My Support My Choice:

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

National Report, October 2020

Self Directed Support Scotland
the organisation of choice

ALLIANCE
HEALTH AND SOCIAL CARE ALLIANCE SCOTLAND
people at the centre

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Acknowledgements and Dedication

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

About this Report

This report uses data from "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. It starts by broadly setting out the national context for Self-directed Support (SDS) and social care, followed by information about the project design, methodology and participants. Subsequent chapters explore people's experiences of SDS/ social care across Scotland. Key findings and recommendations are highlighted throughout, and there is a separate chapter on recommendations.

The document is part of a suite of MSMC reports. It contains short thematic accounts of 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 are published separately; these explore the experiences of people with learning disabilities,[1] Black and minority ethnic people,[2] people with lived experience of mental health problems, blind and partially sighted people, and women as users of SDS. A further set of reports focus on people's experiences in specific local authority areas; at the time of publishing this report, these had been interrupted by COVID-19.

COVID-19

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

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

Executive Summary

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

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

Between November 2018 and February 2020, MSMC heard from 637 people 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 COVID-19 in Scotland. However, as the largest direct consultation of its kind to date, this report provides vital evidence, analysis and recommendations for improvement to SDS/ social care in the aftermath of the pandemic, based on people's experiences.

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

Poverty and SDS

An estimated 24% of Scottish households with a disabled person live in relative poverty after housing costs, and 61% of research respondents who provided income data lived below the poverty threshold. National and local public bodies should take action to ensure that reductions in SDS budgets and tightened eligibility criteria do not negatively impact people on low incomes who access or are trying to access social care, given that they can lead to people having to manage without support, deteriorating physical and mental health, and demands on family and friends to assume roles as unpaid carers.

Data Gathering and Analysis

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

Overall Experiences of SDS

Most people reported that SDS had improved their social care experience and shared positive and negative feedback when asked to summarise their experiences.

Information About SDS

People found out about SDS from a range of sources. Many reported positive experiences, however a significant minority highlighted difficulties in contacting social work departments, particularly when trying to obtain information about how to access SDS for the first time. They recommended that those wanting to know more about SDS should get in touch with social work, independent advocacy and independent advice services as soon as possible.

Most people highlighted the value of face-to-face communication with social work and indicated they require more high-quality information at an earlier stage before deciding how their support would be arranged. Many people had not been told about all four options when they started the process of accessing SDS. Some had not been provided with accessible information or documentation, even after requesting it from social work departments.

This pattern of variable information about the four options continued into people's needs assessments – although many respondents indicated that all four SDS options were discussed with them, most people report that they required more information. Women generally received less information about SDS options and budgets than men, and were less content with the quality of information that they received.

Recommendations include ensuring people have good access to high-quality information about SDS/ social care, in a range of accessible and tailored formats at different points in their journey through the social care system. Specific work is required to dismantle communication barriers for older people and Black and minority ethnic people. Some population groups, including women, people with lived experience of homelessness, and younger people would benefit from targeted initiatives on SDS information. In general, work is still needed to ensure everyone is informed about all four SDS options – rather than being given information about a more limited list of options – and are supported to consider the advantages and disadvantages of each SDS option before making decisions.

Informed Choice and Control

Overall, most people felt they had enough time to choose their SDS option. People reported variable wait times for assessments and those who waited the longest also generally report the highest levels of stress and difficulty in accessing SDS.

Over three quarters of participants indicated that they are on their preferred SDS option. While this response is positive, the finding that more than a quarter of people also had their SDS option chosen for them by a social worker – rather than choosing themselves – is problematic. Professionals play important roles in supporting access to appropriate services, however this should not extend to making decisions on people's behalf while the principles of choice and control are clearly embedded in SDS policy.

Similarly, while it is positive that most respondents were offered the choice of who would manage their personal budget, it is concerning that just under a quarter of people reported being offered no choice; this also demonstrates that, amongst other things, they were not fully offered all four SDS options.

Several people highlighted the positive impact of flexible support/ SDS. Budgets and waiting times were prevailing themes when respondents discussed concerns with their needs assessments. People experienced inconsistent approaches on key issues like budget setting, which can leave local authorities open to criticism about unfair application as well as inconsistency in implementation. Reductions to budgets and support has significant negative impacts on people's mental and physical health.

Recommendations include providing social work professionals with training in supported decision making, and targeted efforts to ensure that women, people with lived experience of homelessness, people living in deprived areas, and people with learning disabilities enjoy equal decision making about their SDS option and support. It is essential that people accessing SDS are treated with dignity and respect in all interactions with health and social care professionals and assessments and support must be adequate and tailored to their requirements, way of life and self-identities. No-one should feel or be pressured to move into residential care against their wishes and all resources should be maximised and options exhausted to enable people to remain in their own homes for as long as possible, with appropriate support.

Communication and Relationships with Social Work

People highlighted that good, consistent, trusting relationships with social workers and clear lines of communication are all essential for positive and effective experiences of SDS. Many people 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. Several people shared troubling stories of being treated with disrespect by social work or social care professionals. A small number of people reported significant experiences of discrimination, bullying and harassment.

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

Recommendations include ensuring that social workers have the time and skills to build relationships and trust with the people accessing SDS and unpaid carers that they are working with. People should be informed promptly if their social worker changes and have a right to request a new social worker if trust breaks down. Social work staff should pro-actively gather regular feedback from service users, families and unpaid carers as a way to support continuous improvement, and should also inform service users, families and unpaid carers on a regular basis about how they can challenge decisions, and 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

People outlined a variety of ways that SDS has improved family life and relationships. However, they also highlighted the importance of social workers not assuming that family members will provide unpaid care – or that the service user wishes to be reliant on family members and friends. Recommendations include social work professionals ensuring that all unpaid carers are offered carers' assessments and have their rights explained to them.

SDS and Mental Health

People 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 people's mental health of any reductions or changes to support arrangements – particularly significant reductions in budgets.

Care Staff Recruitment, Training and Quality

People reported mixed experiences of support worker recruitment, training and quality, and several indicated difficulties finding and retaining personal assistants and care workers that were suitable for their requirements. People would welcome more assistance with staff training and recruitment from the local authority or relevant support organisations. 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. Targeted work is required to ensure that people with lived experience of homelessness, Black and minority ethnic people, people with lived experience of mental health issues and LGBT+ people do not experience discrimination or inequality when accessing SDS.

Independent Advocacy and Support

People value and benefit from the provision of independent advocacy, independent advice and support services, which need sustainable resourcing to continue their important role. Focused efforts are required to ensure older people, Black and minority ethnic people, and people from all socioeconomic backgrounds are aware of – and can access – independent advocacy and support services. Local peer networks should also be encouraged and supported.

Recommendations

People 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 people's concerns, build on existing good practice, and increase the effectiveness and reach of positive SDS experiences.

Poverty and SDS

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

Data Gathering and Analysis

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

Information About SDS

3. People (service users and unpaid carers) need good access to 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.

6. Specific population groups like women, people with lived experience of homelessness, and younger people would benefit from targeted initiatives on information.

7. People's socioeconomic status should help inform tailored communications.

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

9. People should be provided with timelines for each stage of the process for accessing SDS, and transparency about where and when decisions about support are made.

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

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

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

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

14. Parent/guardian unpaid carers, who often need support with accessing and understanding information about SDS, should be encouraged to complete carers' assessments and support plans.

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

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

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

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

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

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

21. 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.

22. People may want to take part in several conversations to support informed decision making about care charges, budgets and how they interact with other income like social security.

23. Any proposed changes (particularly increases) in care charges should be communicated clearly to - and discussed with - people who access SDS/social care well in advance of the changes being introduced. Local authorities and health and social care partnerships should ensure that corrective measures are in place to rapidly respond to errors or delays in payments so that people are not negatively impacted.

Informed Choice and Control

24. People should be given longer than a week to consider their SDS options.

25. 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.

26. Work is needed to ensure people fully enjoy their right to a reasonable notice period for needs assessments or reviews.

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

28. Professionals should be trained in supported decision making (and co-production methods more broadly) to help reduce the number of cases of substitute decision making where they choose the SDS option and/or who manages person budgets instead of the service user.

29. Targeted efforts are required to ensure that women, people with lived experience of homelessness and people living in deprived areas enjoy equal decision making about their SDS option, how support is arranged, and access to appropriate support.

30. Targeted work is required to ensure people with learning disabilities and Black and minority ethnic people are offered the four SDS options and that their support is person centred and rights based.

31. Targeted efforts are required to ensure that people living in rural areas of Scotland have a meaningful choice between - and can access - all four SDS options and appropriate person centred, rights based care, without having to incur disproportionate expenditure or move house.

32. 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.

33. Professionals should provide people with up to date lists and contact details for service providers and other forms of support in the local area in accessible formats (e.g. housing assistance, occupational therapy).

34. People must be treated with dignity and respect in all interactions with health and social care professionals and assessments and support must be adequate and tailored to people’s requirements and way of life, taking into account all clinical, dietary, religious, cultural, or any other considerations based on protected characteristics and other self-identities.

35. 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.

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

37. People need flexible budgets and a focus on outcomes to enable them to live as independently as possible and enjoy the full range of their human rights. Flexibility is required in a range of ways: to change SDS option; to be able to choose how, where and when to spend personal budgets; with different amounts of spend and support at different times of the year.

38. 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.

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

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

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

Communication and Relationships with Social Work

42. 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.

43. 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.

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

45. 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.

46. Social work professionals should be given training on how to support disabled LGBT+ people with targeted support and information if required, and local support groups should be appropriately funded.

47. 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.

48. Social work professionals should proactively gather regular feedback – good and bad – from service users, families and unpaid carers as a way to support continuous improvement.

49. 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).

50. Work is needed to ensure systematic good practice and consistent transparency across several elements of SDS/ social care, including eligibility criteria, needs assessments, budgets and support packages, changes to support, participation in decision making and how to challenge decisions. People should not have to resort to Freedom of Information requests or court action to acquire information about their SDS/ social care.

Impact of SDS on Family/ Relationships

51. Professionals should ensure that all unpaid careers are offered carers assessments and have their rights explained to them.

52. Professionals should not assume that family members and friends are able or suitable to provide unpaid care. People who wish to reduce the amount of unpaid care they provide should be promptly supported by professionals, with appropriate future planning for contingencies.

53. Health and social work professionals should respect service users' preferences if they do not wish to be reliant on family members and friends for their care and support.

54. Work is still required to improve systems for transition between children's and adult services so they work well for people who use SDS/social care, their families and unpaid carers.

SDS and Mental Health

55. Social work professionals and decision-makers should consider the impact on people's mental health of any reductions or changes to support arrangements – particularly reductions in budgets and increases in care charges.

56. 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

57. Some people need more help to recruit and train care staff. Local authorities and health and social care partnerships should work with people who access SDS and unpaid carers to improve systems and processes related to care staff recruitment, training and quality, including diversification of the workforce.

58. Care staff training costs (e.g. specialist first aid or medical training required for them to carry out their job appropriately) should be included in people's SDS budgets. This would help ensure a quality care workforce (including personal assistants) in each local area.

59. 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.

60. Targeted work is required to ensure that particular population groups, including LGBT+ people, Black and minority ethnic people, people with lived experience of mental health issues, and people with lived experience of homelessness do not experience stigma, discrimination or inequality when accessing SDS/ social care.

Independent Advocacy and Support

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

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

63. Local authority and health and social care partnership staff should be given information and training about local independent advocacy, advice and support organisations, so they can refer people to these resources.

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

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

66. Local peer networks should be encouraged and supported.

National Context for SDS/ Social Care

Self-directed Support (SDS) is Scotland's approach to social care. It is defined as "the support individuals and families have after making an informed choice on how their Individual Budget is used to meet the outcomes they have agreed."[3]

SDS is enshrined in legislation[4] which came into force on 1 April 2014. It is also guided by a ten-year national strategy,[5] the 2019-2021 SDS Implementation Plan,[6] and the Reform of Adult Social Care Programme.[7] SDS is underpinned by the fundamental principles of choice and control and the human rights principles of equality, non-discrimination, participation and inclusion.

The national SDS strategy notes that, "The process for deciding on support through SDS is through co-production [...] support that is designed and delivered in equal partnership between people and professionals."[8] The goal is to shift the balance of power from people who provide services towards those who access them. In this way, people become pro-active agents instead of passive recipients of care.

People should have choice and control over how to use their SDS. For example, they could decide to use it to support their right to independent living through help with personal care in the home, equipment or temporary adaptations. People can also choose to use SDS to enjoy their rights outside the home, for example to attend college, go to work, participate in leisure pursuits or take short breaks. People should also be able to choose between using SDS budgets to buy support from a local authority, private or third sector service provider, or by employing personal assistants (PAs), or a combination.

The 2013 Act places a legal duty on local authorities to offer people who are eligible for social care a range of four SDS options. These are:

Option 1 – a direct payment to the individual, who can use it in any way they choose as long as it secures the outcomes agreed between the person and their social worker as set out in their support plan.

Option 2 – when an individual chooses their support and provider but the local authority or a local organisation maintains control of the budget. In order to make an informed choice, individuals should be made aware of all the resources that are available to achieve their support plan.

Option 3 – when the budget and support is managed and provided by the local authority in coordination with the individual. The individual should still retain choice and control over the type of support they receive.

Option 4 – a mix of some or all of the first three options. This is suggested in 2013 Act Statutory Guidance to provide maximum flexibility and may be attractive to those who would like to experiment with direct payments.

The principles of choice and control apply irrespective of which option is taken.

