15. Professionals should proactively check back in with people after assessments to ensure any outstanding concerns are addressed.

16. Women should be offered a variety of ways to contact social work, as best fits their access needs and preferences. Social work departments should consider different opportunities, including online chat functions, a freephone support line, and direct email addresses so that people can communicate effectively with social work professionals.

17. Women should always have access to independent advocacy and support, including translators, for assessments and review meetings, if they desire.

18. Women should be provided with paper or digital (as preferred) copies of all documentation pertaining to their SDS, including Personal Outcome Plans, budget agreements, and decisions about their support package. These documents should be provided promptly and all materials should be available in a variety of accessible formats.

19. Everyone must have access to information about the budget available to them and specific work may be required to ensure this extends to all population groups, including women and people living in areas of deprivation.

20. Women 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

21. Women should be given longer than a week to consider their SDS options, and work is required to ensure they enjoy parity of decision-making time with men.

22. 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.

23. Women have the right to expect a reasonable notice period for needs assessments or reviews.

24. More work is needed to ensure everyone is offered, and can make their own meaningful choice between, all four SDS options.

25. 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.

26. Targeted efforts are required to ensure that women, and particularly people with lived experience of homelessness and women living in deprived areas enjoy equal decision making about their SDS option and support.

27. Targeted work is required to ensure that women with learning disabilities are offered the four SDS options and that their support is person centred and rights based.

28. Ensuring non-discriminatory attitudes and behaviour and a lack of gender bias in the support offered and provided to disabled parents is essential to ensure parity of support.

29. Professionals 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.

30. Women 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.

31. 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.

32. 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 to remain – with appropriate support – in their own homes for as long as possible.

33. 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.

34. 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.

35. Women – particularly those living in rural areas and those who are blind or partially sighted – require more acknowledgement and accommodation of travel costs in their SDS budgets.

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

37. Professionals should consider equality assessments in their processes – both for service users and their families.

Communication and Relationships with Social Work

38. 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.

39. 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.

40. Women should be informed if their social worker changes and have a right to request a new social worker if trust breaks down.

41. 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.

42. 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.

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

44. 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).

45. 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

46. Disabled mothers' parenting decisions should be respected and supported by social work professionals and support workers.

47. 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.

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

SDS and Mental Health

49. Social work professionals and decision-makers should consider the impact on women's mental health of any reductions or changes to support arrangements – particularly substantial reductions in budgets.

50. People with mental health problems should be supported to access local mental health support services, which should be appropriately funded and resourced.

Care Staff, Recruitment, Training and Quality

51. Some women need more help from local authorities and health and social care partnerships 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.

52. 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.

53. 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.

54. Targeted work is required to ensure that LGBT+ people and people with lived experience of homelessness do not experience discrimination or inequality when accessing SDS.

Independent Advocacy and Support

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

56. Focused efforts are required to ensure older women, Black and minority ethnic people, and women from all socioeconomic backgrounds are aware of – and can access – independent advocacy and support services.

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

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

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

60. Local peer networks should be encouraged and supported.

Research Participants

The MSMC project heard about the experiences of 321 women who used or were being assessed for SDS. 249 women completed the survey, we interviewed 54 women who spoke about their own experiences as well as the experiences of other women in their household who used or are being assessed for SDS, and 18 women who used SDS participated in focus groups. More women also participated in interviews and focus groups in their role of unpaid carers; their responses, while important, have not been included in this report, which focuses on women's experiences of using SDS for their own care and support.

Throughout this report some participant details (e.g. age) have been changed slightly to preserve anonymity, while maintaining the most important information. Where changes have been made to quotations those alterations are indicated via square brackets (e.g. "My advocate, [Name], has been great").

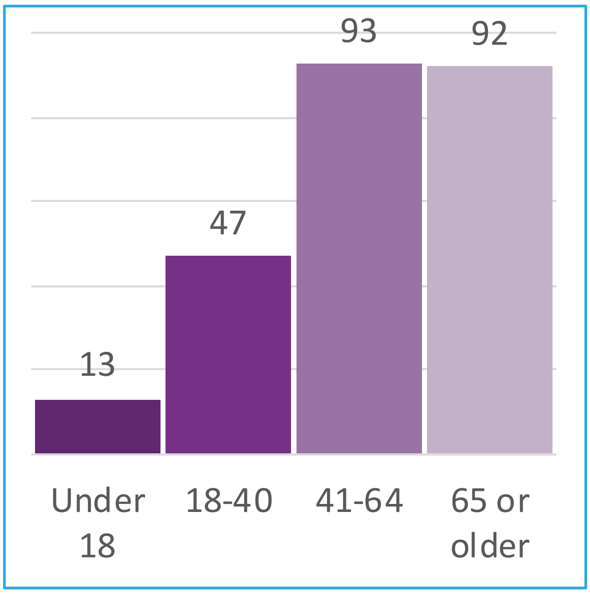
Where possible, we have compared participant data to figures from Information Services Division's (ISD) experimental statistics on social care in Scotland.[4]

ISD data is not available for the number of men and women accessing SDS in 2017-18, however there is data on the number of men and women receiving 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 38% of people accessing social care support were men and 62% were women.[5]

Age

We asked all participants to share their age. Of those who chose to answer the question, 13 (5%) were under 18 years old, 47 (19%) were between 18 and 40 years old, 93 (38%) were between 41 and 64 years old, and 92 (38%) were 65 or older.

Chart 1: Respondents' age



The ISD dashboard does not provide an overall breakdown of age groups accessing SDS in 2017-18, although age group data is provided by SDS Option Chosen and Client Group Profile. ISD estimate that in 2017-2018, 868 girls aged 0-17 received social care support (1% of women and girls receiving social care support), 20,264 women aged 18-64 (16%), and 103,626 women who were 65 or older (83%).[6] Age group data for women and girls accessing SDS in 2017-18 is not available on the SDS dashboard.

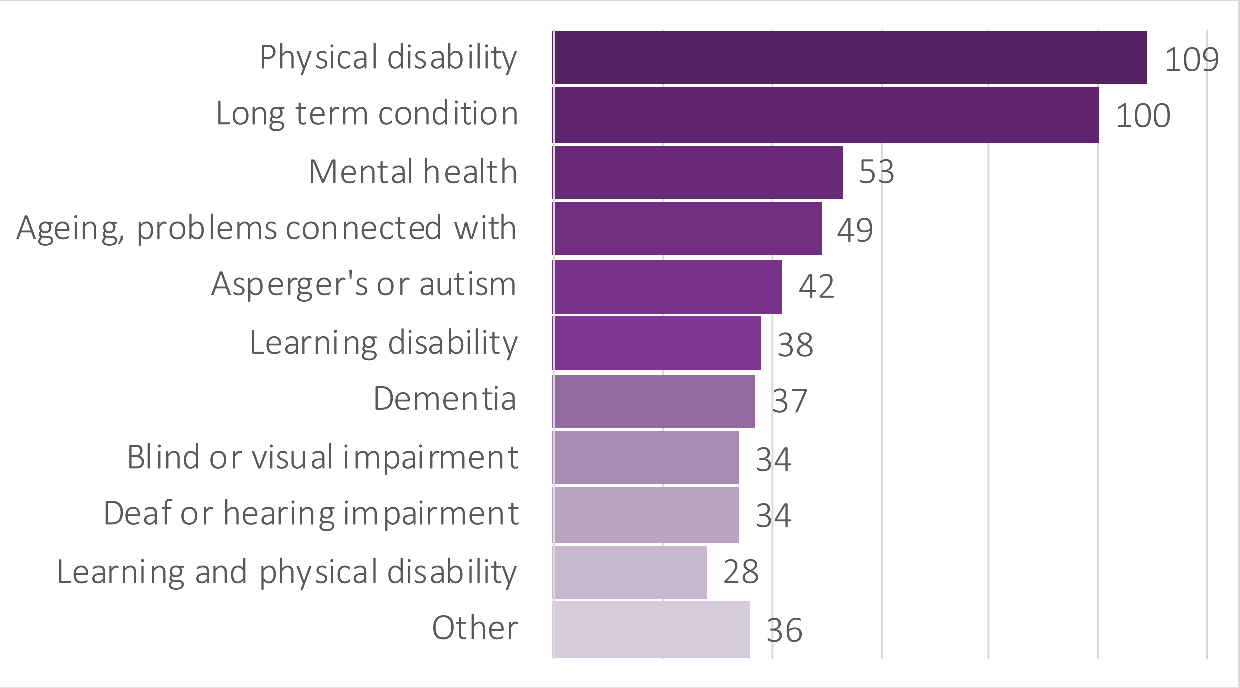
Ethnicity

In the MSMC survey, 241 women identified as white, six women identified as belonging to other ethnic groups and one woman chose not to describe her ethnicity. Most interviewees and focus group participant did not disclose their ethnicity when self-describing themselves, and the majority of those that did described themselves as "white". The overall spread of MSMC respondents is therefore slightly less ethnically diverse compared to the general 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".[7]

Disaggregated data on the ethnicity of people accessing SDS in 2017-18 is not available on the ISD dashboard. There is 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".[8] 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").[9]

Chart 2: Client Group/Disability/Long Term Condition (Survey)



Client Group/Disability/ Long Term Condition

Survey respondents self-identified as living with a range of conditions, and the majority reported that they live with multiple conditions. 109 women (33%) selected physical disability, 100 women (30%) said they live with a long-term condition, and 53 women (16%) indicated they have lived experience of mental health problems.

Interviewees and focus group participants also discussed their conditions, and – if they were unpaid carers – those of the women for whom they care. Their reasons for accessing SDS were broadly in keeping with survey respondents'.

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.[10] 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).

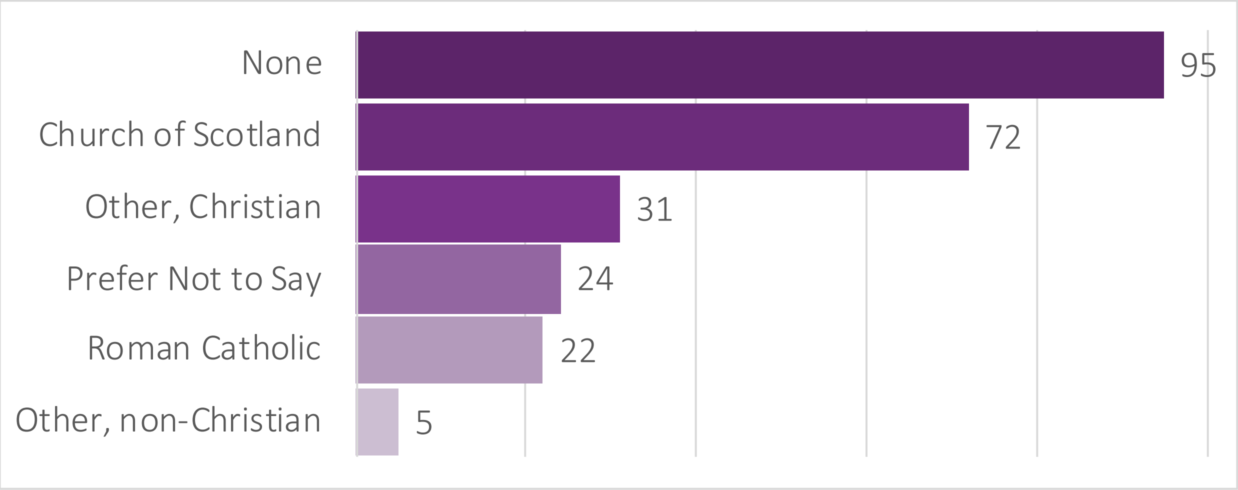
Gender-disaggregated data for SDS client groups in 2017-18 is not available on the ISD dashboard.

Religion

When asked about their religion (if any) in the survey, 95 women (28%) stated "none", 72 (21%) were part of the Church of Scotland, 31 (9%) described themselves as "other Christian", 22 (7%) were Roman Catholic, and five women chose another religious group. 24 women (7%) preferred not to answer. Most of the interview or focus group participants did not choose to explicitly disclose their religion when self-describing themselves. These results are slightly 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 3: Survey respondents' religion



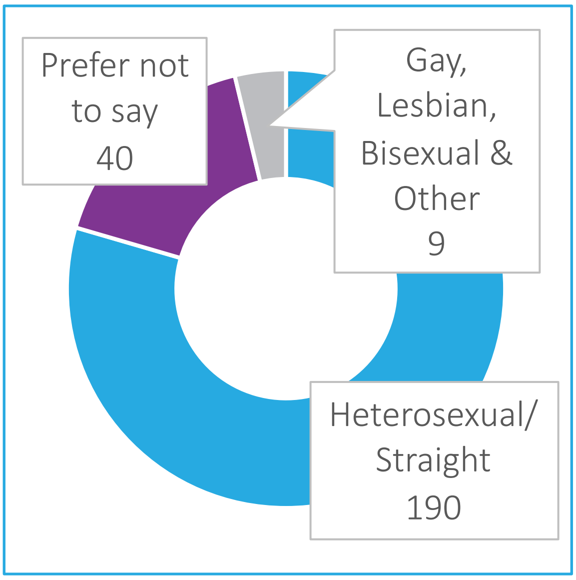
Sexual Orientation

In the survey, 190 women described their sexual orientation as heterosexual or straight, four women identified as lesbian or bisexual, and five women selected "other". A further 40 women stated that they preferred not to disclose their sexual orientation, and ten women did not answer the question.

The 2011 Scottish Census did not record data on sexual orientation at local authority level; 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 4: Survey respondents' sexual orientation

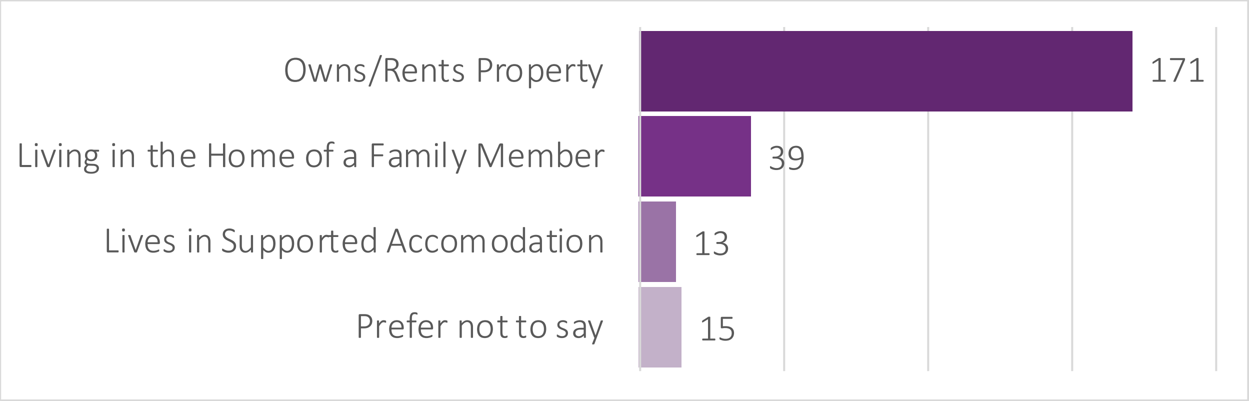


Housing

Among the women who answered this question, 171 either rented or owned their own home, 39 reported that they lived in the home of a family member, 13 lived in supported accommodation, and 15 women selected "prefer not to say".

When discussing housing, several interview and focus group participants spoke about their current situations, spanning a similar range of options to survey respondents. Of those who discussed their housing arrangements, most women live independently in their own home, followed by those who live with a family member.

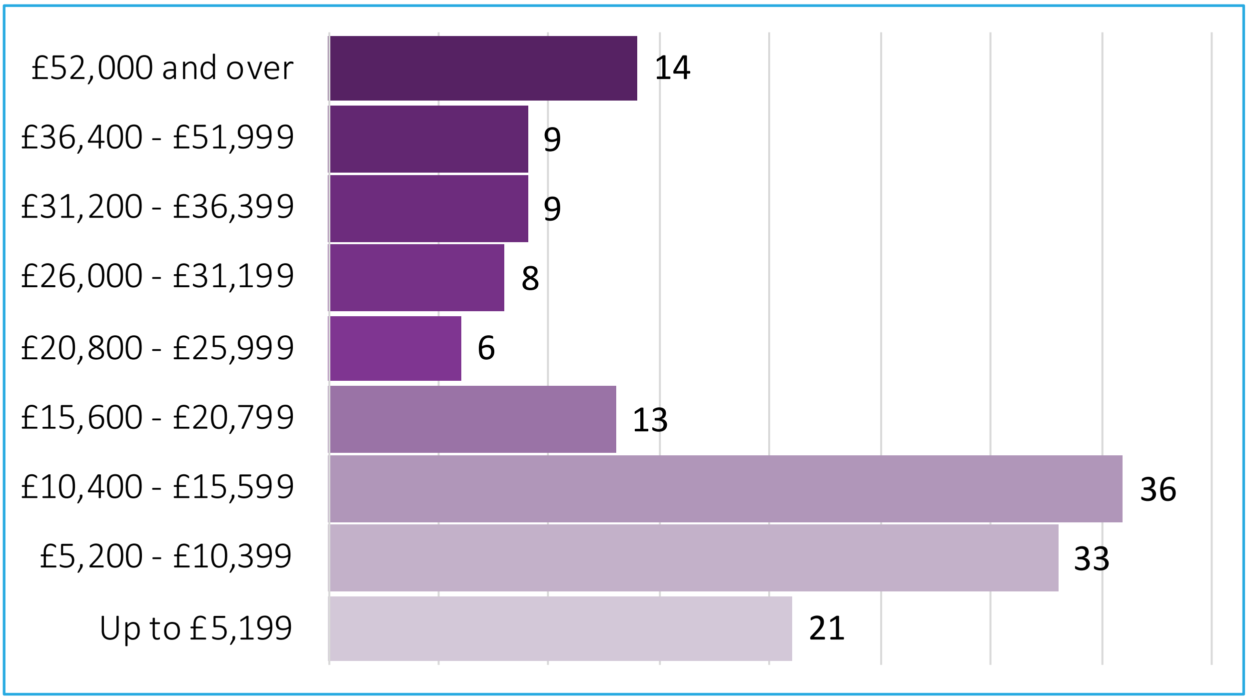
Chart 5: Survey respondents' housing arrangements



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.[11] 143 chose to disclose their annual household income in the survey.

Chart 6: 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).[12] 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).[13] Based on this definition, 90 women (63%) who chose to provide details on their household income are living below the poverty threshold (compared to 59% of men).

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

SDS Option

Of the MSMC survey and interview participants who shared which SDS option they used, 30 women (56%) indicated they used Option 1, five women (9%) used Option 2, 11 women (20%) used Option 3, and eight (15%) used Option 4.

Figures from ISD indicate that in 2017-2018 there were 8,390 people in Scotland using SDS Option 1, 7,435 using Option 2, 78,054 using Option 3, and 4,257 using Option 4.[14] In some instances, people are logged as being on two options simultaneously (e.g. Options 1 and 3) rather than Option 4, which distorts these figures.

Data on the SDS options chosen by women in 2017-18 is not available on the ISD dashboard.

Data Gathering and Analysis

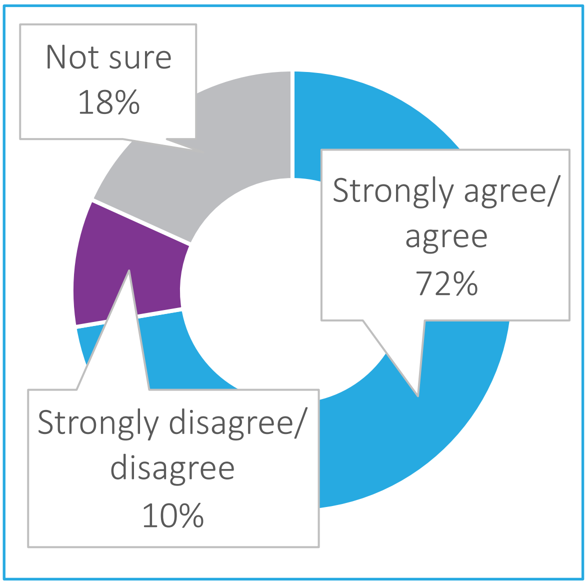
As this chapter demonstrates, there are concerning gaps in SDS data gathering and analysis. Information Services Division (ISD) have reflected on difficulties gathering disaggregated data on people's use and experiences of SDS/social care in their experimental statistics publication Insights into Social Care in Scotland.[15] 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.[16] 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".[17] Information and analysis about women's experiences is not provided in the Care Inspectorate's 2019 thematic review of SDS,[18] nor Audit Scotland's 2017 progress report and subsequent 2019 impact report[19].

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 women, following human rights principles of equality, non-discrimination, participation and inclusion. To avoid gaps and improve analysis, we recommend systematic and robust data gathering by local and national public bodies on people who access SDS, disaggregated by all protected characteristics, including age, gender, sexual orientation, ethnicity, and religion, as well as socio-economic information like household income and 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. Overall, 123 women (72%) stated that they "strongly agree" or "agree" with the statement "SDS would/has improve/ improved my social care experience". 16 women (10%) disagreed or strongly disagreed with that statement, and 31 women (18%) responded that they were unsure. 79 women did not answer this question.

Chart 7: "SDS has improved my social care experience" (Survey)



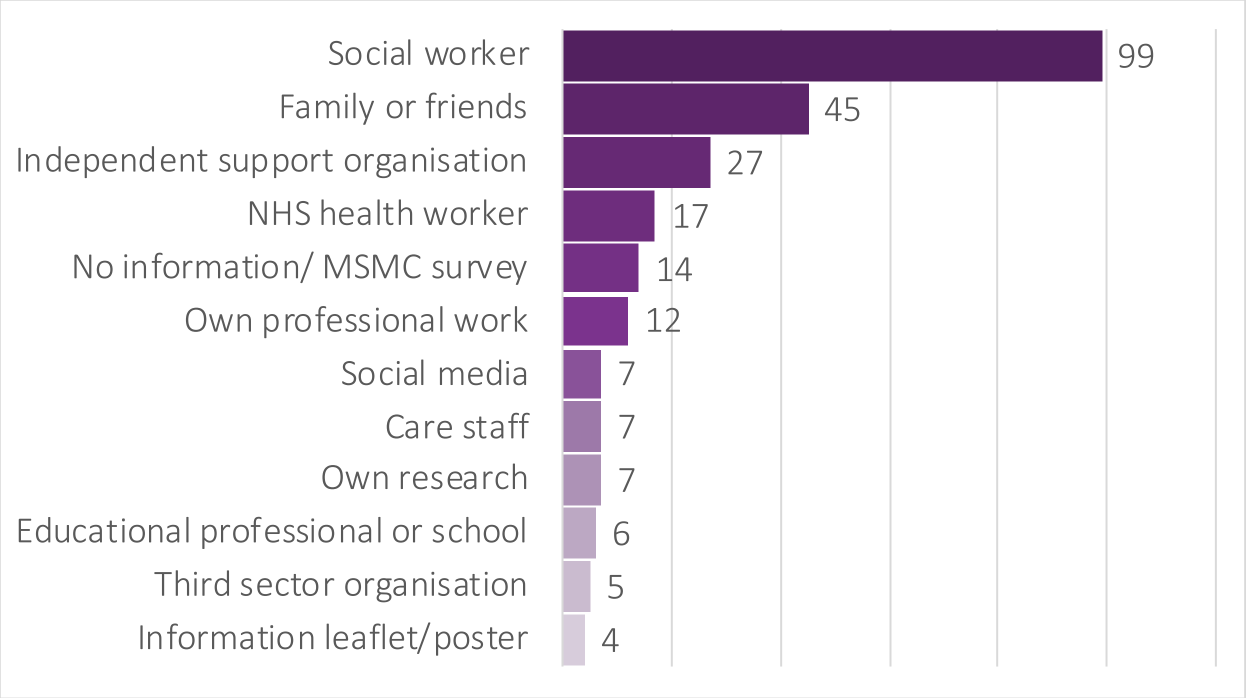
Many women's statements about their overall experiences of SDS were positive, with several women stating that it had "changed my life" and people should "go for it".

However, while most women were positive about their experiences of SDS, some respondents were more cautious or explicitly negative, particularly relating to difficulties with paperwork and assessment processes, and insufficient budgets. One interviewee, whose experience of SDS had featured both positive and negative incidents, offered the following summary of the process and advice to others considering accessing SDS:

> *"If they want full control, if they want full control or choice, […] of their life then the way to do it is get SDS. It's got its problems, but you can do an awful lot more than when you don't have support via SDS. […] The context of SDS is fantastic, and when it operates as it should, with support given to people who are directing their support, with appropriate support given to them wherever they need it, then it's a great way of life for people who need support. "*

Information About SDS

Chart 8: How did survey respondents first hear about SDS?