Nationally, SDS sits within the Scottish Government's programme to reform adult social care,[9] as well as the integration of health and social care.[10] As the 2019-20 Programme for Government clarifies,[11] all this work is intended to contribute towards achieving the National Performance Framework's National Outcomes.[12] One highly relevant national policy for social care is the growing ambition to ensure that human rights is embedded in everything that we do.[13] This ambition is evidenced by the development of human rights based National Health and Social Care Standards,[14] Scotland's second National Action Plan on Human Rights[15] and plans to incorporate international human rights law into Scots law,[16] amongst other initiatives.

There have been several reviews of SDS since its inception in Scotland. These include a 2019 Care Inspectorate thematic review,[17] a 2018 SDS Implementation Study commissioned by the Scottish Government,[18] and a 2017 Audit Scotland report.[19] The Scottish Parliament's Public Audit and Post-legislative Scrutiny Committee (PAPLS) also published an SDS progress report in 2017.[20]

Overall, the Care Inspectorate found that when SDS is effectively implemented, people accessing social care find it transformational and experience positive personal outcomes.[21] However, they also found that effective SDS is not accessible to all. Some of their key messages include:

- More needs to be done to inform, empower and enable people to fully participate in decisions that affect them.
- Eligibility criteria can stop staff from working in ways that support the SDS principles.
- Case records do not routinely document the various discussions and decisions about SDS options, choice and control.
- It is hard to evaluate the good progress – or otherwise – of SDS (and therefore monitor improvement) because of problems gathering evidence on personal outcomes.
- Some key processes lack transparency and accountability.
- There is inconsistent availability of all four SDS options around the country and some people don't have access to all four options.
- There is inconsistent understanding, knowledge and engagement in SDS across different professional staff groups.

The findings from the Care Inspectorate thematic review reflect many of the same issues identified in the other independent inquiries by Audit Scotland and PAPLS, as well as the MSMC research project.

About My Support My Choice

Aims and Objectives

"My Support My Choice: User Experiences of Self-directed Support in Scotland" (MSMC) is a joint project between the ALLIANCE and SDSS, funded by the Scottish Government. MSMC stems from two pilot projects carried out separately by SDSS and the ALLIANCE in 2016-2017.[22]

MSMC sought the experiences of anyone who receives SDS or had been assessed in the previous 12 months, regardless of the outcome of this process. At the time of data gathering and reporting, it is the largest direct consultation with self-selecting respondents who access or have attempted to access SDS in Scotland.

The aim is to gain a better understanding of the personal experiences of SDS among people who access social care and support across Scotland. Increasing awareness and understanding of these experiences, and working collaboratively with people who access SDS and partners in local authorities, Health and Social Care Partnerships, the third sector and the Scottish Government, will help inform and improve practice at local and national levels.

The overarching research questions were:

- Are new and re-assessed social care users being given all of the relevant information about options available to them under SDS, and is this done in a way that is supportive and accessible?
- Are people aware of and able to access advice and support from other agencies to help them to make an informed choice and to set up their preferred arrangements?
- Are people able to access care and support arrangements that are flexible and tailored to meet their own personally defined outcomes?
- To what extent are people able to obtain non-conventional forms of social care?

MSMC provides a valuable contribution by helping to fill the evidence gap on people's experiences of SDS. The co-production methodology adopted is in line with good practice as highlighted by a suite of disability related research projects, including those funded by Disability Research on Independent Living and Learning (DRILL).[23] This research demonstrates the benefits of a co-production methodology, as well as the potential challenges and considerations for future social inquiry.

Design

MSMC used a mixed methods approach, working nationally and in closer partnership with nine local authorities during the period November 2018 – February 2020. Within each local authority area, the following research methods were adopted:

- Contextual research on local SDS policies, delivery and practices.
- Up to ten semi-structured interviews exploring the experiences of people who access / are interested in accessing SDS.
- Survey provided online and by post. In areas where print survey distribution was agreed with the

local authority, a random sample of up to 1000 surveys were distributed by post to people who access or are interested in accessing SDS. In some areas print survey distribution was carried out by other local partners, primarily third sector organisations.

- A free support line number was provided on the online and print surveys and associated project advertising, and people could complete the survey with the help of a member of the research team over the phone.
- Feedback sessions in local authority areas are planned to explore the combined findings from interviews, the survey and focus groups. The aim of these sessions is to raise awareness of good practice and develop recommendations and potential implementation plans. At the time of publishing this report, local authority feedback sessions and report publication had been interrupted by COVID-19.

In addition to research activity within specific local authority areas, focus groups were carried out across Scotland with seldom heard groups who are often under-represented in policymaking. Separate thematic reports explore findings from these focus groups, interviews and survey on the experiences of people with learning disabilities, Black and minority ethnic people, people with lived experience of mental health problems, blind and partially sighted people, and women as users of SDS.

The research conducted ethical approval and a risk assessment through the internal procedures of the project partners. Local authority areas were chosen to provide a mix of urban and rural geographical areas and contrasting population sizes.

This project adopted a co-production approach and involved disabled people and people living with long term conditions throughout. There were three key elements to this process, namely the founding of a Project Advisory Group (PAG), the recruitment and training of peer researchers, and organising feedback sessions in each locality.

Project Advisory Group

MSMC has been overseen by an online Project Advisory Group (PAG), which has advised the research team throughout the project. The project partners recruited six individuals to join the PAG as voluntary members. They represent local or national organisations involved with SDS and people with lived experience of social care/SDS, from a variety of local authority areas, and provided a breadth of experiences. The PAG used a secure online platform within SharePoint and were invited to consider the proposed research design, preliminary findings, reports, recommendations and the dissemination strategy.

Peer Researchers

MSMC recruited eight peer researchers who self-identified as disabled people. Research interviews were carried out by the SDSS lead researcher, the ALLIANCE lead researcher, and our team of peer researchers. Focus groups were facilitated and organised by the lead researchers and additional team members from the project partners.

Interviewee Recruitment

SDS users' experiences and the experiences of individuals interested in using SDS were captured through qualitative semi-structured interviews. The aim of collecting and analysing qualitative data is to understand participant perspectives in order to infer trends and patterns, not to generalise findings.[24] The question of what constitutes an adequate sample for qualitative research is a complex combination of ensuring reasonable depth and breadth in data within resources available. It is a more complicated decision than merely experiencing the saturation of themes.[25] The MSMC target to recruit up to ten interviewees in each local authority area was considered sufficient to provide depth of comparative analysis. In some instances, multiple interviewees who use SDS resided in the same household.

To aid recruitment, the MSMC team shared an interviewee invitation with local organisations involved with SDS, including the local authority. These local contacts then approached individuals to ask if they would like to take part. Contact details for those who expressed an interest in taking part were passed to the MSMC team who then made direct contact to provide additional information about the study.

We interviewed a range of people who use SDS in Scotland. We interviewed disabled people and people living with long term conditions who use SDS and unpaid carers speaking on behalf of the people for whom they care (e.g. parent-carers). Interviewees could choose to be interviewed at home or in a local public place with access to a quieter area. Most interviews lasted approximately an hour. Meeting people face-to-face was preferred in order to build a rapport between the researcher and the interviewee.[26] It was recognised that interviews with disabled people and people living with long term conditions can touch upon stressful topics. All interviewees were able to withdraw from the project at any point in the process should they wish.

Survey Distribution

Some participating local authorities greatly assisted MSMC by distributing up to 1000 survey packs to people in receipt of SDS or who were interested in accessing SDS. Each pack contained a stamped, addressed envelope for anonymous return of completed surveys. Participants were also able to fill out the survey by phone or online. The link to the online survey was also publicised via local and national organisations involved with SDS, who distributed information on their websites, social media platforms, newsletters and among their networks. We closed the survey on 14 February 2020. The survey was available in large print and Braille (as well as other accessible formats) on request.

Telephone Support Line

The project partners set up a free telephone support line for the survey, answered by members of the project team. Potential survey respondents were invited to call the freephone number if they had any questions or if they would prefer to complete the survey over the phone.

Seldom Heard Groups

To ensure that we included the experiences of seldom heard groups who are often under-represented in policymaking, we carried out thematic focus groups with people from across Scotland. We heard from 58 people who use SDS and unpaid carers from seldom heard groups across eight focus groups. Groups included: older people from Black and minority ethnic communities, people with learning disabilities, blind and partially sighted people, people with lived experience of homelessness, people from rural areas, people with lived experience of mental health problems, and parent/guardian carers. A focus group with people who are LGBT+ was cancelled due to COVID-19.

Local Authority Feedback Sessions

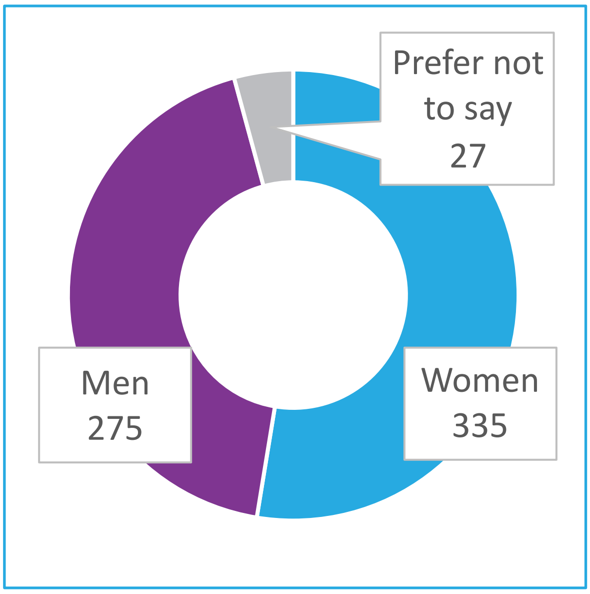
As well as helping inform national SDS policy, one of the aims of MSMC is to support learning and SDS improvement at the local level. Project partners have therefore worked to engage local authorities from the early stages, including survey dissemination. When it is safe to do so in the COVID-19 recovery and post-pandemic phases, we will reactivate plans to hold local feedback sessions with all relevant stakeholders, to share emerging findings and recommendations and explore opportunities for further action. Local authority area reports will also be published at this time.

Research Participants

MSMC heard about the experiences of 637 people who use or were being assessed for SDS. We interviewed 104 people who spoke about their own experiences and the experiences of other members of their household who use SDS (spanning the experience of a total of 119 people who use SDS or who were being assessed for SDS). A further 460 people completed the survey, and 58 people who use SDS participated in our focus groups. Throughout this report some participant details (e.g. age) have been changed slightly to preserve anonymity, while maintaining the most important information. Where changes have been made to quotations those alterations are indicated via square brackets (e.g. “My advocate, [Name], was great”).

Where possible, we have compared our participant data to figures from Information Services Division’s (ISD) experimental statistics on social care in Scotland.[27] While not comprehensive, ISD have demographic statistics on people using SDS, and accessing social care support services more generally – although not every local authority submitted disaggregated data. ISD include people who use SDS within their wider discussions of people receiving “social care support”, but also include care home residents and people who use community alarms and telecare services (with or without SDS) in that wider definition.[28]

Chart 1: Respondents’ gender



Gender

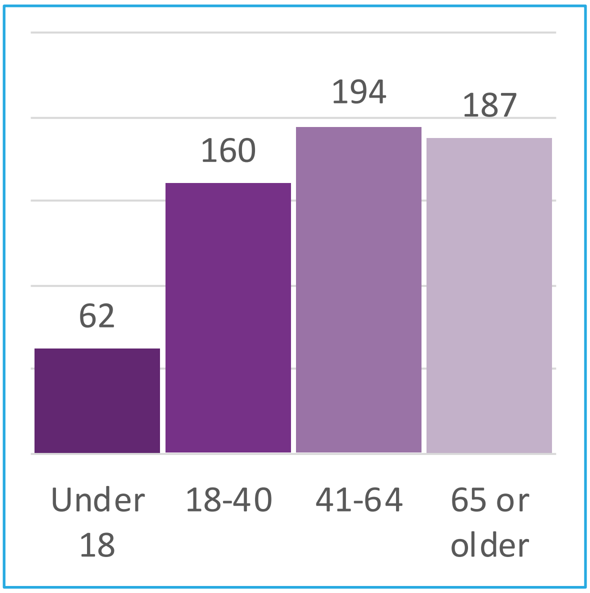
Overall, 335 women (53% of respondents) and 275 men (43% of respondents) participated in MSMC. A further 27 people preferred not to disclose their gender.

While ISD figures are not available for the division of men and women accessing SDS, they do publish statistics 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.[29]

Age

We asked all participants to share their age. Of the people who chose to answer the question, 62 (10%) were under 18 years old, 160 (27%) were between 18 and 40 years old, 194 (32%) were between 41 and 64 years old, and 187 were 65 or older (31%).

Chart 2: Respondents' age



ISD do not provide an overall breakdown of age groups accessing SDS, although age group data is provided by SDS Option Chosen and Client Group Profile. ISD provide age disaggregated data on people receiving social care support services more generally (of whom an estimated 45% access SDS) – although not all local authorities submitted data on age to ISD. ISD report that in 2017-2018 87% of people accessing social care support were over 75 years old, with 21% of people aged 18-64, and only 1% of people under 18 years old.[30]

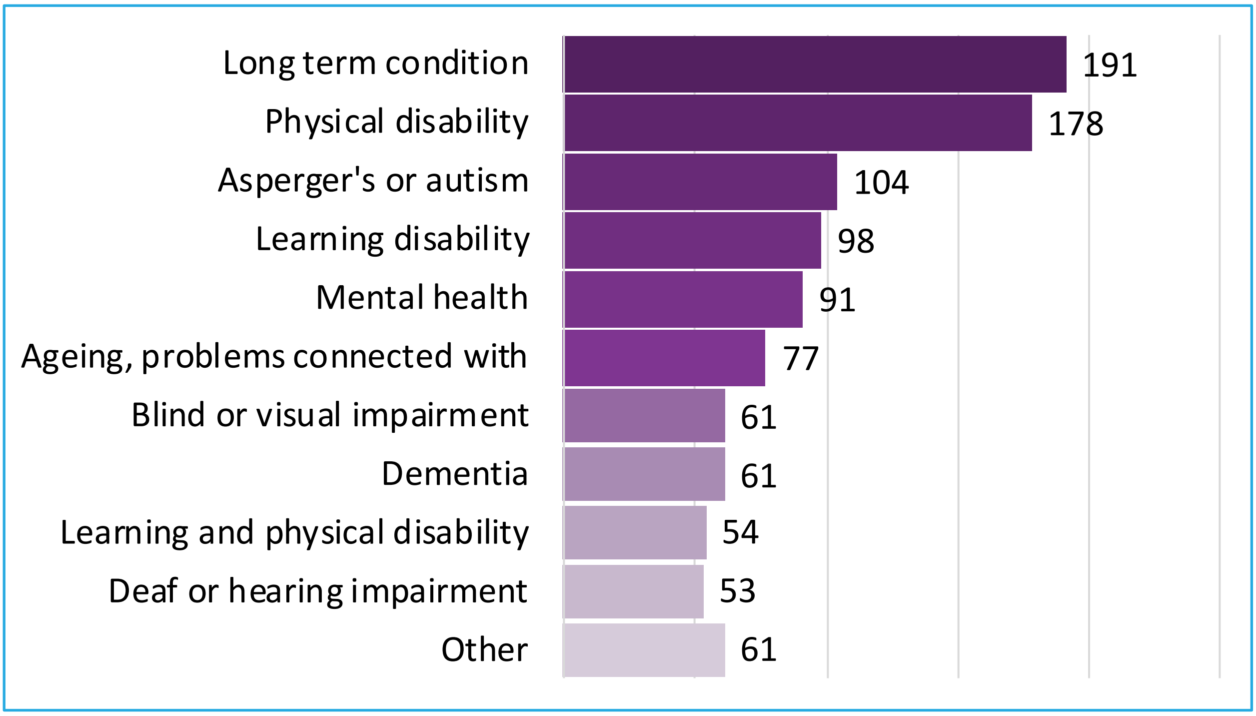
Ethnicity

429 MSMC survey respondents identified as white, four people identified as "Asian, Asian Scottish, or Asian British", three people described themselves as "mixed or multiple ethnic groups", one person identified as "African, Caribbean, Black, Black Scottish or Black British", and one person stated that they were part of an "other ethnic group". A further 22 people chose not to describe their ethnicity. Most interviewees and focus group participants did not disclose their ethnicity when self-describing themselves, and the majority of those that did described themselves as "white". 16 people who took part in our focus groups described themselves as belonging to Black and minority ethnic communities. The overall spread of MSMC respondents is accordingly slightly less ethnically diverse than is typical for Scotland, with 25 respondents who described themselves as Black, Asian, or from mixed, multiple or minority ethnic groups (4% of participants).

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".[31]

ISD do not provide a disaggregated breakdown of the ethnicity of people accessing SDS. They have some disaggregated data on the ethnicity of people receiving social care support services more generally (of whom an estimated 45% access SDS), using the limited categories of "White", "Other", and "Not provided/Not known".[32] 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").[33]

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



Client Group/Disability/ Long Term Condition

MSMC survey respondents self-identified as living with a range of conditions, with the majority reporting that they live with multiple conditions. 191 people (42%) said they live with a long term condition, 178 people (39%) selected physical disability, and 104 people (23%) selected "Asperger's or Autism".

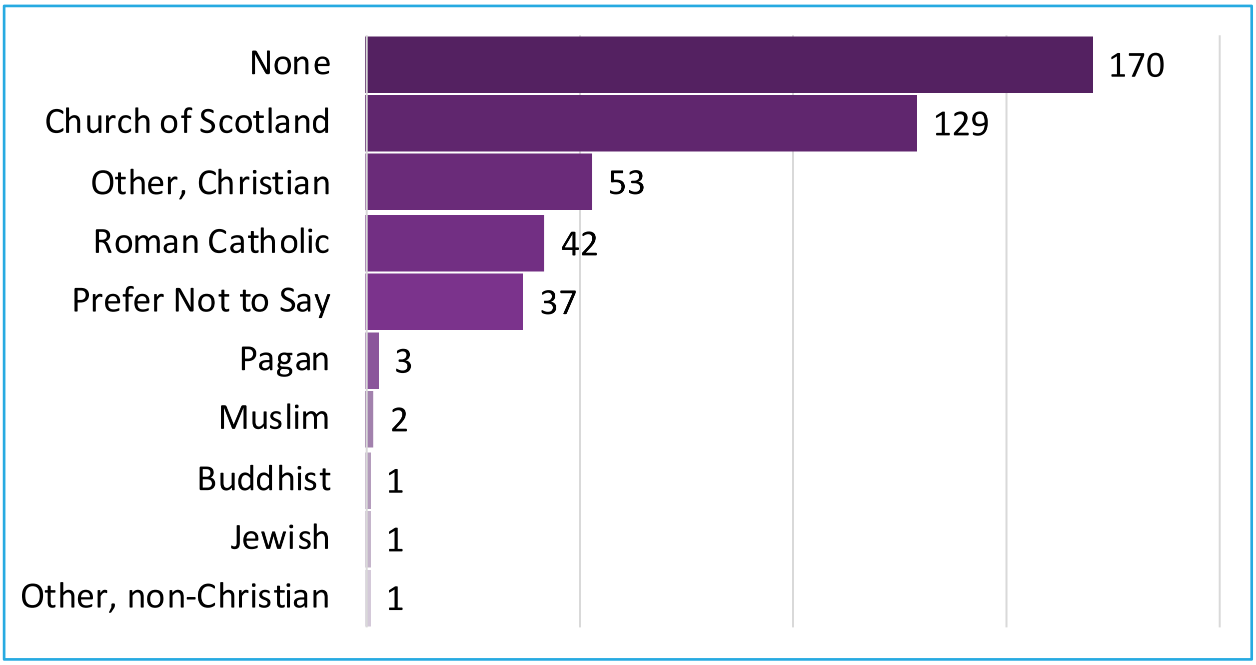
Interviewees and focus group participants also discussed their conditions, and – if they were unpaid carers – those of the people for whom they care. Their reasons for accessing SDS were broadly in keeping with survey respondents'.

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.[34] These broad categories do not directly align with those tracked in MSMC, and not all local authorities submitted data to ISD. As with MSMC, people could feature in more than one client group simultaneously. Overall, ISD estimate that 47% of people accessing SDS did so because they were "elderly/frail", 35% due to a physical or sensory disability, 10% because of a learning disability, 8% due to dementia, 7% as a result of their mental health, and 17% for "other" reasons. A further 8% did not have their reason for accessing SDS recorded by the local authority (not including those that did not submit data).

Religion

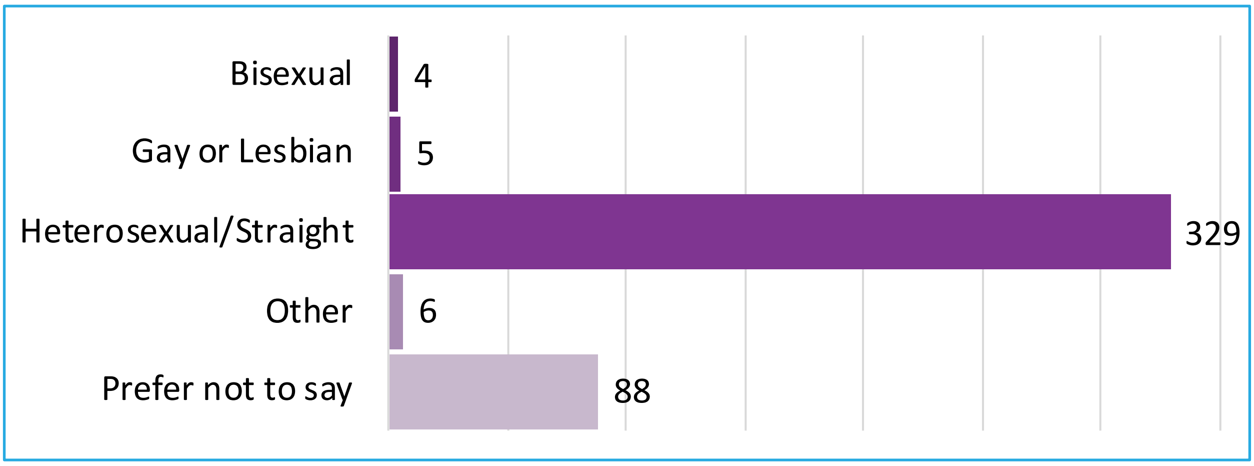
When asked about their religion (if any), 170 survey respondents (39%) stated "none", 129 (29%) are part of the Church of Scotland, 53 (12%) described themselves as "other Christian", and 42 (10%) were Roman Catholic. Three people described themselves as "Pagan", two people as Muslim, one as Buddhist, one as Jewish, and one person follows "another religion (non-Christian)". 37 people (8%) preferred not to answer.

Chart 4: Survey respondents' religion



Most of the interviewees and focus group participants did not choose to explicitly disclose their religion when self-describing themselves. The overall spread of MSMC respondents is slightly less religiously diverse than 2011 Scottish Census data for Scotland. Data about people's religion is not available on the ISD dashboard.

Chart 5: Survey respondents' sexual orientation



Sexual Orientation

329 survey respondents described their sexual orientation as heterosexual or straight, five people were gay or lesbian, four people were bisexual, and six people selected "other". A further 88 people stated that they preferred not to disclose their sexual orientation, and 28 people did not answer the question. The 2011 Scottish Census did not record data on sexual orientation at local authority level (although the 2021 Scottish Census will do so); as such, we do not have local statistics on sexual orientation available as a comparison. Data on people's sexual orientation is not available on the ISD dashboard.

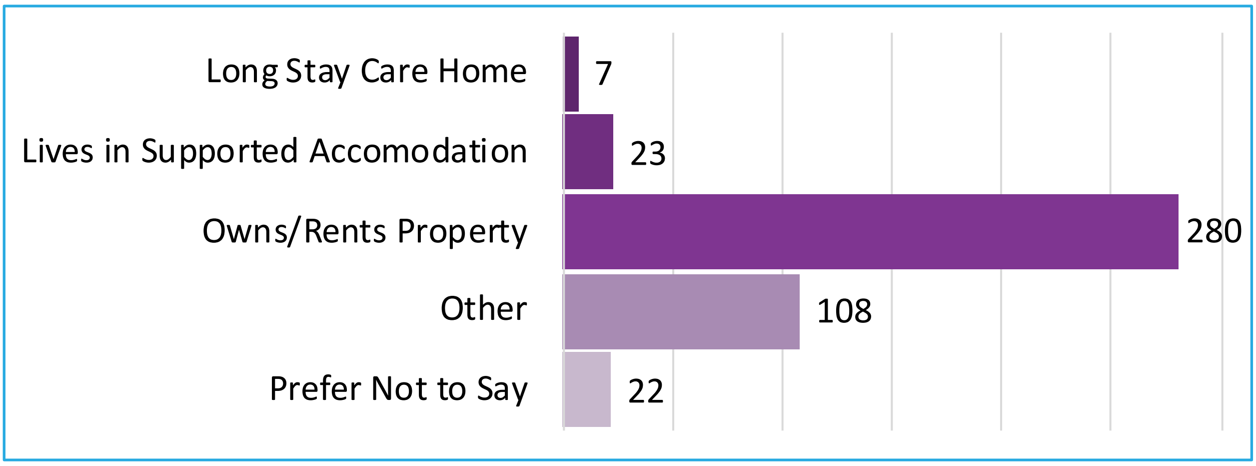
Housing

280 survey respondents (64%) either rented or owned their own home, 23 (5%) lived in supported accommodation, and seven people lived in a long stay care home. A further 180 people (25%) selected "other", and 22 people selected "prefer not to say" (5%). Data on people's housing situations (other than residential care) is not available on the ISD dashboard.

Of those who answered "other", 88 people (20% of all respondents to the question above) reported that they lived in the home of a family member. Six people did not provide further details, four stated that they lived in a "council house", four people simply stated "home", one person said that they were "homeless" and staying with a friend, another was living in a "friend's home", one lived in their "partner's house", one in a "retirement flat for the elderly", and one "stays with [their] carer". Finally, one person was living in their own home but in the process of moving into supported accommodation.

When discussing housing, several interviewees 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 people lived independently in their own home, followed by those who lived with a family member.