Finding Out About SDS

We asked women how they first found out about SDS.

99 women (41%) had first heard about SDS from a social work professional or occupational therapist. 45 women (19%) heard from friends or family members,

27 (11%) from an independent support organisation, and 17 (7%) from NHS staff, including nurses working in the community. 12 women (5%) learned about SDS through their own professional work before they accessed it themselves – as social workers, academics, care workers, health staff, legal professionals, third sector employees, and people who work for a local authority.

Seven women learned about SDS via social media, seven from care staff, and seven discovered SDS through their own research – primarily using the internet, with several referencing local authority or Scottish Government websites as sources of information. Six women were introduced to SDS by an educational professional or school, five from third sector organisations involving disabled people and people living with long term conditions, four from an information leaflet or poster, and two from an independent advocate. Two women knew about SDS as they had received it in England before moving to Scotland. One woman first heard through a local carers' network, and one through a community brokerage.

Among interviewees and focus group participants, the most common method through which women first heard about SDS was also from a social worker. This was followed by hearing from friends or family members, independent advice or support organisations, or a health professional.

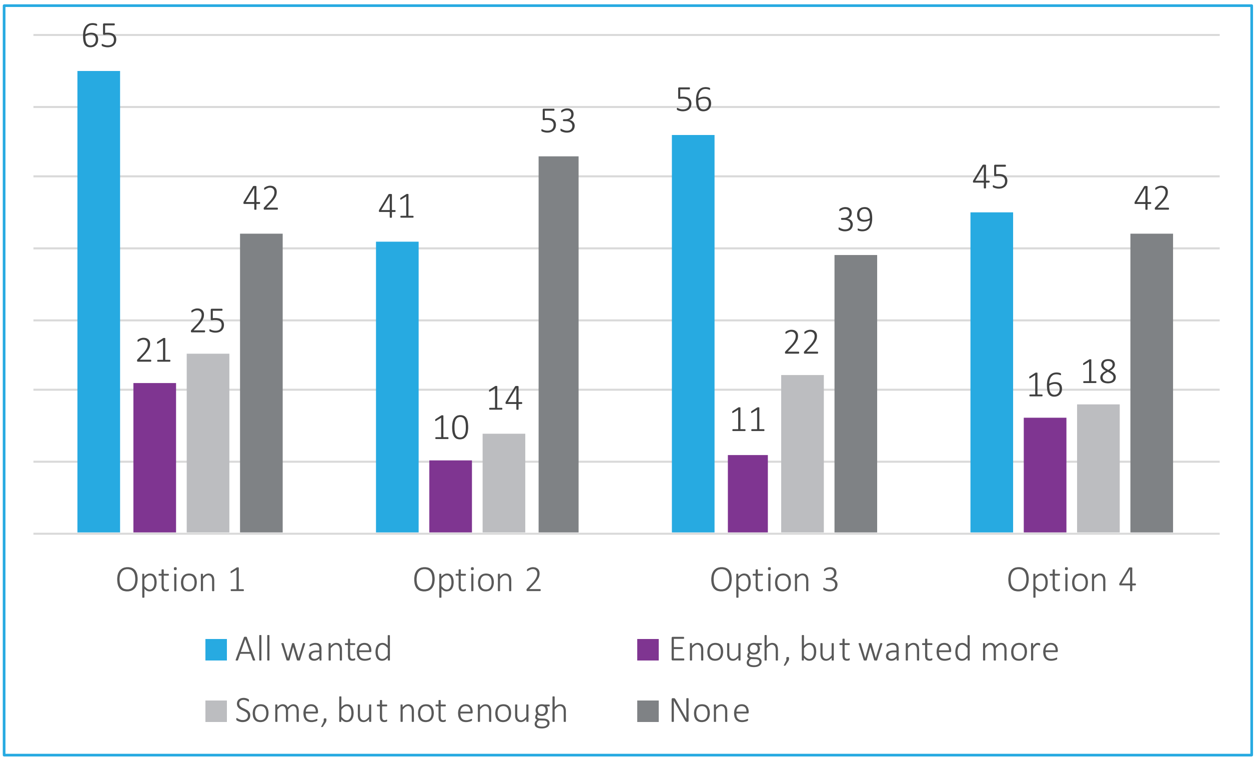
14 women who completed the survey reported that they had never received information about SDS – including seven who stated that they first heard about SDS via the survey itself. Several interviewees also stated that they did not understand or had not had SDS fully explained to them. Some women spoke eloquently about receiving insufficient information about SDS – even when they were in receive of services.

Finding Out About SDS: Overall, the results indicate that it would be helpful to widen the pool of professionals who are informed about SDS and can encourage women 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.

Chart 9: Information received before discussing support (Survey)



Of the women who answered this question, across all four SDS options, a large minority received "all the information [they] wanted" (42% (Option 1), 35% (Option 2), 44% (Option 3) and 37% (Option 4). However, it is concerning that the majority of women who answered this question either had no information or were left wanting more in advance of their needs assessment across all four options.

Of the women who felt they needed more information before meeting with a professional to discuss their support, 44% of respondents stated that they either received "some, but not enough" or no information at all about Option 1, while a further 14% said they had received "enough" information "but wanted more". With Option 2 (which had the lowest satisfaction rate across the options), 57% of respondents reported that they had either "some, but not enough" or no information, with 8% receiving "enough, but wanted more". For Option 3, 48% of respondents said that they had either "some, but not enough" or no information, and 8% of had "enough, but wanted more". Finally, 50% of respondents said they had received either "some, but not enough" or no information about Option 4, while 9% received "enough, but wanted more". Across the board, women who answered this question reported lower satisfaction levels with the information they were given about the different SDS options than men.

Some interviewees and focus group participants had been fully informed about the options prior to their assessments, but many women had not been told about all four options when they started the process of accessing SDS, which had 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 people). Many women who currently access SDS stated that they had never heard of a needs assessment.

Information and Preparedness Before Assessments: These findings indicate that many women still 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 women about the different 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 women reach crisis point; and reduced demands on staff time because women are better prepared for discussion and assessments. Furthermore, women whose SDS starts following discharge from hospital should receive follow-up information and discussions once support is in place, to ensure that the original arrangements continue to suit their needs and preferences.

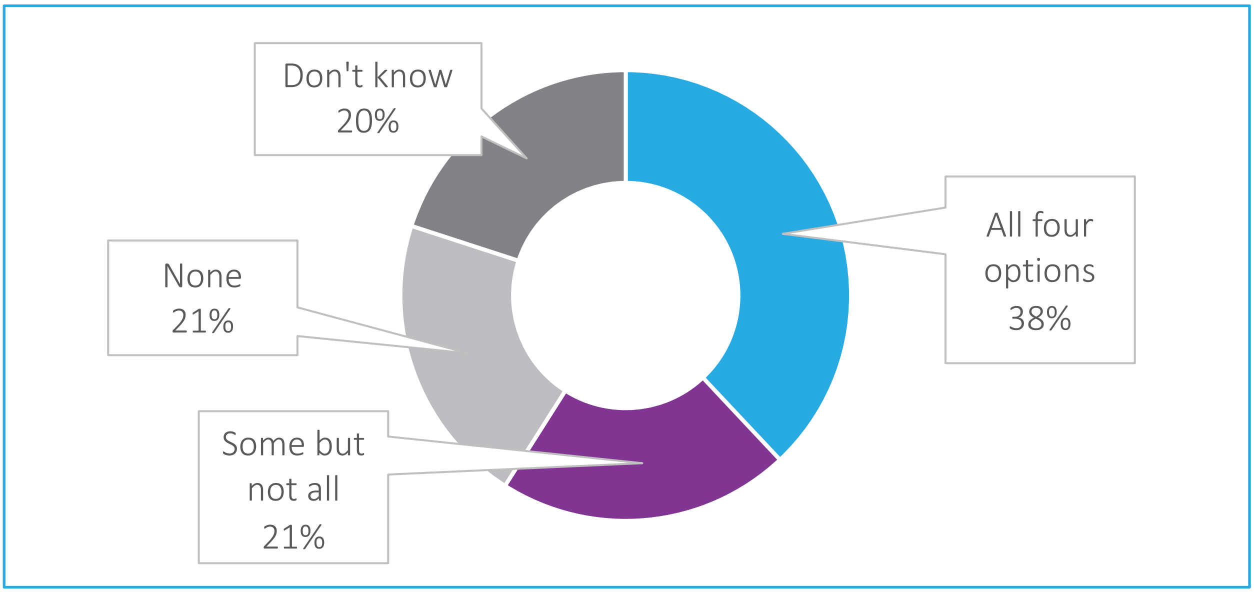
Information During Assessments

This pattern of variable information about the four options continued into women'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 233 women who answered this question, 90 (38%) stated that the professional discussed “all four options” with them. However, 48 (21%) reported that “some but not all” options were discussed with them, and 48 (21%) stated that “none” of the options were discussed. A further 47 (20%) stated that they were “unsure” which options were discussed with them during that meeting. This pattern indicates that more work needs to be done to fully outline and discuss the four options with women during their needs assessments and reviews. Women are less likely than men to have had all four SDS options discussed with them in their needs assessment; 39% of women reported that all options were discussed compared to 46% of men.

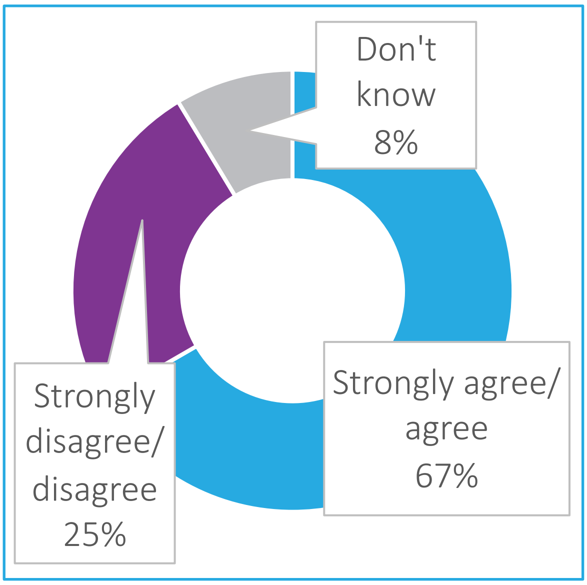
Chart 10: Discussing SDS options with professionals (Survey)



Many interviewees and focus group participants reflected on positive experiences during their needs assessments; however, the majority of women recounted more mixed experiences. Several reported that they felt that the conversations they had with social work professionals were rushed, and many stated that social workers did not explain the process around SDS properly to them in a way they could understand. Many women interviewees and focus group participants stated that they were offered reduced choice, without all four SDS options being offered.

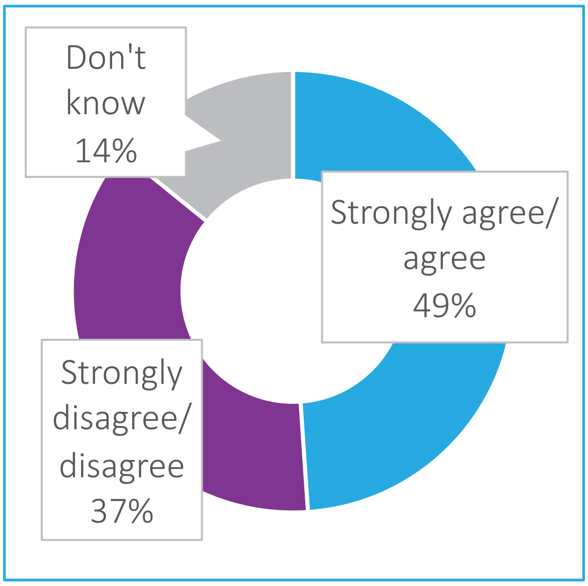
In the survey, we asked respondents a series of questions about their interactions with social work professionals. When asked whether they agreed with the statement “The person I met with explained things clearly to me”, 154 women either “strongly agreed” or “agreed” (67%) with the statement, while 57 women (25%) disagreed or strongly disagreed. A further 20 women (8%) were unsure. 15 women did not answer this question.

Chart 11: "The person I met explained things clearly to me" (Survey)



We also asked respondents about whether they had had any questions during their needs assessments or reviews. In the survey, we asked women to respond to the statement "All my questions were answered", regarding their meeting with a social work professional. Of the 233 women who answered this question, 114 (49%) "strongly agreed" or "agreed", while 86 (37%) "strongly disagreed" or "disagreed". A further 33 women (14%) said that they did not know. Interviewees and focus group participants indicated similar experiences.