Chart 6: Survey respondents' housing arrangements

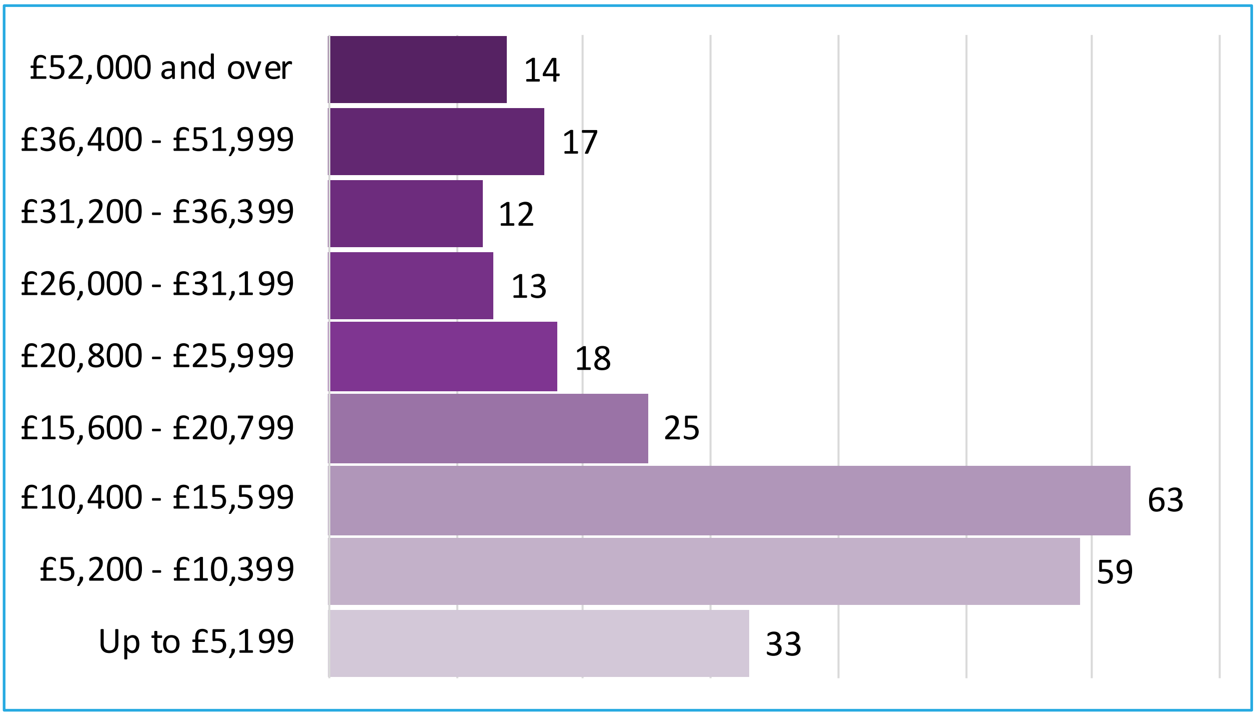


Household Income

We asked survey respondents about their household income. We were interested in this information because in Scotland an estimated 24% of households with a disabled person live in relative poverty after housing costs, compared to 17% of the population with nobody with a disability in the household.[35] 254 survey respondents chose to disclose their 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.

Chart 7: Survey respondents' annual household income



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).[36] The relative poverty threshold was defined as a household income of £302 per week (£15,704 per annum), or an income which is 60% below that which is recognised as the middle income for people.[37] Based on this definition, 155 (61%) of the respondents who chose to provide details of their household income are living below the poverty threshold. Data on the household incomes of people accessing SDS is not available on the ISD dashboard.

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

Scottish Index of Multiple Deprivation (SIMD)

The Scottish Index of Multiple Deprivation (SIMD) is used to measure relative deprivation. It combines information on income, employment, education, housing, health, crime and geographical access, based on postcode. Following ISD's use of these categories, the project team used the 2016-2019 SIMD boundaries for MSMC, dividing Scottish postcodes into five equal groups based on population size. Deprivation quintile 1 relates to the most deprived areas in Scotland; deprivation quintile 5 relates to the least deprived areas.

ISD do not provide an SIMD breakdown for people accessing SDS, but they do have SIMD data on people receiving social care support services more generally (of whom an estimated 45% access SDS) – although not all local authorities submitted SIMD data to ISD. Of those that did, 21% of people accessing social care services lived in quintile 1, 24% in quintile 2, 22% in quintile 3, 18% in quintile 4, and 16% in quintile 5.

306 MSMC survey respondents provided postcode information to enable us to analyse their responses alongside SIMD data. 13% of MSMC respondents who provided SIMD data lived in quintile 1, 18% in quintile 2, 26% in quintile 3, 27% in quintile 4, and 16% in quintile 5. Where question response rates were high enough for meaningful cross-analysis with SIMD data, we have presented those findings throughout this report – sometimes combining results from quintiles 1 and 2 and quintiles 4 and 5 to demonstrate broader trends.

SDS Option

Of the research participants who shared which SDS option they used, 239 people (54%) indicated they used Option 1, 35 (8%) used Option 2, 96 (22%) used Option 3, and 47 (11%) used Option 4. 29 people (7%) did not know what option they used.

Figures from ISD indicate that in 2017-18 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.[38] In some instances, people are logged as being on two options simultaneously (e.g. Options 1 and 3) rather than Option 4, which distorts these figures.

Data Gathering and Analysis

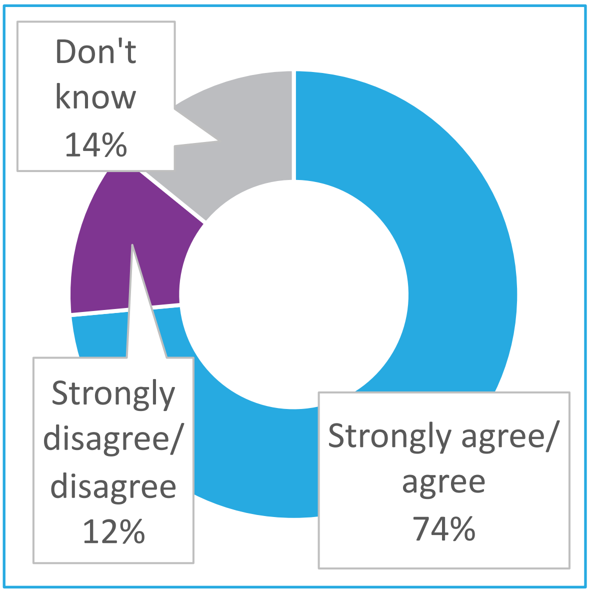
As the chapter on research participants demonstrates, there are concerning gaps in SDS data gathering, analysis and reporting. ISD have reflected on difficulties gathering disaggregated data on people's use of and experiences of SDS/ social care in their experimental statistics publication Insights into Social Care in Scotland.[39] 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. 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".[40]

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

Overall Experiences of SDS/ Social Care

We asked survey respondents whether they felt that SDS had improved their social care experience. Of the 325 people who answered this question, 239 (74%) stated that they "strongly agree" or "agree" with the statement "SDS would/has improve/d my social care experience". 40 people (12%) disagreed or strongly disagreed and 46 (14%) were unsure.

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



Survey participants were also asked to share an overall summary of their experiences and any advice they might have for people considering SDS. One person, who had previously received more rigid social care before the introduction of SDS, summarised their experiences as follows:

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

Most people's statements about their overall experiences of SDS were positive:

> *"I am now living my life to its full potential."*

> *"It is a great way to shape the care you need."*

> *"The […] flexibility and choice it gives is priceless."*

> *"If properly and appropriately carried out it can make a huge difference in people who want to direct their support."*

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

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

> *"Keep your eyes on the outcome that you are hoping to achieve. The assessment is time consuming*

> *and a bit overwhelming but tell the social worker everything relevant. Check the draft assessment and make sure that it is accurate. For us, Self-directed Support is the perfect solution."*

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

> *"Be prepared for a nightmare of paperwork."*

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

> *"It isn't worth the stress and judgemental interference in your life."*

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

> *"Don't hold your breath. Process takes ages, too many long forms with stupid questions. Wait ages for SW [social worker]. Then pushed into PA [personal assistant] option as it's cheaper for local authority. That's if you can meet criteria."*

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

> *"Go through it – […] it's tough, upsetting, difficult and feels like it's more trouble than it's worth, but you need to start somewhere."*

Information About SDS

Finding Out About SDS

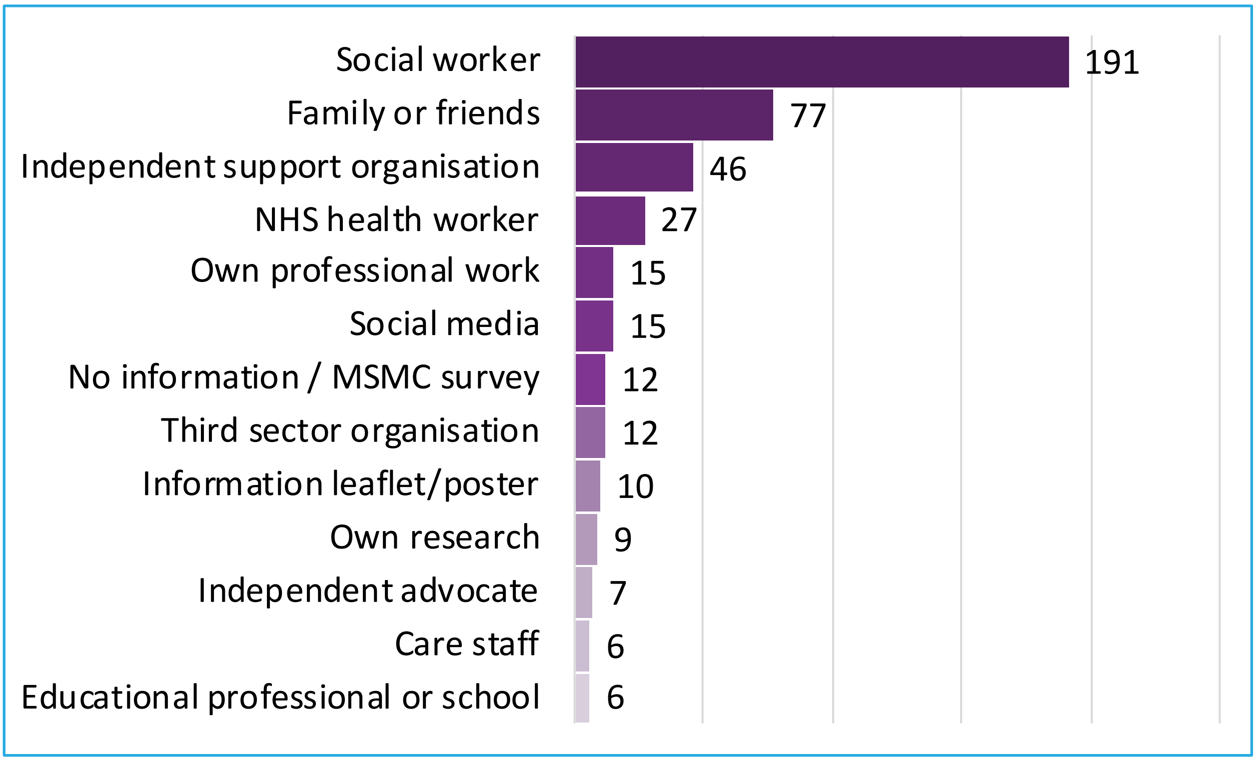
We asked participants how they first found out about SDS.

191 survey respondents (43%) had first heard about SDS from a social work professional or occupational therapist. 77 people (17%) heard from friends or family members, 46 (10%) from an independent support organisation, and 27 from NHS health staff (6%), including nurses working in the community. 15 people (3%) knew about SDS through their own professional work before they accessed it themselves – as social workers, academics, teachers, care workers, health staff, campaigners, legal professionals, third sector employees, and people who work for a local authority. A further 15 people (3%) first heard about SDS via social media, 12 from third sector organisations, and ten from an information leaflet or poster.

Nine people discovered SDS through their own research – primarily using the internet, with several people referencing local authority or Scottish Government websites as sources of information. Seven people heard about SDS from an independent advocate, six from an educational professional or school, and six from care staff.

Two people knew about SDS as they had received it in England before moving to Scotland. One person first heard through a local carers' network, one through a community brokerage organisation, one from a neighbour, and one from a landlord or local housing professional. One person did not remember how they first heard about SDS.

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



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

12 survey respondents reported that they had never received information about SDS – including eight people who stated that they first heard about SDS via this research project. Several interviewees and focus group participants also said that they did not understand or had not had SDS fully explained to them, stating that they "never heard of" SDS, even though they were receiving social care support that in ways sounded identical to SDS to the researchers. For example, one person discussed how their support was arranged on a day to day basis in some detail, but also stated that "I don't actually know if I get Self-directed Support."

Some people spoke about receiving insufficient information about SDS – even when in receipt of services – stating that "there's a lack of clarity on what people want and what people are given. It's not clear, what they get, and what they want or need." In terms of getting in touch with social work, one person stated that they "don't know what it means to have a social worker." Another person reflected that this uncertainty was common amongst particular groups of people:

> *"The first question is that people don't even know how to get in touch with social work or find a social worker. Most ethnic minority people do not know who to contact and where."*

Another respondent also framed knowledge about and access to SDS explicitly in terms of cultural context and ethnicity. They concluded that:

> *"I think mostly, especially for ethnic minority people, nobody knows, nobody gets in touch with them, nobody asks them. There are different barriers and different issues – that needs to be highlighted. When you do the [MSMC] report, it needs to be part of that. These are people who are English speaking – there are many, many people who do not speak the language, they will never know who to contact, where to phone, what they get or don't get. Just think about it, their situations, where they're just left, in such a dire situation sometimes. [...] It has to be highlighted."*

Black and minority ethnic peoples' experiences of SDS are explored in more detail in a separate thematic report.

One interviewee highlighted that their knowledge of SDS came through their professional work. They reflected that while SDS has been beneficial to the person for whom they care, "I think had I not worked in the environment that I work in, I wouldn't have given it a second thought." When asked how they would have found out about SDS outwith their workplace, the interviewee reflected that in retrospect their GP could have done more to assist them in considering SDS and support options, as well as medical interventions specific to the person's health:

> *"I think certainly the GP could be more proactive [...] I think they have had a very hands-off approach to a lady at [specific age] that had hardly been to the doctors in her life and their family has never ever phoned before, but*

they're phoning being concerned about her, her very low mood and her lack of appetite [since sight loss]. […] So, yeah, I would say they've had a very hands-off, almost unhelpful approach."

Finding Out About SDS: The research indicates that work could be done to help dismantle communication barriers faced by some population groups, including Black and minority ethnic people, so that people can find out about SDS quickly and easily. It would also be helpful to widen the pool of professionals who are informed about SDS and can encourage people to access it. Making more use of educational professionals, hospital staff, GPs and other community health practitioners would be particularly valuable, as well as building on the existing expertise of social workers, independent advice and support organisations.

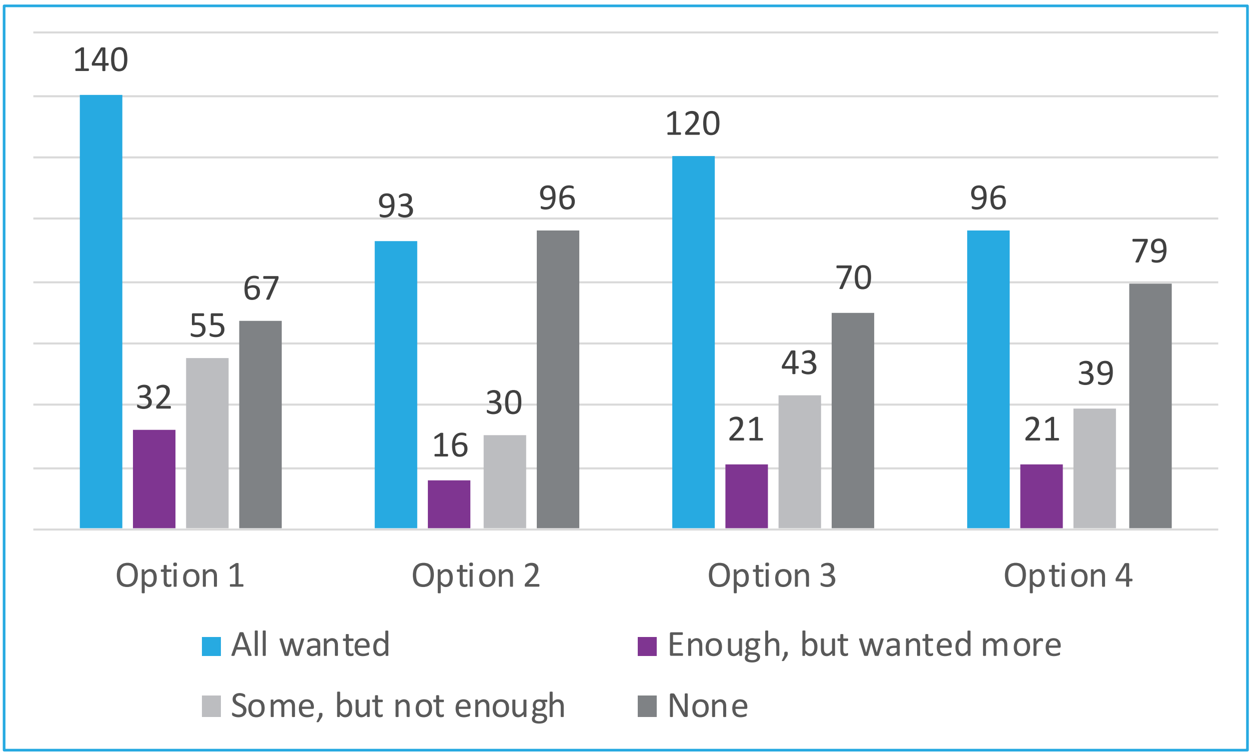
Information and Preparedness Before Assessments

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

As the chart indicates, across all four SDS options a large minority of respondents received "all the information [they] wanted" (respectively, 48% (Option 1), 40% (Option 2), 47% (Option 3) and 41% (Option 4)). However, it is concerning that the majority of people across all four options either had no information or were left wanting more in advance of their needs assessment.

Of the people who felt they needed more information before meeting with a professional to discuss their support, 41% stated that they either received "some, but not enough" or no information at all about Option 1, while a further 11% said they had received "enough" information "but wanted more".

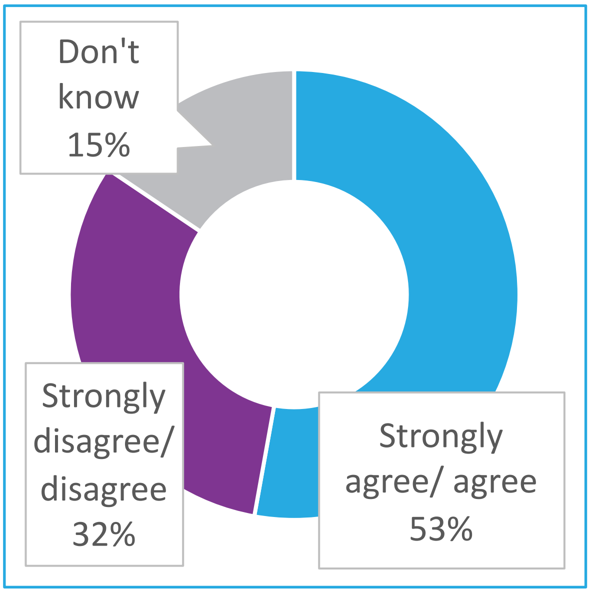
Chart 10: Information received before discussing support (Survey)



With Option 2 (which had the lowest satisfaction rate across the options), 54% reported that they had either "some, but not enough" or no information, with 7% receiving "enough, but wanted more". For Option 3, 44% of people said that they had either "some, but not enough" or no information, and 8% of had "enough, but wanted more". Finally, 50% of people said they had received either "some, but not enough" or no information about Option 4, while 9% received "enough, but wanted more".

We also asked survey respondents whether they felt prepared for their needs assessment. Of the 424 participants who answered the question, 224 people (53%) either strongly agreed or agreed, while 134 (32%) disagreed or strongly disagreed. A further 66 (16%) stated that they were unsure. It is encouraging that just over half of respondents felt prepared for their needs assessment, however it is concerning that nearly a third of people felt unprepared and the rest were unsure.

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



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

Information and Preparedness Before Assessments:
These findings indicate that many people 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 people 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 people reach crisis point – and reduced demands on staff time because people are better prepared for discussion and assessment. People 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.

Older People and Information about SDS

Amongst older participants (people aged 65 or older), several people offered input on how they would expect to find information about social care. Friends and family (including extended family living outwith Scotland) were many people's first port of call, followed by medical professionals. One older respondent, whose spouse accessed SDS (which they described as "very, very good"), first engaged with social workers for their own care following a recommendation and referral from their doctor. Several other people also stated that their first action should they need social care support – specifically in times of crisis – would be to contact their GP. One person summarised their approach as follows:

> ***"You can also ask your GP, because there will be a social work team connected to them, your doctor. When I have problems, my [spouse] is very ill, and I just saw the doctor and said, 'this is a crisis we're in and I don't know where to go'. And I don't think it's my responsibility to search the internet to find help."***

However, the same person reflected that following contact with a GP, accessing information to obtain support is not easy. They went on to explain that in their experience, "you speak to ten people and they all tell you, 'it's not me, it's somebody else."

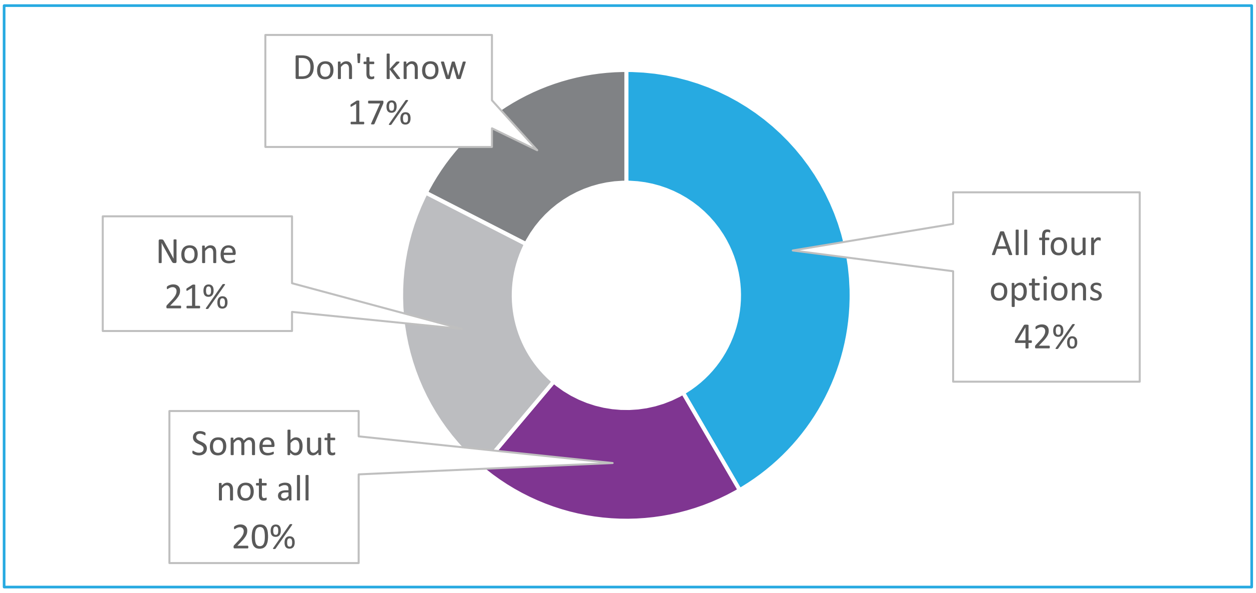
Another older person echoed the above comments about some people not having the capacity – or the responsibility – to carry out online research about SDS. They stated that they "don't want a helpline", and that they preferred face-to-face communication. They went on to point out that:

> ***"On top of that many people don't have access for the computer. How then do you check online? Online, not everybody [is] comfortable there. It's very difficult for ethnic people, especially our generation. When we came here we didn't study here, we didn't have access, or very few – so we can't really manage it. We need help. Also language."***

Finally, older participants also spoke of their confusion regarding the overlaps between Free Personal Care and SDS, and what was covered within social care support more broadly.

Work could be done to dismantle communication barriers faced by older people so they can find out about SDS quickly and easily. This would include widening the pool of professionals who are informed about SDS and can encourage people to access it, streamlining information processes and clear signposting, and ensuring people have access to information in a range of formats.

Chart 12: Discussing SDS options with professionals (Survey)



Information During Assessments

The pattern of variable information about the four options continued into people's needs assessments. We asked respondents whether all four SDS options were discussed with them when they met with a professional to discuss their support needs (e.g. a social worker/social work assistant or an occupational therapist).

Of the 435 people who answered this survey question, 181 (42%) stated that the professional discussed "all four options" with them. However, 85 (20%) reported that "some but not all" options were discussed with them, and 93 (21%) stated that "none" of the options were discussed. A further 76 (17%) 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 people during their needs assessments and reviews.

Many interviewees and focus group participants reflected on positive experiences during their needs assessments and reviews; however, the majority recounted more mixed experiences. Several people reported that they felt that the conversations they had with 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.

One respondent outlined that they did not feel that professionals in their area were equipped with enough information about the different SDS options – and so struggled to share information with service users. They summarised their perspective as follows:

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

> *are Option 3s because that's the easiest option to do."*

One focus group participant also stated that they were given incomplete information about the four options:

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

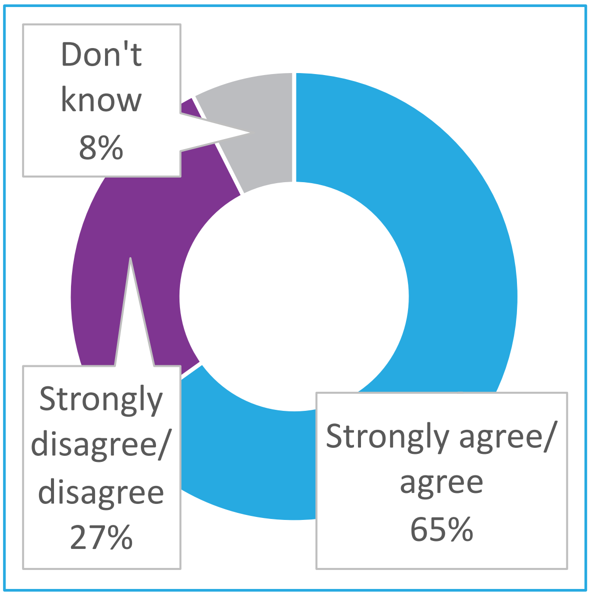
Significantly, several people reported that they struggled to access large print, Braille, or Easy Read versions of documents and information leaflets – even when professionals knew that they required documents in accessible formats. One respondent suggested that an information and support line would be useful in preparing people to access SDS:

> *"There should be a phone number [...]. If people knew, if anybody did know about it [they] [could] phone and find out if they would be entitled to [...] and they could sort of ask questions and give people a guide. 'You should apply for it', 'you should be entitled to it', or 'you should apply and you might get it' – if they questioned them over the phone, if they knew what they were talking about with the person at the other end."*

Respondents also raised concerns about language and the need for local authorities to provide translators for people for whom English is an additional language. One person summarised the need for this service as follows:

> *"At one time we used to get [...] a translator in order to help, because people did not understand. [...] Also, in fact how can people actually gain redress if something isn't right, or they're not satisfied – where do they go, and to whom? Because we were just talking back and forth if they don't know how to access their rights. Without language, people have no rights. And thus, this is critical."*

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



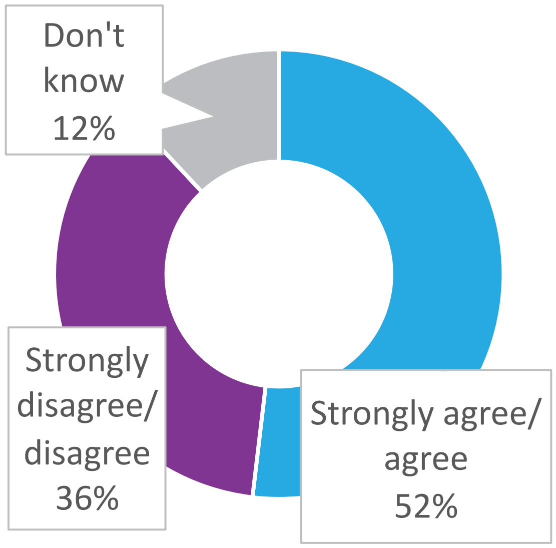
In the survey, we asked respondents a series of questions about their interactions with professionals. When asked whether they agreed with the statement "The person I met with explained things clearly to me", 280 people either "strongly agreed" or "agreed" (65%) with the statement, while 118 people (27%) disagreed or strongly disagreed. A further 32 people (7%) were unsure. 30 people did not answer this question.