Chart 12: "All my questions were answered" (Survey)



Women were less likely than men to think that all their questions had been answered. 57% of men either "agreed" or "strongly agreed" with the statement "all my questions were answered", while 49% of women "agreed" or "strongly agreed" with that statement.

Several women spoke about difficulties in obtaining answers to their questions during or after needs assessments or reviews. One woman summarised her experience as follows:

> *"I had plenty [of questions]; they weren't properly answered. I think the biggest question for me was that there were some parts for me that actually got ridiculous. In your needs assessment you have to answer A to E – so, A being you need very little support and E being full support. There was no discrepancy in the personal care side of things because obviously I need full support. But, for example, for making a cup of tea, I put I need full support and she said, 'can you not boil the kettle?'. I said 'yes, but when it is boiled, I can't lift it'. She said, 'can I see your kettle?' – and she went and checked and came back and said 'you know the answer to that, don't you? Get a bigger cup'. I said 'you are missing the point; […] I can't lift it. With a bigger cup, it will be harder and I can't lift it'. It was even wee things like that. It didn't matter what I said, she always shot me dead. It wasn't because she wasn't giving me what I wanted, it was because there was no meeting in the middle, there was no 'okay, let's compromise'. It was point blank 'no'."*

From the survey responses, around half of women felt that social work professionals provided good information and answered all their questions – even if an important minority also wanted more information. These findings indicate constructive interactions between women who require social care support and social work professionals. The minority who disagreed with these statements invite further work to improve services to ensure consistently good experiences in this area, and particularly to ensure that women are offered the same level of information and opportunities to ask questions as men.

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 women's first port of call for information about SDS, including eligibility criteria, wait times and available support. The research indicates that further work is needed to ensure that all women are fully informed about the four SDS options during assessments and given the opportunity to consider them. For some women, information is best provided face-to-face, more than one conversation may be needed, and women should have access to independent advocacy and support and foreign language translators during these meetings if they want. Women should have access to information in a range of accessible and inclusive communication formats in advance of and during meetings. Further, targeted work by social work is required to ensure that women are fully involved in all decision making about their care and support, and to make sure their questions are answered. Women would benefit from targeted initiatives to ensure that they are fully involved in all processes about their social care and support, and to make sure their questions are answered. Options for assisting this process may 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 had any concerns that were not addressed during their last assessment. Of the 234 women who answered this question, 104 women (44%) had no concerns, 65 women (28%) had outstanding issues that were not addressed by social work, and 65 women (28%) were unsure.

Of those women with unaddressed concerns, budgets, delays in implementing care, and a lack of information about SDS were the main concerns – with women highlighting that these issues had direct and negative impacts upon their health and the health of those for whom they care. Two women who had been the victims of crimes reported that they did not feel their safety concerns were addressed during their needs assessments.

Speaking more broadly, 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 overall who answered the question, 25

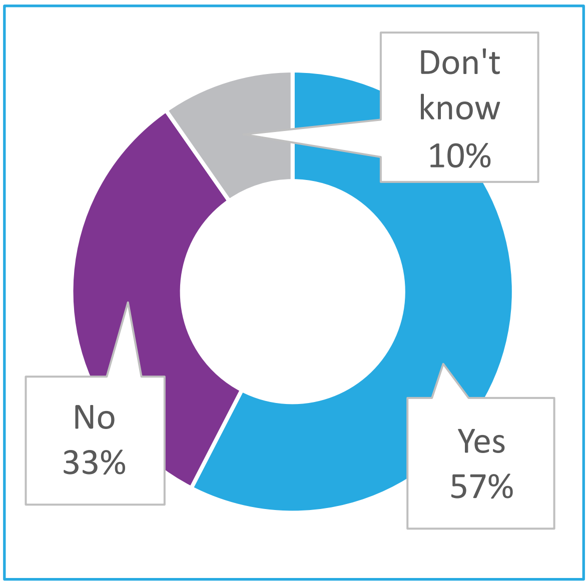
(7%) indicated that they were in the process of appealing the outcome of their last social care assessment or review, of whom 12 were women.

Outstanding Concerns and Appeals: The research invites further work to strengthen and embed existing good practice to ensure that women are not left with unaddressed concerns following needs assessments. Women 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 women 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 165 women who answered the question, 95 (57%) said yes, they had been told how much money they could spend, while 54 women (33%) said they had not been told how much money was available to them. A further 16 women (10%) stated that they did not know if they had been given a budget. That most women had received information about how much money was available to them is a positive finding. However, it is concerning that substantial minority had either not received that information or were unsure.

Chart 13: "Have you been told the amount of money you can spend on your support?" (Survey)



Furthermore, women were less likely than men to have been given information on their SDS budget. 58% of women stated that they had been told the amount of money they could spend on their support, compared to 76% of men. This finding invites sustained effort from social work professionals to ensure that women are given appropriate information about their budgets.

Interviewees and focus group participants who were not given information about their budgets reported similar concerns. One woman summarised her experience as follows:

> *"At the moment, I have a budget. [...] I don't actually know what the budget is because the previous social worker said it was something ridiculous, but even the broker who supported me at the time said, 'it can't possibly be that because if you calculate it, it's not even costing that.' So, I don't actually know what my budget is."*

The interviewee is currently having their budget reassessed following their latest review; while they are pleased with the proposed plan, and assistance from a new social worker, they stated that “the biggest difficulty is that it still remains unresolved. I don’t know when it will be agreed, what the budget going to be agreed.”

Overall, women 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 women to make informed decisions about their care, measures should be in place to ensure they are provided with accessible information about the budget available to them. Women 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.

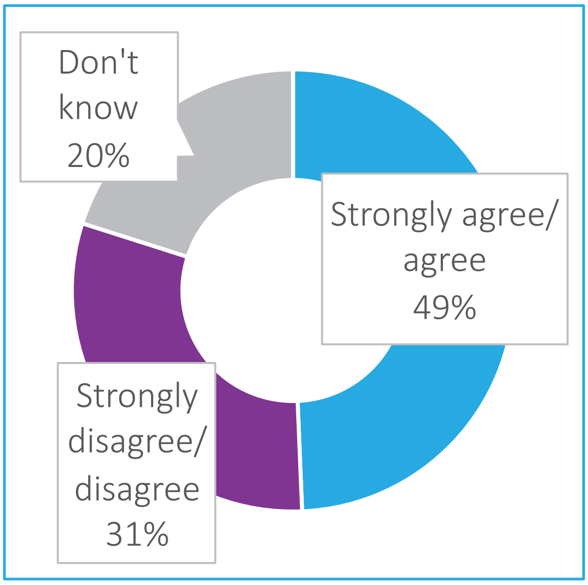
Informed Choice and Control

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 229 women who answered this question, 113 (49%) either “agreed” or “strongly agreed”, 70 (31%) either “disagreed” or “strongly disagreed”, and 46 women (20%) stated that they did not know.

When discussing time to choose, men were more likely than women to think that they had had enough time to choose their options. 64% of men either “agreed” or “strongly agreed” that “I had enough time to choose the option of SDS that suited my needs”, while only 49% of women “agreed” or “strongly agreed” with that statement.

Chart 14: Enough time to choose SDS option (Survey)

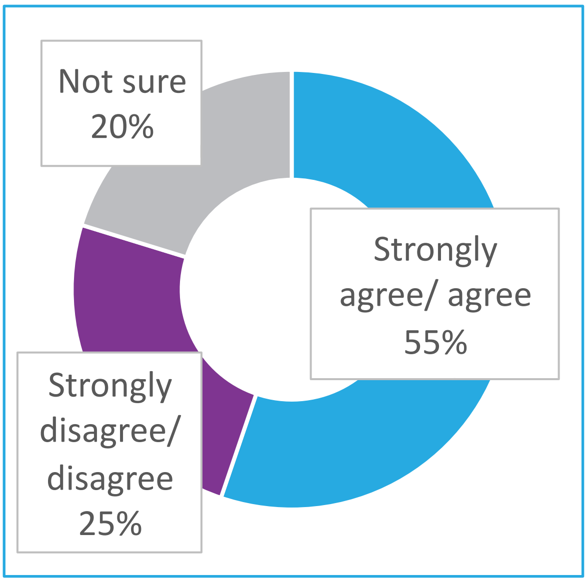


Time to Consider Options: The research suggests that there is a correlation between the time women are given and the need for clear, prompt and accessible information so that they can make informed and appropriate decisions about their support. Work is required to ensure women enjoy parity of decision making time with men.

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 163 women who answered, 90 women (55%) either "strongly agreed" or "agreed" with that statement, while 40 women (25%) "disagreed" or "strongly disagreed". A further 33 women (20%) stated that they were unsure.

Chart 15: "Waiting times, or waiting for responses, makes SDS more difficult for me" (Survey)



Women who took part in interviews and focus groups appreciated short waiting times for a response or decision from social work. They also commented on problems caused by long waiting times to access needs assessments or reviews, following a request for support, with some women waiting over a year.

Other women commented on additional waiting times that they did not expect, between initial phone contact with social work, assessments, decisions on packages and finances, and finally the eventual implementation of support. For those that waited longest, family members reported concern about how to provide support, especially when the service user needed increasing levels of support. One interviewee reported that they considered inviting a female service user to move into their home during this interim period (which spanned nearly a year), but was concerned that this would adversely affect both the person's independence and happiness, and local authority decisions on whether they could access SDS:

> *"I almost don't want to mention the idea of [Name] coming to stay with me, in case somehow that then impacts on getting a reassessment and getting more care. So, I don't want to shoot myself in the foot by mentioning something that actually might not be able to go forward. It's so difficult. I suppose what I always fear is if [Name] ever got to the stage in her own house where she couldn't navigate by herself anyway, she would be in my house unable to navigate, you know. It wouldn't make any difference, but where [Name] is able to navigate in her own house, it wouldn't be an advantage to her be in mine, because you're taking away that. […] And she wants to be in her own house. […] She doesn't want to go into a [residential care] home, she's terrified of going to a home, she's terrified of going into a hospital."*

Eventually, the individual in question did obtain a suitable SDS package – but the prolonged wait period caused substantial stress to those providing unpaid care, and deterioration in the service user's physical and mental health. Had decisions been quicker, those adverse consequences for the interviewees may have been reduced.

The unpaid carer also reflected that had they known how long it would take to access SDS, their family member would have selected another option which would have enabled a quicker provision of support via Option 3 – even if care was then less tailored.

Waiting Times: Short waiting times are greatly appreciated because when women 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 women's physical and mental health and wellbeing. Timely support can help women avoid reaching crisis point and the potential for more serious and expensive intervention later.

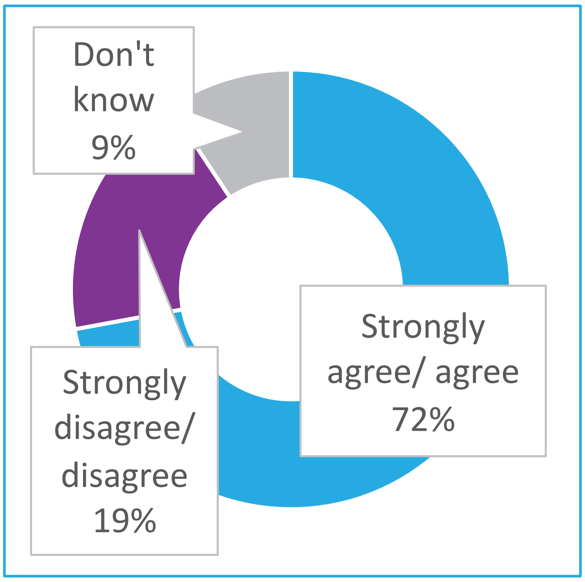
Choice Over SDS Options and Support

We asked survey respondents if they were on their preferred SDS option. Of the 174 women who answered, 143 women (82%) were on their preferred option, 19 respondents were unsure (9%), and 12 women reported that they are not on their preferred option (7%).

Women who were on their preferred SDS 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.

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 172 women who responded, 124 (72%) "strongly agreed" or "agreed" with that statement, while 32 women (19%) "disagreed" or "strongly disagreed". A further 16 women stated that they did not know (9%).

Chart 16: "I am fully involved in all decisions about my care and support" (Survey)

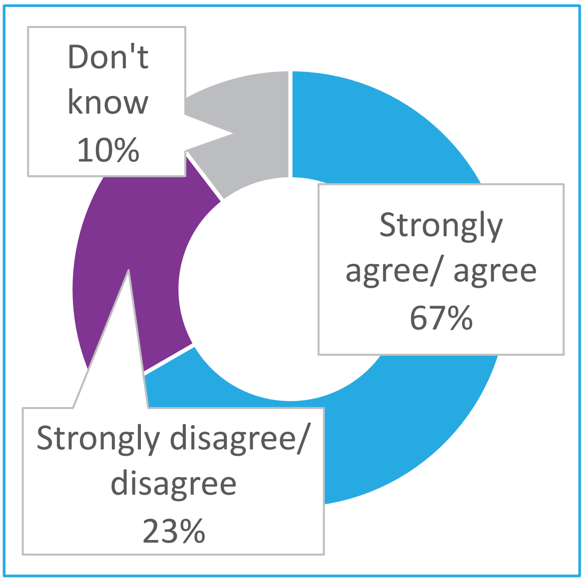


These survey findings were reflected in the experiences reported by interviewees and focus group participants. Many women reported that they felt that they were fully involved in decisions about their care and support. However, others reported that conversations with social work professionals were rushed, and several stated that social workers did not explain the process around SDS properly to them in a way they could understand.

An important minority of women from across Scotland stated that they were offered reduced choice, without all four SDS options being offered. Troublingly, several respondents with learning disabilities reported that their social workers had informed them that SDS was not suitable or accessible for them. Other women had similar experiences – particularly when leaving hospital, and without any subsequent review or discussion of options later.

In the survey, we asked participants to respond to the statement "I had a say in how my help, care or support was arranged." Of the 231 women who responded, 154 women (67%) either "strongly agreed" or "agreed" with that statement, while 53 (23%) "disagreed" or "strongly disagreed". A further 24 (10%) stated that they did not know.

Chart 17: "I had a say in how my help, care or support was arranged" (Survey)



We also asked survey respondents who chose the way that their support is arranged now. While men and women were equally likely to have chosen the way their support was arranged themselves (respectively, 36% and 37%), women were more likely to have had their support chosen for them by a health or social care professional than men (29% versus 20%). Men were more likely than women to have their support chosen by friends and family, with 35% of men selecting that option, in comparison to 20% of women.

These findings indicate that just over a third of women who answered this question were free to choose their own support arrangements, and a fifth had their care and support chosen by friends or family members. While the former results are welcome, the fact that 29% of women who answered this question state that social work or health professionals chose for them invites further work in supported decision making and to ensure parity of choice for women.

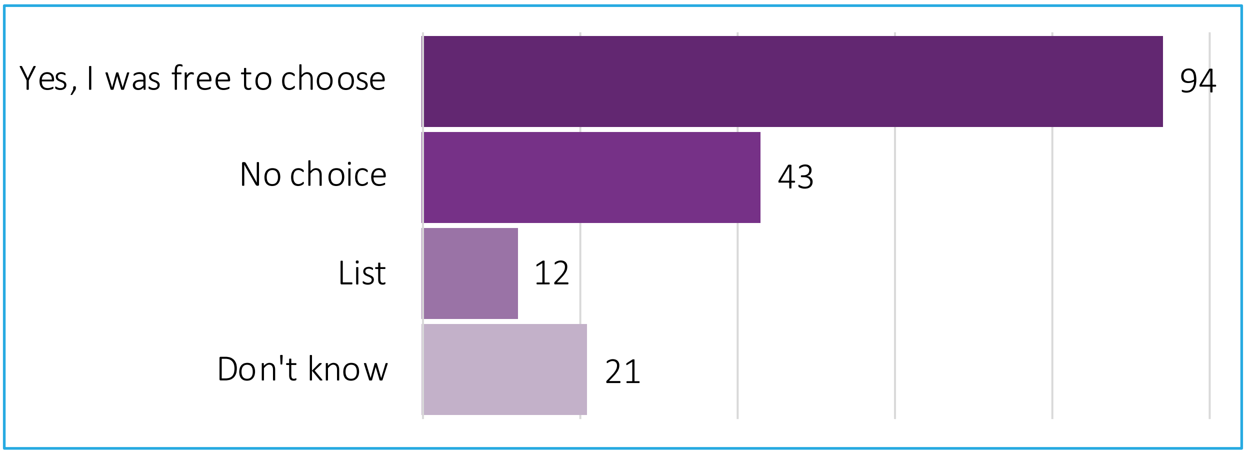
Some interviewees felt that their social worker had decided what SDS option they would choose before completing the needs assessment. Other interviewees highlighted the importance of access to information to make informed decisions, since they felt that they were at the mercy of what knowledge their social worker had, especially around Option 1.

Choice Over SDS Options and Support: The research suggests that more work is needed to build on good practice and examples and ensure all women are offered a meaningful choice between all four SDS options. Although many women indicated they were happy with their support, improvements could also be made to decision making. While health and social care professionals play an important role in helping women access appropriate services, that should not extend to making decisions on their behalf – the principles of choice and control are clearly embedded in SDS legislation and policy, and extend to all population groups, including women. Staff could be given more training about 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 170 women who answered this question, 94 (55%) said that they were free to choose who they wanted to manage their personal budget. 12 women (7%) were able to choose from a set list of providers given to them by a social work professional. 43 women (25%) stated that they were not given a choice. Finally, 21 (12%) were unsure of whether they had a choice.

Chart 18: Did you choose who manages your personal budget? (Survey)



It is encouraging that most women were offered the choice of who to manage their personal budget. However, the fact that a quarter of women were offered “no choice” is concerning – and indicates, among other things, that they were not fully offered all four SDS options (as that would necessitate discussion of who would manage their personal budget).

Women were less likely than men to have been able to choose who managed their personal budget. 55% of women stated that they were free to choose who manages their budget, while 25% stated that they were given “no choice”. In comparison, 65% of men reported that they were free to choose, and 17% stated that they were given “no choice”.

Budget Management: These findings reinforce earlier recommendations that further work is needed to ensure that women are offered a meaningful choice of all four SDS options. The disaggregated data also indicates that there needs to be sustained work to ensure women are given the same choices as men.

Adequate Support

Several women spoke in detail about the impact on their physical and mental health of substantial reductions to their SDS budgets and support.

For example, one interviewee had previously had a comprehensive SDS package that covered regular personal care throughout the day. This assistance enabled them to be active in the community and have a good quality of life. However, following a reassessment, their package was cut by two-thirds, even though their health and support needs remained the same. This change has meant that the person no longer has assistance to use the toilet during the day; as a result, they cannot participate in social activities or community life. They have also had serious health complications as a result of the reduced care available to them. The interviewee summarised the impact of their reduced provision as follows:

> *"My [carer] said that he soon will have to look for another job and that he doesn't know how I'm going to manage. And that has taken me over the edge. I just feel like ending it all. I am constantly in tears. […] Him and my other carer moved all my medications out the way and things like that. I'm not eating. In the morning they were watching me eat my breakfast, they made me breakfast, but I just couldn't eat it. I am at my wits end. And I don't know what I'm going to do. […] While I had the original package in place, I was never suicidal. With the original package they gave me hours for shopping, socialising and all that. You know, right now that's all out the window. […] All the stress. I can't sleep, I'm always in tears."*

When the interviewee sought further support and clarification, the same social worker visited, and dismissed their mental health problems:

> *"I'm not proud of the fact, but I have attempted suicide before, because of the pains and that, it just gets too much for me. And she turned around, she just turned around and said, 'don't be silly'. She said, 'don't be silly, it's not that bad.' And I thought, but you aren't in my position, you aren't in my position, you aren't getting the pain, you can't see how I am, how I live my day to day life. Now she's taken those hours off me I can't get out. I'm stuck in the house day in day out, and I'm going to be stuck for appointments. […] I've never ever been treated that way before; I'd always been treated with respect."*

The interviewee summarised one consequence of this reduction, and its impact on their mental health, as follows:

> *"If I need the toilet, I just sit in my own mess […] for up to 12 hours until somebody comes in and cleans me. […] It makes me feel very frustrated and upset. The two are totally different. You get frustrated, that's kind of normal. But actually, physically upset – I get upset when I'm in a position to refer to the past tense. When […] I had all the hours and all was fine, I […] used to speak to people and refer people to direct payments. […] And I said 'Well, put it this way, you've got your own life, you're going around about and doing things, you've got a life.' The way I am with myself just now is not a life, it's just an existence – and it's a very minimum form of existence as it is. […] Quite often I feel suicidal. And what's the point? Because there isn't any point. Because nobody is trying to do anything to help you. Nobody is helping you – they could help you, but they're not helping you."*

At time of interview the participant was appealing the decision and awaiting a reassessment with a different social worker, with support from independent advocacy.

Several other women recounted similar experiences – and particularly highlighted the contrast with previous levels of support and good quality of life with their current situation. One interviewee summarised her experience as follows:

> *"At the beginning [SDS was] quite flexible in how I could use it. Over time it's become more restricted in in what you're allowed to do. Budgets got cut and they changed their criteria so it's really affected what you can do. [...] Social workers were saying, 'oh no, you can't do this anymore, you can't go to the gym, you can't use it to make sure your house is tidy or make sure your house is fine. Now the criteria is such that you don't need actual physical help getting washed, dressed and fed so no, you don't need it anymore.' [...] It stopped in [specific month] because they changed the criteria and it's personal care only."*

Other participants related similar stories. One person reflected that much of their difficulties in accessing support stemmed from problems accepting and verbalising that they need help:

> *"[My son] said, 'mum, why don't you say when you need help? Ask, don't do things just for your ego. But you're living alone, you need help, you ask someone. We are not here, but you can get help.' But our culture says, 'I'm fine. I'm dying, but I'm still fine.' [...] That's how we're acting in our culture."*

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

For example, one participant reflected on experiences of at 12pm still not receiving breakfast or help to get up; "getting the provision, but in a very inappropriate way". Another recounted an experience of a care worker arriving to put someone to bed in the middle of winter, and that it was only on being asked why she had arrived so early that the care worker realised it was 2.30pm. Her response was "oh, blimey, I never realised, I've already put another lady in bed!" While the participant relayed this story with good humour, they outlined the underlying problem with inflexible care provision, and – crucially – a lack of awareness that they had other options.

Another interviewee discussed how she was not allowed to choose Option 1 or 2 and was instead expected to accept support from a care provider selected by the local authority under Option 3. The interviewee expressed strong concerns to her social worker about not being able to choose who provided personal care – in particular, that the provider could not guarantee that she would be supported by women. She was very uncomfortable with the idea of men she didn't know providing personal care. The interviewee summarised her feelings as follows:

> *"I don't care what age the woman is, she could be big, wee, short, tall, you know. I don't care about*

> *her ethnicity or anything. Even bad language if she likes, but just as long as it was a woman, you know what I mean?"*

Despite these objections, the interviewee reported that the social worker "said, 'this is the best for you'" and insisted on Option 3, without ensuring the interviewee would only be supported by women or addressing her concerns. Other women reported similar concerns around being able to state a preference to be supported by other women. One interviewee linked this preference explicitly to her role as a new parent:

> *"I refuse to have male support workers because I was breastfeeding a tiny baby which meant I spent most of my life breastfeeding. […] They were fine with that, that was good."*

It is important that women feel safe in their support arrangements. As with the latter interviewee, women should be able to request support from a team of other women if they prefer, and have their preferences respected without being forced onto another SDS option.

Adequate Support: The research suggests that some women are not receiving adequate person centred support. Good quality, adequate support via SDS can be instrumental in improving women's quality of life and plays an important role in helping women enjoy their right 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, mental ill-health and suicidal ideation. It is therefore vital that women 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 women'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. Women should also be able to request support from a team of other women if they prefer, and have their preferences respected.

Residential Care and Independent Living

The MSMC research team heard from several women 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 interviewee from a rural area recounted that she had received a letter from her local authority stating that "there is currently no available agency in the area of [specific town] to support you" until a further needs assessment could take place. The letter went on to state that if family members were not able to provide unpaid care in the interim period, "the only alternative we would be able to offer […] would be either an intermediate care bed for assessment within a 24-hour setting for up to six weeks or as a residential placement".

The interviewee was distressed by these severe reductions in choice, and the abrupt change to her support arrangements, which she did not feel was person centred care.