Analysing responses by SIMD quintile, 77% of people living in quintiles 1 and 2 (the most deprived areas of

Scotland) agreed or strongly agreed that the person they met explained things clearly, with 17% disagreeing or strongly disagreeing. In contrast, 68% of people living in quintiles 4 and 5 (the least deprived areas of Scotland) agreed or strongly agreed with that statement, with 26% disagreeing or strongly disagreeing.

We also asked respondents about whether they had had any questions during their needs assessments or review. In the survey, we asked people to respond to the statement "All my questions were answered", regarding their meeting with a professional. Of the 425 people who answered this question, 221 (52%) strongly agreed or agreed, while 154 (36%) strongly disagreed or disagreed. A further 51 people (12%) said that they did not know. Interviewees and focus group participants indicated similar experiences.

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



Men were more likely than women 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 only 49% of women agreed or strongly agreed with that statement. Women's experiences of SDS are explored in a separate thematic report.

Older people were more likely to agree or strongly agree with the statement "all my questions were answered", regarding their last meeting with a professional. 70% of people who were 40 years old or younger stated that all their questions were answered, compared to 73% of people 41-64 years old, and 81% of people who were 65 or older, with a comparative decrease in the number of people who strongly disagreed or disagreed with that statement.

Several people expanded on difficulties obtaining further information from their social worker – and the importance of receiving answers to their questions. One respondent stated:

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

Another person reported that their social worker was well intentioned, but that:

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

A different interviewee reflected on whether their needs assessment had scope for questions. They summarised their experience as follows:

Respondent: There wasn't much opportunity to ask questions. Again, I was just too accepting. They made it sound so final and that there is no opportunity anywhere else, you know; that was it.

Interviewer: You don't feel that there was any opportunity for any good or effective conversation?

Respondent: No.

Information During Assessments: Social workers and other professionals play a significant role in informing, influencing and implementing decisions about social care, and they are often many people's first port of call for information about SDS, including eligibility criteria, wait times and available support. The research indicates that further work is needed to ensure that everyone is fully informed about the four SDS options during assessments and given the opportunity to consider them. For some people, information is best provided face-to-face, more than one conversation may be needed, and people should have access to independent advocacy and support and foreign language translators during these meetings if they want. People should have access to information in a range of accessible and inclusive communication formats in advance of and during meetings. Further, targeted work by social work is required to ensure that people are fully involved in all decision making about their care and support, and to make sure their questions are answered. Specific groups like women and younger people would benefit from targeted initiatives, and issues like people's socioeconomic status should inform tailored communications. 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 outstanding concerns that were not addressed during their last assessment. Of the 434 respondents who answered this question, 209 people (48%) had no concerns, 127 people (29%) had outstanding issues that were not addressed by social work, and 98 respondents (23%) were unsure.

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

Younger people were more likely to have unaddressed concerns following their last meeting with a social work professional. 34% of people who were 40 years old or younger stated that they were left with outstanding concerns, compared to 27% of people 41-64 years old, and 14% of people who were 65 or older, with a comparative decrease in the number of people with no unaddressed concerns.

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.

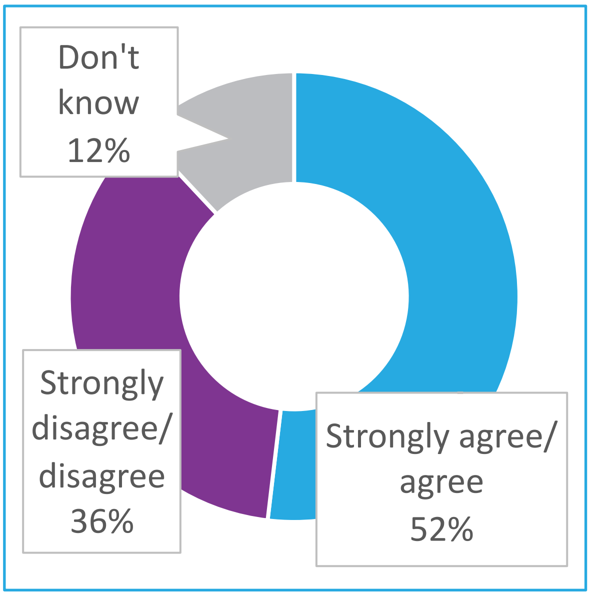
We also asked survey participants whether they were in the process of appealing the decision made in their last review or needs assessment. Of the 361 people who answered the question, 25 people (7%) indicated that they are in the process of appealing the outcome of their last social care assessment or review. Of those people who were appealing the latest decision on their care, six people were being supported by friends or family, six people had sought help from an independent support and advice organisation, four people were being assisted by an independent advocate, two by their personal assistants, two had found their own internet research helpful, one person had been helped by receiving information leaflets, and three people selected "other" (including one person supported by a Guardian, and another two people by a variety of people). Five people did not provide further details of sources of support.

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

Information About Budgets

We asked survey respondents if they had been told the amount of money they can spend on their support (sometimes called an estimated or a personal budget). Of the 315 people who answered the question, 205 people (65%) said yes, they had been told how much money they could spend, while 81 people (26%) said they had not been told how much money was available to them. A further 29 people (9%) stated that they did not know if they had been given a budget.

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



Analysing responses by SIMD quintile, 73% of people living in the least deprived areas (SIMD quintiles 4 and 5) indicated that they had received a personal budget, with 22% stating that they had not been given that information. 64% of people living in SIMD quintiles 1 and 2 received a personal budget, with 27% reporting that they had not received that information. The contrast between these results was even more marked when comparing people living in SIMD quintiles 1 and 5: only 54% of those in quintile 1 received a personal budget, in comparison to 80% of those in quintile 5. It is troubling that there is such disparity between those living in the least and most deprived areas of Scotland.

That most people had received information about how much money was available to them is a positive finding. However, it is concerning that a significant minority – over a third of people – either had not received that information or were unsure. In particular, it is vitally important that measures are put in place to ensure that people living in areas of deprivation are given full information about their personal budgets, to enable informed decision making.

Furthermore, women were significantly 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, in comparison to 76% of men.

One respondent explained that "I was not given enough information about how much of a budget I would receive, which made it difficult to know if my needs were going to be met." Another person reported that "I was not told what my budget would be, so neither my partner nor myself could look at options. There was no information on how […] this would affect household benefits and my PIP."

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

> *"I would also say that I completely understand it when money is so tight. […] This isn't a witch hunt; I don't think that I and my family deserve anything extra. It's that the promise that's made by the Government's statement is not always matched up, and I would like more transparency there too. […] Something that's open across the country, not just broken up into each individual council. But it doesn't work like that."*

Another person said:

> *"The charging policy and its implementation. The carer's budget and my budget. The assessment was unchanged from last year but my budget was reduced by almost £2,000. There is no clear logic to how budgets are calculated, and the eligibility criteria is changing. As someone with [specific condition] this is very anxiety provoking, giving no confidence about the future."*

Similarly, another interviewee was confused by a rise in care charge contributions. They explained to the social worker that they have limited income from social security entitlements and outlined what they could afford. At the time of the interview they had not heard confirmation about the situation from the social worker. The interviewee felt frustrated that conversations focus upon the potential reduction of hours using SDS, rather than support needs and outcomes. They asserted that:

> *"The thing that I try to put across is that my disability is not going to get any better, my disability is still going to be the same, so I'm still going to need the same amount of care. I've been in a wheelchair for […] years. The older I get it's going to get worse […] so there's no reason to cut it."*

Another interviewee also raised the issue of unpredictable personal contribution care charges. These, they explained, can eat into an individual's weekly budget. They outlined that:

> *"The contribution went up from £4.50 to £32 per week and [in] some of the cases it went up from £5 to £70 so you can imagine how much that takes out of the weekly budget."*

Similarly, a different person outlined problems caused by insufficient and inaccurate information about their budget, and delayed transfer of funds:

> *"We had an annual review last [month] and we received a letter to say that [Name] was getting the same budget, but that they would only send half the money and that the other half would come in [month]. Not a problem; I understand how budgets work and if that helps them manage their budget a bit better fine."*

The person went on to explain that, due to an oversight by the local authority, payment of the first half of the budget was delayed by four months, despite repeated emails. This caused the participant and the person they care for substantial stress and nearly resulted in the cancellation of much-needed respite.

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

Information About Budgets:
In order to support and enable people to make informed decisions about their care, everyone must be provided with accessible information about the budget available to them. People may want to take part in several conversations to support informed decision making about care charges, budgets and how they interact with other income like social security. Measures should be in place to ensure that all population groups, including women and people living in areas of deprivation, are given full information about their personal budgets. Any proposed changes (particularly increases) in care charges should be communicated clearly to - and discussed with - people who access SDS/ social care well in advance of the changes being introduced. Local authorities and health and social care partnerships should ensure that corrective measures are in place to rapidly respond to errors or delays in payments so that people are not negatively impacted.

People with Lived Experience of Homelessness and SDS

People who have experienced homelessness reported very poor implementation of SDS – particularly when they accessed social care support via addiction or housing services rather than mental health support. Most people only received information about the different options after decisions about their care had already been made. In most cases the service users did not have any input into decisions about their care and support.

Many research participants with experience of homelessness reported a lack of communication between different service providers (especially between health, housing, and social care sectors). This disconnect meant they were required to revisit trauma and recount their experiences unnecessarily – and “you get sick of telling your story all the time.” People who had been or were homeless also stated that they were not routinely provided with paperwork about their care and support arrangements, even when they requested these material (e.g. copies of budgets, personal outcome plans). One person stated that their difficulties accessing information about their care led to a Freedom of Information request:

> ***“I actually requested my documents under the Freedom of Information Act. I had some problems with some of the case workers. I got it eventually. Not all of it, I had to go back and tell them that they’ve missed some. I saw some of the stuff that had been written about me, and I just could not believe it. It was downright lies.”***

People highlighted the need for prompt responses when they seek help from social care services. They stressed that there may be only brief windows in which people can request help (e.g. due to drug addiction or alcoholism), and that long waiting times mean support frequently comes too late to be of use.

People in some local authority areas reported that they were informed by social work departments that SDS is not available for people who are homeless. One person stated that they had been told by their local authority that SDS was “too complex to administer” for people who were homeless.

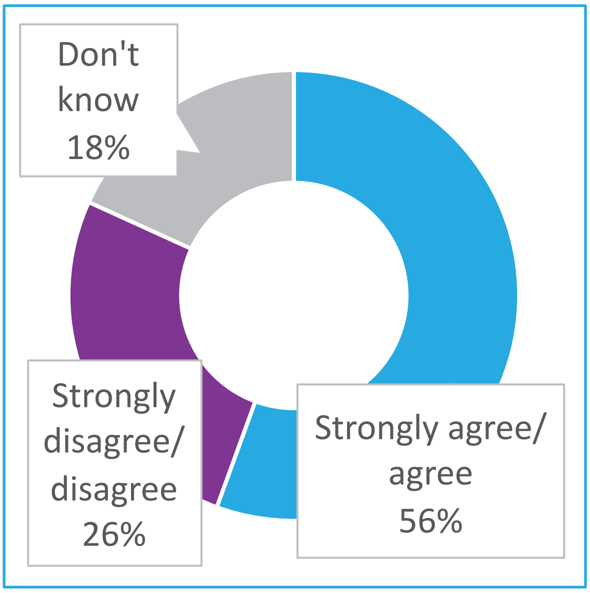
People with lived experience of homelessness reported widespread stigma amongst social care staff, as well as difficulties in building up trusting relationships due to high staff turnover. They suggested that there was a need for more training and empathy for health and social care professionals about people’s human rights. Across the people we heard from with lived experience of homelessness, there was widespread support for the need for more training in supported decision making and person centred care for health, housing, and social work professionals alike.