Several women also reported that social workers made assumptions about their ability and desire to live independently from their families, as adults. One interviewee reported that she was supported to move out of the family home and into a residential unit. When that residential unit closed, social workers assumed that she would move back in with her parents, "because they just saw that [the] house is accessible". The interviewee stated that her social worker "didn't see the bigger picture", and that she had to challenge the decision not to support her to live in her own home. Since moving into her own home, the interviewee's arrangement of support through SDS and Access to Work has enabled her to live and work independently.

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 women to live – with appropriate support – in their own homes for as long as possible, if that is what they wish.

Flexibility

Many women commented on the value of and need for flexibility for the effective use of SDS – particularly around budgets.

Interviewees and focus group participants spoke eloquently on this theme. For example, women reported difficult experiences in obtaining suitably flexible assistance with day to day tasks. One woman spoke of issues with restrictions on what council carers could do to provide support within her local authority:

> *"The bigger issue was that they were very restricting on what the carers could and would do [...]. For example, they wouldn't cook a meal, they would only heat up a microwave meal. It was the lack of flexibility around that that I guess was the reason for us to choose Option 1, so that we could employ staff and direct them to do. I guess it's all down to health and safety, but it was quite rigid really what [the carers from the agency] could do."*

Other interviewees use a "family budget", covering two or three members of a household, all of whom use SDS as disabled people. One person explained that this has worked well for them in terms of flexibility. They reported that:

> *"It was good at being a family budget because sometimes, because we had a period where [Name 1] was ill for a few years and majority of the budget went to [Name 1]. [Name 2] was stable so didn't really need anything and took a little but not as much [...]. So it has worked really well and we have been able to move things, when one of them has been ill and one of them has had a higher level of need, we have been able to move from one to another. We couldn't do that if they had individual budgets, it wouldn't have that flexibility. We would end up underspending and overspending on one and the other all the time."*

One woman reflected upon the challenges of fitting the local authority eligibility criteria. They noted that their social worker had informed them that no support was being funded towards social activities, shopping or domestic tasks. However, they knew of other SDS users who do get social support and they had read adverts for personal assistants setting out that assistance with social support was required for the post. The interviewee felt confused and let down by these conflicting messages and pointed out that people do require support for occasional tasks beyond personal care – such as assistance voting. In particular, the interviewee had requested support from social work to complete their postal vote in the 2019 General Election, as without assistance they would not be able to vote. They were informed that support with post and administrative tasks was only available via a third sector organisation. However, that organisation did not have the capacity to assist the interviewee before the voting deadline. The interviewee felt that the assumption is that disabled people and people living with long term conditions have a network of unpaid carers who can fill in the gaps in the arranged SDS package – and that without that additional support, they were substantially disadvantaged. They called for a more flexible approach to support, which could respond to occasional need as well as regular personal care (e.g. voting).

While many of these examples demonstrate troubling practice across Scotland, and the clear and negative impact that inflexible practices can have on people's quality of life, we did also hear from one focus group participant who felt that a gradual and supported reduction in their SDS budget had been beneficial to them. That person related how she had originally moved into independent accommodation, and had overnight care seven days a week, plus support in the day. As she became accustomed to living on their own, this support was gradually reduced, following regular consultations between the service user and their social worker. The participant 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. She reported that now she could "never go back to having seven sleepovers – being told to come in at half past ten every night!" and that she is happy with her 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 her input, ideal outcomes, and consent.

Flexibility: The research suggests that some women 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 women are empowered and supported to use their SDS, but also relates to their opportunities 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. Women who use 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 women 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.

However, many women spoke about problems accessing respite, even when it was included in their personal outcomes plan, and the difficulties that could cause. One woman stated that problems over accessing respite had had serious consequences for her relationship with and trust in her social worker. She summarised their experience as follows:

> *"The last [assessment] meeting I had, I left in tears as they threatened to cut my hours if I continued to ask about respite. It's the first time I've ever felt ashamed/apologetic/a burden to have a disability. They hadn't read my file so had no idea what [name of condition] was, made assumptions that I could do more for myself, and couldn't understand why I needed someone with me when I go outside."*

Women 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 women 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 women who access social care, their 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 women living in rural areas. This was not always linked directly to women's SDS packages, but where women employed personal assistants, the time to travel by public transport to carry out activities was not always acknowledged in care plans. Women 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 women tended to reflect on transport issues and SDS without clearly delineating between the two parts of their experience of social support.

One interviewee reflected on difficulties with sharing transport with a service user (who resides at the same address) and their paid care worker – even though both interviewees use SDS as disabled people. The interviewee stated that:

> *"I find it quite frustrating, because these carers who drive the cars to take [Name] out, they are not allowed to take me in the same trip. I find that very frustrating. […] I think they [the local authority] are putting unnecessary stumbling rocks. Because they are times when I would really like to […] go out together and, you know, do little bit of shopping and have lunch together as a couple."*

The interviewee's inability to share transport with the other member of their household and their carer is compounded by the fact that they have limited access to buses and no trains where they live. The interviewee and other respondents' reservations about public transport is also connected to variable and sometimes poor service provision – both in terms of frequency and staff training around accessibility.

Finally, transport also emerged as a conversational topic during focus groups, where women reflected on different approaches to travel costs and access across different local authorities.

Travel Costs: Women – particularly those living in rural areas and those who are blind or partially sighted – require more acknowledgement and accommodation of travel costs in their SDS budgets. Many would also welcome assistance from social workers and third sector organisations in navigating the bureaucratic processes to obtain mobility vehicles and travel passes.

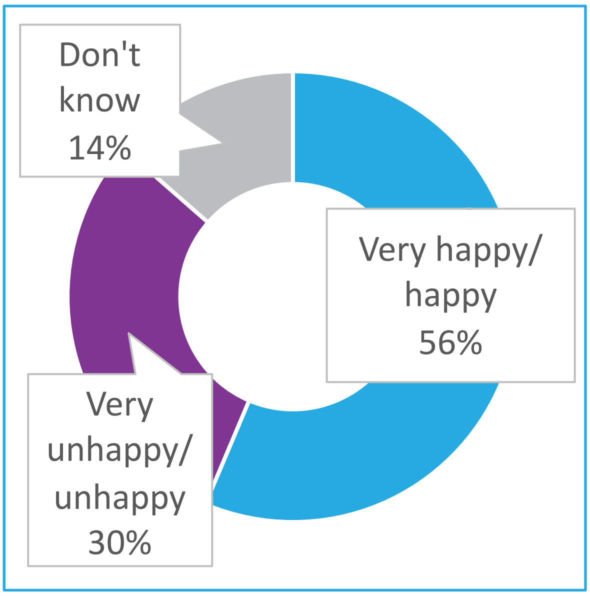
Communication and Relationships with Social Work

Good Conversations and Consistent Relationships

The importance of productive conversations in arranging appropriate social care support was highlighted explicitly in the 2019 Care Inspectorate thematic review of SDS.[20] 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 236 women who answered this question, 133 (56%) were either "happy" or "very happy" with their conversations with social work professionals, 71 (30%) were either "very unhappy" or "unhappy", and 32 (14%) did not know.

Chart 19: “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.

Interviewees highlighted that good conversations require effective communication, access to information, prompt decisions, and good future planning. Many research participants commended the assistance and efforts of proactive social workers, including social workers who signposted them to local services provided by third sector organisations (paid for through SDS). One woman summarised her experience as follows:

> *“And then [social worker] started suggesting groups that I could go to so that I wasn’t on my own all the time. It would be peer support with people who also have mental health; people with lived experience. So, I went along […] and it took me a wee while to settle in, but I settled in. And it was very helpful.”*

Several women also spoke warmly in praise of condition-specific teams in their local authority areas (e.g. mental health or sensory impairment teams). One interviewee outlined that their positive relationship with their social worker was crucial for their well-being. They shared that:

> *“When it comes to the SDS, we have a really good relationship. When I have a dip in my mental health mood, I shut everybody out – but he perseveres, and he phones me or chaps on the door or things like that. He is there for me for everything really. I would say our relationship is really good […]. When I used to go downhill, I never ever got in touch with him and he is the person I should have gotten in touch with. I didn’t get in touch with anybody, just shut the house down, didn’t answer my phone, got into my jammies. […] I overdosed […] so many times. My liver hasn’t fully recovered yet. If I refused the phone calls, he would knock on the door. And if I didn’t answer the door, he would come the next day again. He certainly knows his job. He cares about the people he looks after. He is a good social worker.”*

Women repeatedly referenced prompt communication and easy access to information as key to smooth communication with social work and effective SDS provision. Respondents appreciated short waiting times for a response or decision from social work. While talking about their local social work team, one interviewee reported that:

> *"It is a good team at getting back to you and that. You know, if you leave a message there is no days later they haven't got back to you. The lady who is in the office is quick – they are an excellent team."*

Consistency of social workers was also viewed as a positive factor, as it gave women time to build up trust and awareness of their needs and individual situations. Social workers being able to take time to get to know women also facilitated flexibility of support arrangements – and that it could be difficult and time consuming to build trust. One interviewee summarised their experience of struggling to trust their social worker as follows:

> *"She was actually really good, the social worker assistant; she was trying to understand what you were saying […]. But it was really difficult for me to open up completely because it's a stranger. You're thinking, this is your life and its things you could do 15 years ago you couldn't do now and […] it's kind of difficult to say to somebody. […] So, I was very distrusting, that [my SDS package] had been up to 15 hours, because there was nothing in writing."*

Cumulatively, these results 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.

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 are many different elements and examples of this in the experiences shared by participants. It is important that social workers have a good breadth and depth of knowledge about SDS and local services, can demonstrate good listening skills and empathy, and take time to listen to women and become familiar with their requirements. These findings also highlight the benefits of consistent relationships with social workers, including direct and varied lines of prompt communication available. Overall, we would recommend that work to ensure positive conversations and meaningful, consistent engagement with women should continue, with ongoing planning to guarantee high quality practice for everyone using SDS – especially around clear and accessible communication.

Poor Communication and Relationships

Some women described less positive experiences of communication and relationships with social work professionals. 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. One person summarised this experience as follows:

> *"It doesn't matter how good they [social workers] are, because it's the team leaders that don't want to put that budget to you. Two of the things I was told were if you come across too well, you still work and look good, that goes against you. So, you [would] rather I sit in the house with a big dinner stain down my top, no bra on, my hair all sticking up, watching Jeremy Kyle. If I do that, will I get better hours?"*

Other women reported that they found wider parts of the assessment process problematic. One interviewee stated that they found the process of repeat assessments – particularly deficit-led assessments – difficult:

> *"You've got to say everything and your personal life, you have got to prove that you are disabled. The fact that you are sitting in a power chair doesn't seem to matter. You have to sit and prove it and write all these things down. I find this really intrusive – sitting with somebody and having to go through and all, especially when you've already been through all with other things."*

Some women were sharply critical of their experiences, particularly around having decisions and preferences respected. Several recounted difficult attitudes from, and interactions with, staff in their local social work departments. One person commented on her social worker's lack of engagement and knowledge of her circumstances, and the impact of that unfamiliarity on her needs assessment:

> *"The main barrier was the Social Worker. She had no interest in my needs, had not read my support plan, she knew nothing about me. She couldn't care. She wasn't interested in getting to know me or what my needs are. Everything I said, she had an answer for it not to happen. Instead of sitting down and say 'look, this is what we can do, let's look outside the box', she was very much like 'no, we'll cut your hours, no, you can't be flexible'. She was asking to speak to the people who provide my support – which I had no problem with. One of the providers who have known me for […] years through supporting me came back to me and said that they want to make me aware that the social worker wasn't even aware of my personal abilities and personal needs – she thought I was catheterised. That pushed me to make a complaint, because if she didn't know that I was fully continent and able to use the toilet, I felt there was a major issue there. How could somebody who knew so little of my needs fight my corner?"*

One interviewee shared their distress at realising that their new social worker had recorded incorrect information during their last review. They stated that:

> *"Well she didn't really go through everything. I mean, on the sheet – I couldn't read it, but I had a friend come over from [location] and he bullet-pointed, and there must have been about what, 13 or 14 things that she'd got wrong. She'd put that I could go*

> *out on my own, I could do my own shopping, I could do my own cleaning, […] she'd even taken out – when I black out I'm supposed to have somebody with me for eight hours, in case anything else happens because I'm confusable afterwards, disorientated. And I'm supposed to have someone with me for eight hours after. And she'd even removed that."*

Interviewees highlighted a range of areas where improvements could be made. One interviewee recounted that after a reduction in their support hours during a review, they felt that their new social worker was not on their side. The lack of consistent communication, and their difficulties in chasing for further information also enforced their feeling of powerlessness. As they explained:

> *"I've been miffed from the word go, and nobody has been able to give me any answers. I […] talked to some of the people in the local SDS team, and again I get promises [that] somebody will contact me […] but have I heard from any of them? No, unless I keep on and keep on and keep phoning – that's hard for me because I can't use my hands to make phone calls, if somebody does use my phone I can't phone them, you know, it's just hard work and this is where I could do with somebody coming round to help me."*

Poor Communication and Relationships: Examples of poor communication raise clear concerns about decision making and autonomy; if women'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 women's 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.

Discrimination, Intimidation and Bullying

Several women shared their experiences of social workers appearing not to empathise or understand the extent of their requirements, to the extent that they felt intimidated and bullied. Other experiences demonstrate unacceptable behaviour and discrimination. While these accounts were rare, in contrast to most women's experiences, they were important enough to include within this report as examples of poor practice and as part of efforts to improve and ensure high quality care across Scotland.

One woman described an experience of her needs assessment that highlighted a variety of problems with the behaviour of the social work professionals involved – to the point of being an abuse of power. Having received support for several years, the interviewee's recent needs assessment was carried out by a social worker and an occupational therapist. The interviewee provided the professionals with information about the development of her compound health conditions (with letters of support from medical professionals) and the need for more care, as her unpaid carer was no longer able to provide the level of support she required. During the assessment, the social work professionals stated that they needed to observe the interviewee carry out daily tasks that they found difficult to complete – including applying creams and bandages. The interviewee carried out these tasks as requested.

The social work professionals then required the interviewee to demonstrate how they cleaned themself, and what parts of the process she found difficult. The interviewee was expected to take off her clothes and underwear and shower in front of the social work professionals, then get dressed again. The interviewee was extremely uncomfortable but did not feel that she was able to refuse. She feared that if she did not comply then she would be denied the support they needed. The interviewee described the experience as follows:

> *"The OT says, 'well I need to see you stripped off and how you do it and wash. Now what do you do for soap and things, if your hands are that bad?' So, I got my shower gel […] and swooshed it round and got a face cloth, you know, and – so I had to re-wash myself totally, in front of the OT. The pair of them standing taking notes and here's me trying to kid on I wasn't – it felt –' [interviewee unable to continue]."*

The interviewee queried whether it was necessary to strip in front of the social work professionals in order to demonstrate her process. She stated that the social work professionals responded to her query by saying, "and what's the problem with somebody seeing you like this?" The interviewee replied that her discomfort with nudity in front of people she did not know stemmed from her religious and cultural background:

> *"I said, 'well, I'm [specific age], I was brought up in a Catholic household, with the best will in the world it's held.' I'd dressed and undressed the night I got married without showing an inch of flesh. It sounds ridiculous to a younger person because it's different now."*

This reason was not deemed an acceptable justification by the social work professionals; the interviewee felt sufficiently pressured that she then complied and showered in front of the two assessors. She stated that she was crying throughout the process of showering, but the social work professionals did not allow her to stop, nor did they attempt to reassure the interviewee or make her feel more comfortable.

The needs assessment that this interviewee described was not person centred, did not respect the interviewee's autonomy or preferences, and at points violated her human rights. It is one of the most extreme examples of unacceptable practice in social care that the researchers have ever heard about, including outwith this project.

A lack of cultural awareness was also highlighted as directly connected to reductions in women's support. One person gave an example of how, during a needs assessment, a disabled Black woman was asked by her social worker about her personal grooming – "your hair, is it a wig or not?" Embarrassed by the framing of the question, the individual said “it’s my hair”, rather than stating that she was wearing a wig. The social worker then commented that “if you’ve got hair, it looks beautifully combed, so how do you get your hand up?” Embarrassed, the person did not respond and explain that they used a wig and could not raise their arm to arrange their hair. As a result of this interaction the woman had her SDS package removed, as the social worked concluded that if she could carry out hair care tasks she did not require assistance with personal care. The respondent reflected that this problem stemmed from the social worker not knowing enough about Black hair care, framing their question poorly, and “not knowing that sometimes people in self-respect and dignity, they won’t say a few times.”

Overall, several other respondents stated that they would welcome more empathy and respect during their interactions with social work. Furthermore, a small but important minority of people discussed the limitations of available feedback and complaint options when they were unhappy with their interactions with social work.

Discrimination, Intimidation and Bullying: No-one should have to deal with discriminatory, intimidatory or bullying language, attitudes or behaviour from social work professionals and women must be treated with dignity and respect. Appropriate training and ongoing support on equalities, human rights, intersectionality, conscious and unconscious bias and anger management should be provided to staff at regular intervals. Training and guidelines should also be developed for staff to help them prioritise supported decision making (rather than substitute decision making). All processes and paperwork should be transparent and shared in an accessible format with service users. Social work staff should pro-actively gather regular feedback – good and bad – from service users, families and unpaid carers as a way to support continuous improvement. Social work professionals should also 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).

Transparency

Research participants commented on the importance of transparency in a variety of ways, centred around the need for clear information about what to expect from SDS, social workers, the process of accessing support, and how to challenge decisions. Some women 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 worked “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. One participant reflected that they wanted to access SDS, but when they requested a review they were informed that “you’re a category 4”. When the respondent asked for further information on what the categories meant, she was given the following response:

> *"You're not at risk, you've got your husband there and there's no adult protection issue so we can't support you – we can only support Category 1s, which is people at risk of harm, either by themselves or others, you know, or vulnerable adults."*

The respondent's impression was that their local social work department were "just trying to put us off basically" and assumed family or friends would be able and willing to provide unpaid care.

Another interviewee related how, after their SDS package was cut completely, she submitted an appeal and a complaint about the lack of transparency around the process. She summarised her issues with changing information around eligibility criteria as follows:

> *"All they say that you don't meet the criteria. That's all, that's the only reason they give now is that you don't meet the criteria. Not how you don't meet it or why you don't meet it. Just, you don't meet the criteria. It should be a more detailed response but we're not given that."*

We heard from interviewees who had found it necessary to submit Freedom of Information requests or pursue court action in order to access information about their support. Greater transparency and better communication may have reduced these points of conflict with the local authority. With many women, particularly those with learning disabilities or who are blind and partially sighted, concerns about transparency of process were often synonymous with issues with accessible information.

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

Women identified a range of ways that SDS has enhanced their lives, including a beneficial impact upon family relationships. However, the picture is mixed, with some women reporting that SDS has had a negative impact on family life.

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.

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 women shared the negative impacts of when there was not enough support in place to meet the needs of SDS users. 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 person involved.

One respondent stated that “even living with the families, the families are working, that can be worse sometimes” – particularly when, as another person pointed out, family members “can’t be there all the time” due to other commitments. Another person opined that “it’s OK when the carer isn’t working, but when they work full time, and they have children, and caring responsibilities – it doesn’t work.”

Disabled Mothers’ Experiences

Several women outlined difficult experiences of accessing SDS as disabled parents. One interviewee spoke of how she requires support with some household chores and help to access community life with her child. However, she reported substantial prejudice about her capabilities, particularly from care workers who are unused to working with disabled parents. The interviewee reflected that the carers who provided help often attempted to override her decisions, including parental decisions. The interviewee summarised the power imbalance of this conflict as follows:

> *“I don’t think many people I’ve talked to have had experiences where their position as parent has been considered as well as their position of what you need for you. I think a lot of people who use support services – not everybody, but a lot of people – are elderly, have dementia, or have severe disabilities. A lot of them aren’t married with children. And some people just weren’t really able to process a disabled woman with a baby. […] It’s weird, when you’ve got on the one side people that are infantilising you because they’re your care worker, therefore they must be above you, but actually you are quite a bit brighter than them.”*

The interviewee, who uses Option 2, requested a change of care provision following a series of problems with staff. She was particularly concerned with the high staff turnover, and the impact on their child of having a series of unknown carers in the house on a regular basis. The interviewee requested two or three regular care workers, who she and her child could know and trust (and was the original arrangement for their care); this request was turned down by the agency. The interviewee recounted how high turnover of staff affects communication and the standard of service delivery, and summarised her experience as follows:

> *“It was very, very stressful for me, because I don’t really like support workers and we had 15 different ones. […] There is very little training; you get really good ones, but you also get really awful ones.”*

Following these discussions and problems the interviewee requested that social work move them to an alternative care provider. She reported that their social worker was unwilling to support them in changing to a different provider.

It is worth noting that while almost all of the disabled parents we heard from reported assumptions from social workers that family members, friends, and neighbours could provide some degree of unpaid care, there was a difference in support offered to disabled fathers of young children versus that offered to disabled mothers of young children. Of the disabled parents we spoke to, only the mothers were offered support with household tasks and childcare as part of their SDS packages; with disabled fathers, it was assumed that their female partners could carry out that labour (even if they were in full-time employment). Such gender biases are worth challenging as part of assessment training processes for social work professionals to ensure parity of support for disabled people and their families.

Impact of SDS on Family/Relationships: Adequate person centred support via SDS can be instrumental in improving women'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. Disabled mothers should be properly supported through SDS, and their decisions and parental rights are respected by social care workers. It is also important for professionals to consider conscious and unconscious gender bias when assessing women's right to access support and receive regular access to diversity and equality training.

SDS and Mental Health

Some women – particularly those who had experienced problems with needs assessments or reviews – reported that accessing SDS had been a stressful experience. In some cases, women directly linked the stress of accessing SDS to deteriorations in their mental health and some spoke in detail about the negative impact on their mental health of substantial reductions to their support through SDS.

However, most of the interviewees we spoke to concluded that once appropriate support was in place, SDS had markedly improved their mental health and/or the mental health of those for whom they cared.

One interviewee summarised the positive impact of SDS on her life as follows:

> *"If I didn't have [SDS-funded activities], I don't know if I would still be here. I was overdosing at such a rate [that] they didn't expect me to recover. […] [My social worker] pushed really hard at me to get into the groups*

> *because I was just shutting down myself in the house. If it wasn't for SDS, I don't think I would be here."*

Another two interviewees reflected that before they accessed SDS, they were members of Dignitas[21] – but that now "that's gone completely", and the SDS user has "a far more fulfilled life, control over what happens" and better mental health.

Several other women concluded that once appropriate support was in place SDS had improved their health. One interviewee summarised the impact of SDS on her life as follows:

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

SDS and Mental Health: If adequate, person centred support is provided, there are clear benefits of SDS to women's mental health and relationships. However, poorly conducted SDS processes and reductions in support can have a negative impact on women's mental health. 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. Local mental health support services need to be sufficiently resourced to carry out their vital work.

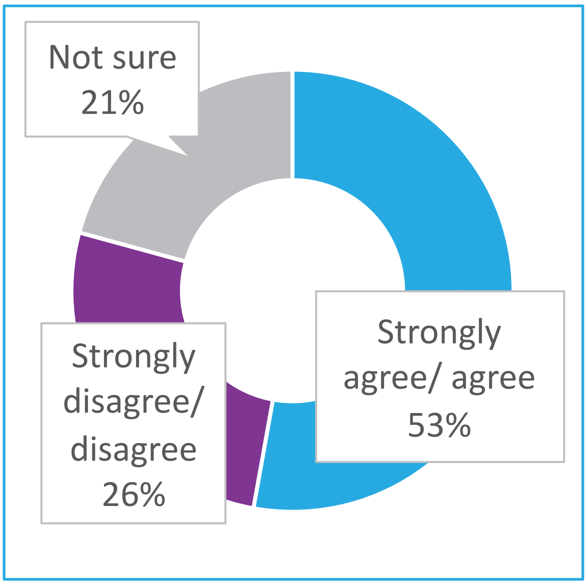
Care Staff Recruitment, Training and Quality

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

Staff Recruitment, Retention and Turnover

Within the survey, we asked research participants to respond to the statement "Lack of a regular personal assistant makes SDS difficult for me". Of the 159 women who answered this question, 84 (53%) either "strongly agreed" or "agreed", 42 (26%) "disagreed" or "strongly disagreed" and 33 (21%) were unsure.

Chart 20: “Lack of a regular PA makes SDS difficult for me” (Survey)



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.