Informed Choice and Control

Time to Consider Options

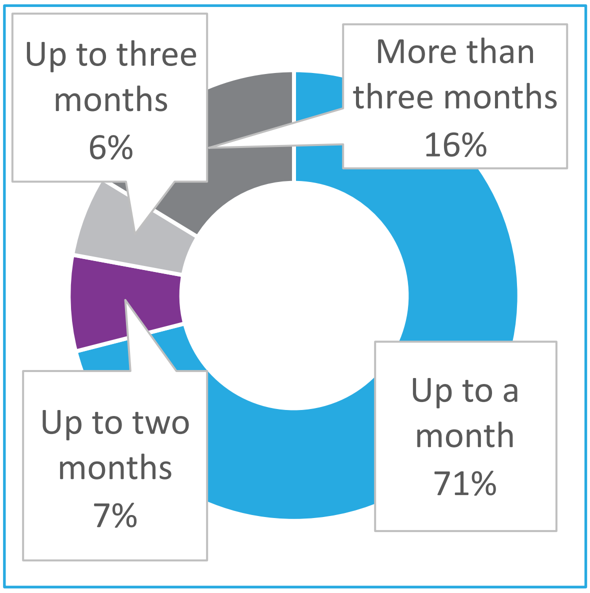
We asked survey respondents whether they agreed with the statement "I had enough time to choose the option of SDS that suited my needs." Of the 423 respondents who answered this question, 235 (56%) either agreed or strongly agreed, 111 (26%) either disagreed or strongly disagreed, and 77 people (18%) stated that they did not know.

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



We also asked people how long they were given to think about the different SDS options before choosing. Most people (71% of all respondents) were given up to a month to decide – with 69 people (25%) given up to a week, 38 people (14%) up to two weeks, and 89 people (32%) up to a month. A further 19 people (7%) were given up to two months, 16 people up to three months (6%), and 45 people (16%) over three months to decide.

Chart 17: Length of time to decide options (Survey)



Although the figures are tight, cross-referencing the findings indicates that those who were satisfied with the time they were given were slightly more likely to have had over a month to make a choice, whereas those who were dissatisfied were more likely to have been asked to choose within one week. Further analysis also suggests a strong overlap between people who wanted more time as well as more information in order to make their choice.

One person summarised their experience of not having enough time to consider all their options as follows:

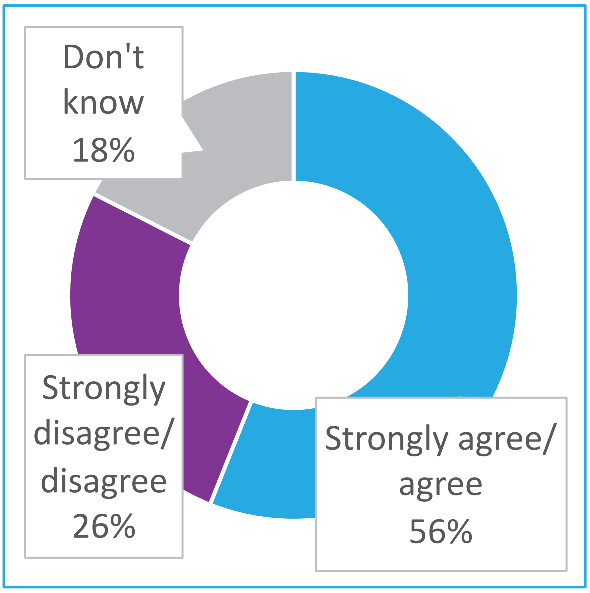
> *"[I] didn't feel I got enough time to think about what options really met our needs. Does feel rushed decision to get it to panel. Also very little options available – either limited council [services] or 'find your own'."*

Time to Consider Options: The research suggests that people should be given longer than a week to consider their options. There is also a correlation between the time people are given and the need for clear, prompt and accessible information so that people are able to make informed and appropriate decisions about their support.

Waiting Times

We asked survey respondents to agree or disagree with the statement, “Waiting times, or waiting for responses, makes Self-directed Support more difficult for me.” Of the 314 people who answered, 176 people (54%) either strongly agreed or agreed with that statement, while 83 people (26%) disagreed or strongly disagreed. A further 55 people (18%) stated that they were unsure.

Chart 18: “Waiting times, or waiting for responses, makes SDS more difficult for me” (Survey)



Interviewees and focus group participants also appreciated short waiting times for a response or decision from social work. While talking about their local social work team, one person stated 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.”*

People also commented on problems caused by long waiting times to access needs assessments or support. Many interviewees and focus group participants had waited longer than six months for a needs assessment or review, following a request for support, and some had waited over a year.

Other respondents commented on additional waiting times that they did not expect, between initial phone contact with social work, assessments, decisions on packages and finances, and finally the eventual implementation of support. One person noted that there were “significant delays in the budget being allocated due to the complexity of the […] process.”

For those that waited longest, family members reported concern about how to provide support, especially when the service user required increasing levels of support. One person stated that they considered inviting a 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 decision 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 caused significant stress to the people 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.

Some interviewees raised the issue of delays around the needs assessment impacting on their access to information and support. One summarised their experience as follows:

> *"We waited so long to get a social worker [dates provided; three years]. So, all that time I had nobody at all. Nobody told me that I could self-refer. And the GP didn't suggest it, the psychiatrist didn't suggest it, nobody did. I didn't know I could refer myself, but my [adult child] googled, you know, what help is there for people, and she came across the fact that there was social services office just around the corner. I think the social worker student came around about [date], and nearly a whole year went by before a social worker actually turned up, by which time I thought the whole thing was complete rubbish."*

It is worth noting that the interviewee described the social worker that eventually assessed them as very helpful, "just a breath of fresh air, just so good." However, the interviewee highlighted that the long wait to obtain support affected their health and caused considerable stress.

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

Choice Over SDS Options and Support

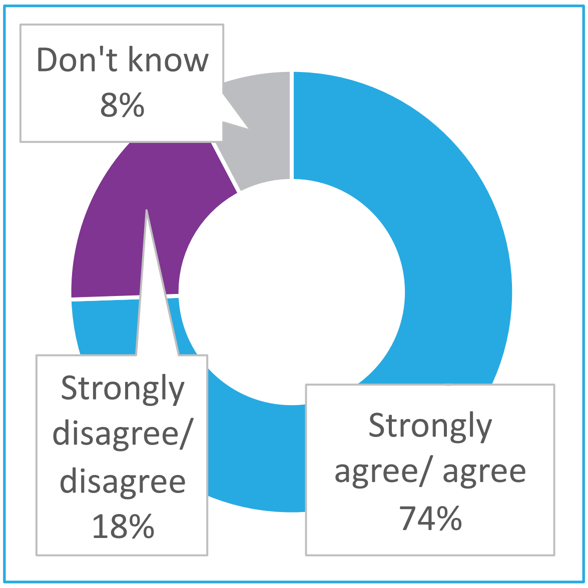
We asked survey respondents if they were on their preferred SDS option. Of the 328 participants who answered, 275 people (84%) were on their preferred option, 29 were unsure (9%), and 24 (7%) reported that they were not on their preferred option. The people who were on their preferred option described how support arrangements enable them to do a diverse range of activities. These included (but are not restricted to): personal care, assistance with household tasks and shopping, respite breaks, access to educational facilities, and support with social activities.

Analysing responses by SIMD quintile, we found that 86% of people whose postcode was in SIMD quintiles 4 and 5 stated that they were on their preferred option. In contrast, for people living in SIMD quintiles 1 and 2 that figure was 77%. While it is welcome that a clear majority of people are on their chosen option, the variance in these results encourages further work to ensure choice and service provision are fully available to people, particularly those living in areas of highest deprivation.

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 325 people who responded, 242 (74%) strongly agreed or agreed with that statement, while 58 people (18%) disagreed or strongly disagreed. A further 25 people stated that they did not know (8%).

Interviewees expressed more mixed experiences of SDS option choice. A significant minority of people from across Scotland stated that they were offered reduced choice, without all four SDS options being offered, with one person reporting that "we are not able to make choices and decisions; it's the ones above us."

Chart 19: "I am fully involved in all decisions about my care and support" (Survey)



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

When discussing the limited choice concerning the different SDS options, another interviewee explained that they received:

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

One person summarised their experience as follows, to widespread agreement from other focus group participants: "I'm not being funny – I never got the choice of who I wanted to support me, if you know what I mean." A different person stated that "I don't get any option at all. I get told I have to have my support […] they tell me what I have to do." Another respondent summarised their concerns as follows: "we didn't have any choice in the matter, as [we] were told it was happening and that was that." Some people commented on how lack of choice over support arrangements had a negative impact on people's physical and mental health.

Troublingly, several people with learning disabilities reported that their social workers had informed them that SDS was not suitable or accessible for them. One person stated that "my social worker, she turned around and said to me, 'SDS isn't suitable for people with learning disabilities.'" Other people reported that they had not had any choice about how their support was arranged and were instead simply informed about their care arrangements. One person was informed by their social worker that they would be placed "on Option 3, that the council is paying towards [their] support" and "all she said is that I will have to contribute", without any discussion of other options. Other people had similar experiences – particularly when leaving hospital, and without any subsequent review or discussion of options at a later date. One respondent summarised their experience as "a binary choice I had, either local authority or direct payment, that was it." They did also go on to state that they were "happy" with their current care arrangements, but that they had "defaulted" to that choice for lack of other options.

One survey respondent summarised their experience as follows:

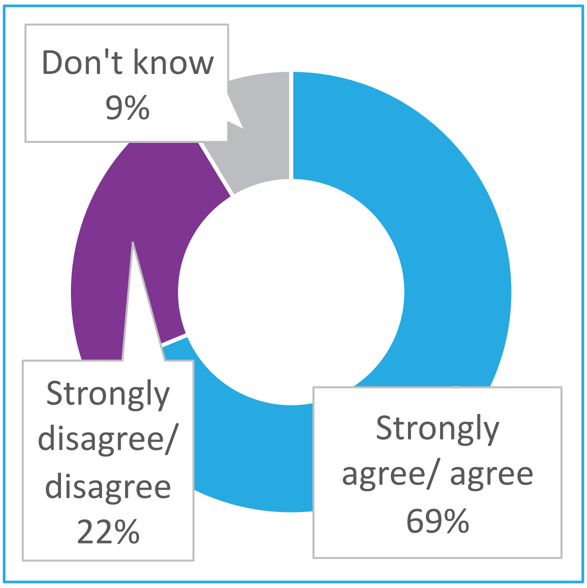
> *"My concerns remain; I was not being facilitated to change options as needs changed. [I was] manipulated into remaining within the current option for the remainder of the assessed year."*

An interviewee stated that they had not realised that there were four SDS options available, having assumed SDS was only available via direct payments. Another summarised their experiences as follows:

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

In the survey, we also asked people to respond to the statement "I had a say in how my help, care or support was arranged." Of the 426 respondents, 293 people (69%) either strongly agreed or agreed with that statement, however 96 people (23%) disagreed or strongly disagreed. A further 37 people (9%) stated that they did not know.

Chart 20: “I had a say in how my help, care or support was arranged” (Survey)



Analysing the findings by SIMD quintile, we found that 84% of people whose postcode was in SIMD quintiles 4 and 5 stated that they had a say in how their help, care or support was arranged. In contrast, for people in SIMD quintiles 1 and 2 that figure was 75%. While it is welcome that a clear majority of people feel involved in how their support is arranged, the variance in these results encourages further work to ensure people have equal say in arrangements for their help, care and support – particularly those living in areas of deprivation.

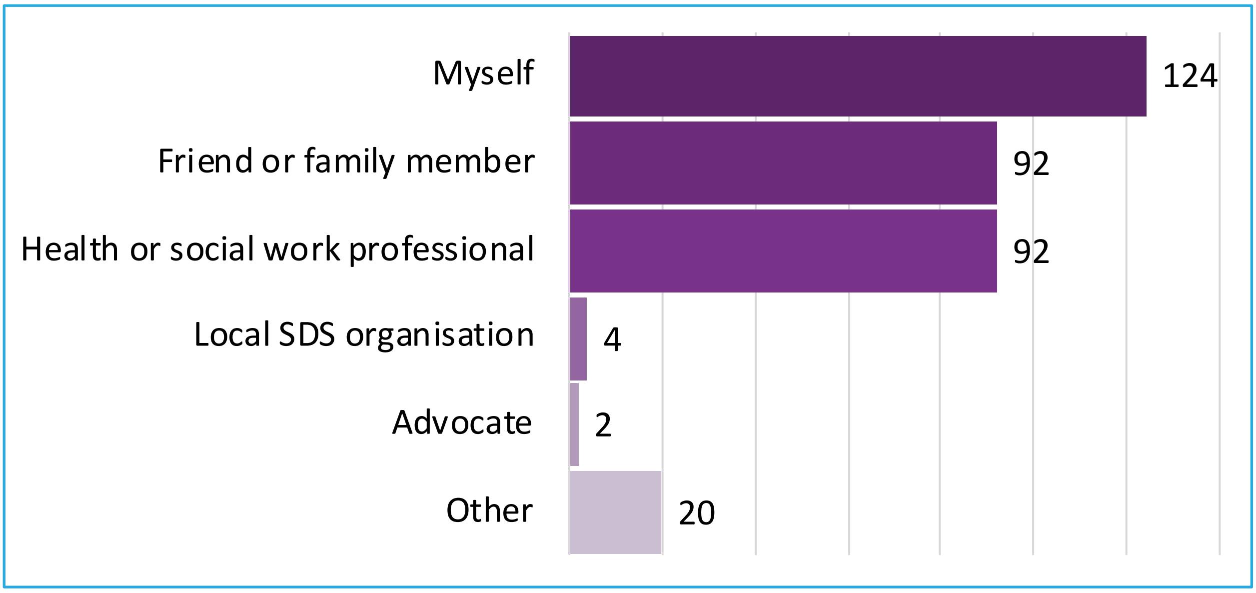
We also asked survey respondents who chose the way that their support is arranged now. Of the 334 people who answered this question, 124 people (37%) said that they chose the way their support was arranged – including one respondent who said “I chose, but I had to fight for it”, another who said “it was what I wanted at the time”, and a respondent who stated that it “took over two years and a change of social work team, but finally we have choice”.