Staff Training

Another important care consideration for research participants is PAs who are qualified to carry out the specific specialised personal care they need, with appropriate medical training. Some women reported that it was not clear whether PA training costs should come out of their SDS budgets. One interviewee summed up a possible solution, along with the dilemmas facing staff and SDS users alike:

> *“You are dealing with the agency, so you have to take what they deem that you should have. So, the personalisation goes out the window. So I’m seeing if what would help is if there would be genuinely self-employed care workers and personal assistants. Not the fake ones where they are trying to pay them their employee benefits, but real, genuine, actual, somebody like yourself, setting up, and genuinely actually responding to local need and offering the services that there are gaps for. There are several barriers to this. One, HMRC does not recognise – I was told, none of these people can be SSSC registered, SSSC and HMRC won’t let them.”*

A different interviewee discussed how some agency staff lack training in how to respect disabled people’s individual capabilities. They recounted how one support worker had little training on how to support people with physical disabilities or visual impairments, and that this led to points of conflict about the interviewee’s independence:

> *“She is very nice, but she has very fixed ideas about how things should be done. […] I remember, once, I got [Name] to walk me to swimming. Then I said, ‘right, see you in an hour or so’ […]. And when I got back, she was having an absolute wobbly because she didn’t know where I was. It did not occur to me that she needed to know where I was; I was swimming. For context, this is a swimming pool where I go every few days. […] And when one of the other support workers took me swimming but […] wanted to get lunch for herself, I said, ‘OK, but I’ll go ahead because I want to get back home’. And [Name] threw an absolute wobbly because she’d allowed me to ‘walk home unsupervised’. […] She said she had a duty of care. So, I brought this up at the social work review, at which the social worker said since I was an adult with legal capacity, I was allowed to walk home if I wanted to. […] I’m not a child!”*

The interviewee felt that the PA would have benefited from more training in how to respect the people they supported and their autonomy and decision making capabilities.

Several Black and minority ethnic women highlighted problems with the cultural awareness of social workers and carers. People's concerns included service users and carers not sharing a common language, organising effective diversity and awareness training for staff, and the practicalities of understanding and accommodating culturally or religiously appropriate food preparation.

One person reflected that "if there are specifics, like the bathing, which we know [are culturally specific], then in fact what we've got to say that within social work training for their degrees […] that these are aspects that need to be considered on the course" – and that this awareness needed to be extended to care workers more generally. This statement was met with broad agreement from other focus group participants, who also concluded that it was important that social care workers should "learn to ask", in order to constantly improve their awareness of people's cultural contexts, as "they have to learn from their experiences."

Important Characteristics of Care Workers

Many women commented on their priorities regarding care staff, and the positive impact of a good relationship with and support from PAs or carers. One interviewee summarised the impact as follows:

> *"Through the PAs, I was able to meet new people and reconnect with some friends that I lost touch with. They have now become a big support in my life. […] And not having to worry about that I need to be home by 8pm. My PAs are quite flexible, so they could wait until I come home, they can be at my house, I don't need to think that I need to be home at exact 10 o'clock when my sleepover starts. […] My PAs are really supporting, and that allows me to do things that everybody in my age could do. It just needs to work more productively – which I'm trying to do."*

Another interviewee, an unpaid carer, outlined the good relationship that a member of their family has with their personal assistants, who provide support while respecting the SDS user's independence:

> *"She still doesn't 100% let them do what I want them to do; she's holding onto what she manages – and rightly so, it is her home. Even things like […] I'd do all the washing and the girls would help with that if anything needs immediate whatever. […] The girls […] help with her medication because she muddles them up. They now make something for her evening meal, they make sure she has something suitable for her lunch time. She just gradually allowed them [to help]. […] And the girls are excellent. Things like filling her kettle at night-time to have it ready for her cup of tea first thing in the morning – just little things. Because she is not seeing. She can see the kettle but cannot see the water level. And she is unable to carry it from the sink to the boiler as it is too heavy. All these little things. The girls seem to pick up the things that prevent a problem later in the day or in the morning. So, she still feels that*

> *she is managing everything, but they're there to support her along."*

Care Workers and Risk

Several women 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 woman, who is blind, summarised their reflections on care workers as follows:

> *"On the visual impairments side as well, if you're having somebody come into your home, especially if it is a stranger and you're getting a different person each week if you're going through your local authority like I did, […] because they couldn't guarantee who was working. […] So, I was getting different people and it was really weird because I didn't know if I could trust them or not. So, you literally had to tidy up your private papers when they came in the door. And then I just felt so uncomfortable, so in the end I hired a person that I knew from the office that I worked in. That was a wee bit better, but I did get to know this lady quite well – but yet again I still feel that if you're blind you are more vulnerable regarding somebody coming into your home. And I think we should have that right to choose somebody that we feel comfortable with and trust our personal information with because it's that kind of aspect that you have got to think about because I don't trust everybody with my private information."*

While this interviewee managed to find a solution to their support that they were reasonably comfortable with, it is important to consider their wider concerns about risk factors for disabled people (and specifically women). In particular, their comments should be read in conjunction with those of the two female survey respondents who were the victims of violent crimes – and their comments that their ensuing safety concerns were not addressed during their needs assessments.[22]

Care Staff Recruitment, Training and Quality: Some women 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. Women 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

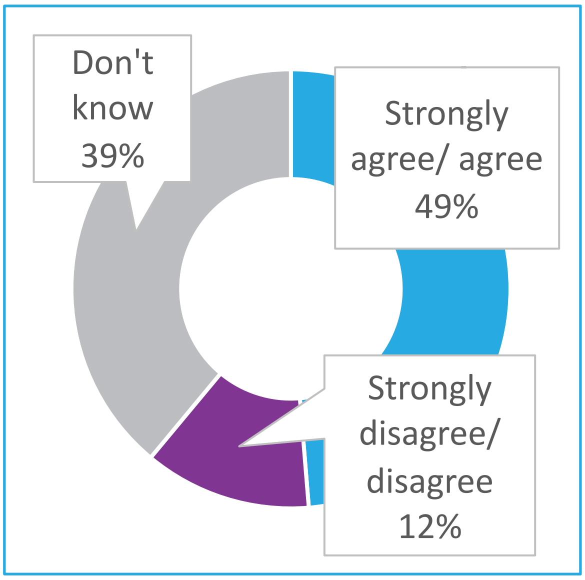
Women respondents accessed independent advice and advocacy services for a range of different reasons. These included access to information, access to needs assessment criteria, assistance to develop a support plan, exploring flexibility with SDS budgets, mediation with social workers, support to appeal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

Women who participated in the MSMC survey 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.

Independent Advocacy

We asked survey participants to respond to the statement “access to independent advocacy makes SDS easier for me”. Of the 154 women who answered this question, 75 (49%) “strongly agreed” or “agreed”, 19 (12%) “disagreed” or “strongly disagreed”, and 60 (39%) said that did not know.

Chart 21: “Access to independent advocacy makes SDS easier for me” (Survey)



Women participants indicated that when good relationships were established, collaboration led to effective support planning and implementation of SDS options. Other women brought up the value of independent advocacy in accessing SDS. One woman summarised her advice to others as follows:

> *“If you’re having trouble with social work, get yourself an advocate. I think that’s the first thing I would say. I think it’s vital for people to have someone to speak for them, and to research.”*

Meanwhile, some women stressed that a further consideration is that “some people don’t have anybody” – they may not speak English or have a support network to agitate on their behalf. Similarly, women may feel uncomfortable discussing personal care needs or the details of their health with others –

including social workers and staff reviewing complaints. One person outlined this problem as follows:

> *"And self-respect, their dignity! They don't want to share their problems with everybody. So many people who don't have anybody."*

One woman stated that "it's important to complain in the higher authority" when social care professionals act in an inappropriate or discriminatory fashion. However, as another person pointed out, complaint is sometimes only possible from a position of (relative) security or privilege:

> *"To be able to challenge, and to complain, you need to be a strong-minded person. In my present state of affairs I can do that very well. But ten or twenty years down the line, when I'm not well, how can I do that?"*

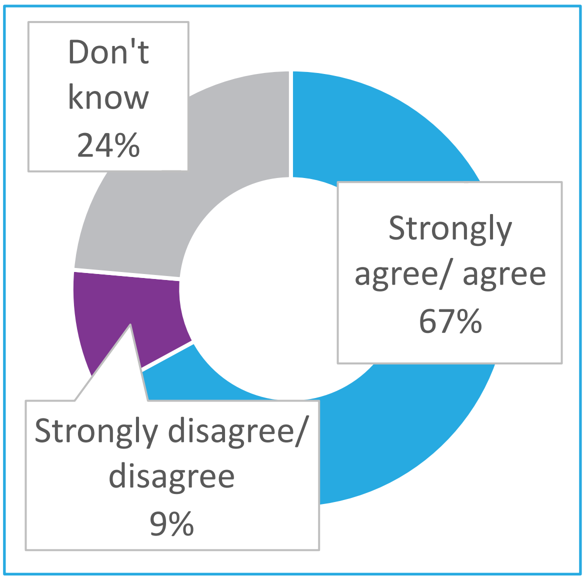
A different person echoed this point, stating that "people who are capable, can do it, no problem. It is for those who are most vulnerable who are not able to, they won't even know where to start. I think that's the challenging part."

Survey respondents and focus group participants noted that confidentiality and time to build up trust was important to the success of independent advocacy. Several women highlighted that they had benefited from the involvement of independent advocacy services during their needs assessment 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 Support and Advice

When asked whether access to independent information and support made SDS easier for them, women responded in a positive fashion. 108 women (67%) "strongly agreed" or "agreed" with that statement, 15 women (9%) "disagreed" or "strongly disagreed", and 38 women (24%) said they did not know.

Chart 22: "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 having access to independent advice and support in accessing SDS. Several women highlighted that they had benefited from the involvement of independent advice and support services during their needs assessment and reviews.

Another respondent stated that "having independent support present had improved the conversations with social work, [...] helped to bridge the gap, have my voice heard and build the relationship with social work." Several interviewees sang the praises of third sector organisations who provide independent advice and support services in assisting them with SDS. One woman summarised her 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."*

The 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 women 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: Women clearly value and benefit from independent advocacy 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 independent services can bring to their own work. 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 is 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 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/.

5 ISD National Services Scotland, Social Care Information Dashboard: https://scotland.shinyapps.io/nhs-social-care/.

6 Ibid.

7 2011 Scottish Census, 'Ethnicity, Identity, Language and Religion' (2011). Available at: https://www.scotlandscensus.gov.uk/ethnicity-identity-language-and-religion.

8 https://scotland.shinyapps.io/nhs-social-care/

9 Ibid.

10 https://scotland.shinyapps.io/nhs-social-care/.

11 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/.

12 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/.

13 Ibid., p. 12.

14 ISD Scotland, 'Social Care Information Dashboard'. Available at: https://scotland.shinyapps.io/nhs-social-care/.

15 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/.

16 Ibid, pp. 6, 48-60.

17 https://scotland.shinyapps.io/nhs-social-care/.

18 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.

19 Audit Scotland, Self-directed support 2017 progress report (August 2017). Available at: https://www.audit-scotland.gov.uk/uploads/docs/report/2017/nr_170824_self_directed_support.pdf. Audit Scotland, Self-directed support 2017 progress report: Impact report (December 2019). Available at: https://www.audit-scotland.gov.uk/uploads/docs/report/2019/ir_191217_self_directed_support.pdf.

20 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.

21 http://www.dignitas.ch/?lang=en

22 See ”Outstanding Concerns and Appeals” on page 25

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

ALLIANCE
HEALTH AND SOCIAL CARE
ALLIANCE SCOTLAND
people at the centre

About the ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for a range of health and social care organisations. We have a growing membership of 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.

Self Directed Support Scotland
the organisation of choice

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.

The ALLIANCE

Phone: 0141 404 0231

Email: **info@alliance-scotland.org.uk**

Twitter: **@ALLIANCEScot**

Website:
www.alliance-scotland.org.uk

Address: Venlaw Building, 349
Bath Street, Glasgow, G2 4AA

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

The ALLIANCE is supported by a grant from the Scottish Government.

Registered in Scotland No.307731.
Charity number SC037475.

Self Directed Support Scotland

Phone: 0131 475 2623

Email: **info@sdsscotland.org.uk**

Twitter: **@SDSScot**

Website: **www.sdsscotland.org.uk**

Address: Norton Park, 57 Albion
Road, Edinburgh, EH7 5QY

SDSS is supported by a grant from the Scottish Government.

SDSS is a company registered
by guarantee No SC371469
Charity No SC039587.

Please contact us to request this publication in a different format.

Self Directed
Support Scotland
the organisation of choice

ALLIANCE
HEALTH AND SOCIAL CARE
ALLIANCE SCOTLAND
people at the centre