79 people (24%) said that a social worker chose their support for them (including one who stated that the decision was shared between their social worker and a community psychiatric nurse). Six people reported that their care manager chose, six people stated that an occupational therapist chose for them, and one person said that a nurse chose their support.

Combined, that is a total of 92 people who reported that health and social care professionals chose how their support is arranged (27%). A further 92 people (27%) stated that a friend or family member chose for them, four people reported that a local SDS organisation chose how their support was arranged, and two people stated that an advocate chose for them.

Finally, 20 people selected “other”; and of those who provided further details, four people shared the decision with friends and family, four people said that they shared the decision with their social worker, one person wrote “everyone”, one respondent stated that they didn’t know, and one person reported that “I had to adapt my choice to suit my care provider”.

Chart 21: Who chose support arrangements? (Survey)



These findings indicate that just over a third of people were free to choose their own support arrangements, and just over a quarter of people had their care and support chosen by friends or family members. While the former results are welcome, the fact that 27% of people state that professionals chose for them invites further work to embed supported decision making (instead of substitute decision making) in SDS/ social work practice.

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.

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 ensure everyone is offered a meaningful choice between all four SDS options. Targeted work is required to ensure people with learning disabilities are offered SDS. Although many people 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 people access appropriate services, that should not extend to making decisions on people’s behalf – the principles of choice and control are clearly embedded in SDS legislation and policy, and extend to all population groups, including women, Black and minority ethnic people, and people living in areas of deprivation. Staff could be given more training about how to support decision making rather than lead it, and on co-production methods more broadly.

Disabled Parents' Experiences of SDS

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

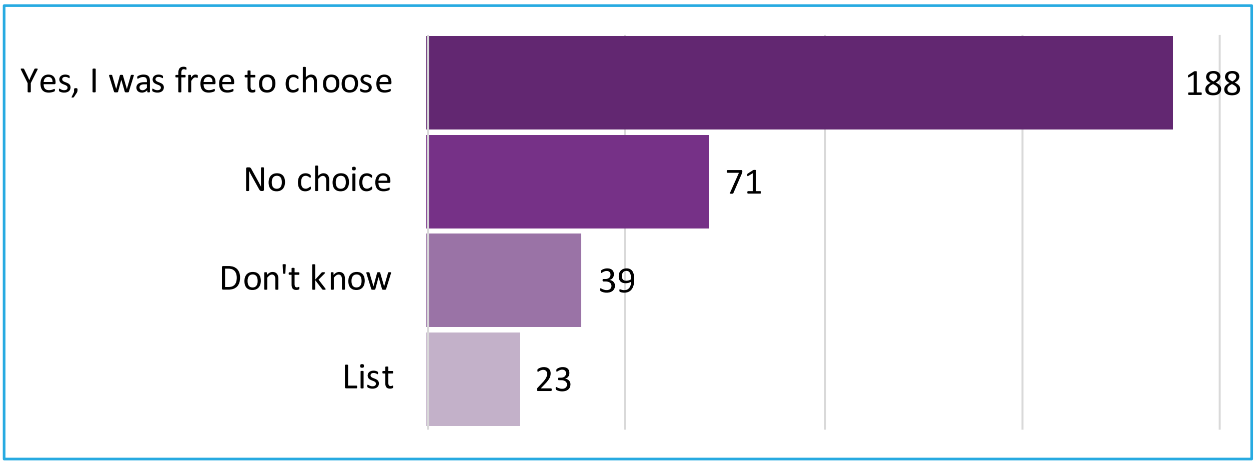
> ***"It's weird, when you've got on the one side people that are infantilising you because they're your care worker, therefore they must be above you, but actually you are quite a bit brighter than them."***

While almost all people 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). One disabled man we interviewed summarised his experience of a social worker's assumptions about the gendered distribution of labour in the household as follows:

> ***"They came to interview me, the people who arrange for home-help, and they've arranged the assessment – a very quick assessment. […] They said, 'once you are married your wife provides every support need you've got'. The thing is that if that was the case, it changes the dynamics of the relationship a lot. If I ever got to the stage where I needed a lot of personal care, I don't think I would want my wife to do that. It changes the dynamic of things. And some people have no choice. She wouldn't want to do it either."***

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.

Chart 22: Did you choose who manages your personal budget? (Survey)



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 321 people who answered this question, 188 (59%) said that they were free to choose who they wanted to manage their personal budget. 23 people (7%) were able to choose from a set list of providers given to them by a social work professional. 71 people (22%) stated that they were not given a choice. Finally, 39 people (12%) were unsure of whether they had a choice.

Of the 188 people who were given free choice of who would manage their personal budget, 32 people (17%) selected the local authority, 26 people (14%) chose a third sector provider organisation, ten chose a private care agency, five selected an independent broker, and seven selected an independent support organisation. A further 99 people (53% of those who were free to choose) selected an individual person (this response could include themselves). Five people did not provide further information, and four people were unsure who they had chosen to manage their budget.

Of the 23 people who chose from a set list, six selected the local authority, eight chose a third sector provider organisation, three chose a private care agency, three an independent broker, one selected an individual person, and two people were unsure who they chose. Of the 71 people who said that they were not given a choice and the 39 who were unsure, none provided details of who manages their budget.

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

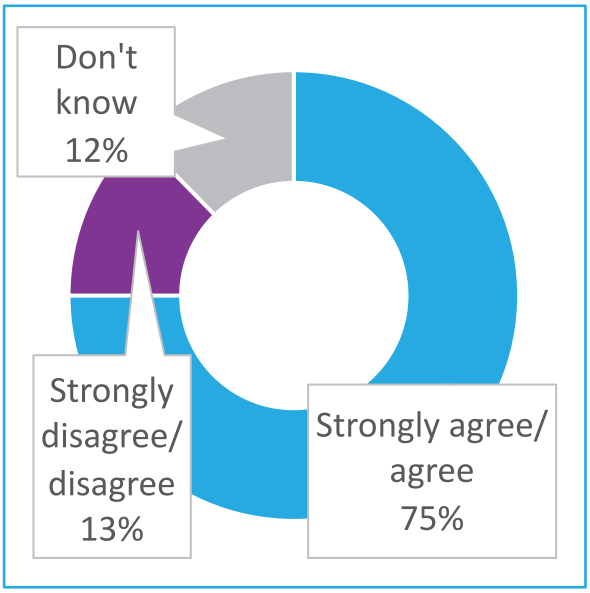
Women were less likely than men to have been able to choose who managed their personal budget. 55% of women stated that they were free to choose who manages their budget, while 25% stated that they were given "no choice". In comparison, 65% of men reported that they were free to choose, and 17% said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

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

Adequate Support

We asked survey participants to respond to the statement "Enough budget to meet my outcomes makes Self-directed Support easier for me". Of the 316 people who responded, 237 (75%) either strongly agreed or agreed, while 40 (13%) disagreed or strongly disagreed. A further 39 (12%) were unsure.

Chart 23: "Enough budget to meet my outcomes makes SDS easier for me" (Survey)



Several people 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 SDS package that ensured that they received appropriate 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 person was appealing the decision and awaiting a reassessment with a different social worker, with support from independent advocacy.

Another interviewee recounted how during a recent review their partner's SDS package was reduced by 75% – a significant reduction in support – even though their needs had not changed. They felt that social work expected unpaid carers to cover more personal care than previously, and that the importance of support to engage in social activities was not acknowledged (despite this featuring within the individual's personal outcome plan). As a result of the reduction in support, both interviewees stated that their lives have been restricted and their quality of life reduced. The interviewees also found the language that their social worker used to describe them ("spoiled", "too dependent") offensive. They summarised the situation as follows:

> *"This person [social worker] who came she said, 'No, that's not right. This is domestic work, you can't have that, it's not paid for anymore.' […] And she wrote in the report, 'This couple are spoiled, and they have become too dependent on the carers.' Well we are dependent on the carers, because without them I couldn't manage to do all the things that I do with my spouse."*

A different person stated that their "budget was cut because of service needs and not any changes to my needs – which impacted negatively on my life in a big way." Another respondent stated that:

> *"I wrote to them outlining the […] risks of reducing my package,*

> *but they went ahead and cut it anyway. Within three months my life was impacted on in a very negative way. I did not have the support available to help as it was removed. Now support has to be sourced […] from elsewhere to fill the shortfall from my SDS."*

These interviewees' experiences were not the only accounts of serious reductions in quality of life and an increase in mental health problems following substantial reductions to packages. Several other people recounted similar experiences – and highlighted the contrast between previous levels of support and good quality of life and their current situations.

In particular, several people with learning disabilities reported sudden cuts to their SDS packages. One person stated that they had an initial SDS package. Following a reassessment within the first year, the individual's budget was cut entirely:

> *"They ask if you are getting on with it OK, and then the answer was 'yes'. And then they heard, […] they were asking how was [support worker] getting on with, was I needing help with this, you can do that yourself?' And then 'nope, nope, you're not needing it anymore. You could do this and all that, you're not needing it. You're capable of doing shopping yourself. You can do all this, you can do that, so you are not needing your help.' […] I didn't get a choice in it. They said, 'you're not needing it now', so it got stopped."*

The respondent reported that the abrupt end of support caused significant difficulties for them and praised the work of a local third sector organisation that provided alternative support instead of the local authority. Other respondents recounted similar experiences, especially around reductions to support with social activities or home help – which generally led to corresponding reductions in their ability to engage with their local communities. Another person highlighted that the abrupt reduction in their support had coincided with their transition from children and young adult's services to adult social work services. They stated that "there was no transition, no nothing", and that "the minute I turned 18 everything got stripped".

Another interviewee, an unpaid carer, who felt that their partner was not receiving enough support also spoke of the isolation that inadequate care provision caused, and their feelings of helplessness in trying to access appeals systems and redress. The following quote demonstrates the profound impact that inappropriate levels of SDS can have on peoples' physical and mental wellbeing:

> *"There were two or three times that I did feel like giving up. […] [Name] has had [long-term condition] for years now. And in all that time [they've] never had to have any kind of antidepressants, [they've] put up with so much, and always had a positive outlook as much as [they] possibly could. And in the last 18 months, fighting [specific local authority] […] it reduced [them] to tears, basically, on a daily basis, and [their] doctor had to prescribe antidepressants for the first time in 30 years."*

Another interviewee recounted that they struggled to get their support needs assessed. Once the assessment had taken place the interviewee was offered a list of available services, which were not geared to their condition or capabilities. They were informed that it was their responsibility to locate services to provide support. The interviewee was already aware of a lack of suitable support in their area but felt that the assessment should have prompted their local authority to respond to that lack. They summarised their experience as follows:

> *"I wanted them to recognise that these services I'm asking for don't exist. And I wanted the fact [recognised] that I was offered things that are not suitable for me – like befriending services where I had to go out with public transport. I turned these things down, and they put down on my social work file 'turned down all help offered' rather than 'we couldn't do anything' [...]. They made it my fault for turning it down. And I object to that sitting on my record."*

Other people 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."*

Another person spoke of problems with having their choices respected during discussions with social work. They had previously had a comprehensive SDS package that covered time for social engagement as well as personal care, which enabled them to be active in the community, attend religious services with their support worker, and have a good quality of life. However, following a reassessment by a new social worker their package was cut substantially – despite no changes to their needs or stated outcomes – with social support removed. The person pointed out that this would mean that they could no longer attend religious services on a weekly basis, as before, and explicitly said that they needed social support two hours a week to attend services, as part of their faith. Their social worker did not accept this as necessary to that person's life, and "reduced [their] hours" anyway. The person is no longer able to attend religious services, as a direct result of reductions to their SDS package. Such a decision does not seem to respect either the individual choices and outcomes of the person involved, nor their right to religious freedom.

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

For example, one person reflected on experiences of at 12pm still not receiving breakfast or help to get out of bed: "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 individual 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.

Other respondents recounted similar experiences ("they used to come for the breakfast at 10am, and at 12pm they'd come and say 'have your dinner now'"). People also spoke of how delays and irregular timings caused problems with medications that had to be taken with food, or at set intervals. Some people also linked reporting problems with this sort of service provision to social workers removing SDS, on the basis that the people had declined support – rather than discussing other care options. One respondent summarised their conclusions as follows:

> *"I think when they write the planning service they should write the timings, for at least a week, so that would make it clear that the person hasn't declined, it's the services that are not up to it."*

Several respondents referred to their eating and food preparation habits in discussions about choice over support arrangements. One person outlined that they were offered a range of dietary choices by their care provider each week – but that none of them were geared to food commonly eaten by people from their ethnic community:

> *"In the afternoon, I get afternoon tea, the service they have, to give you sandwich or soup or whatever it is. There's a lot of options, and they ask me, 'what do you want?' I give them a week before what I would want that particular day. […] But the point is that if you look at the things that they have written down, the food is not ethnic minority at all. Nothing to do with ethnic minority. The potatoes and veg that you get is all mashed up. Chips are also all mashed up! So, it's very difficult."*

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

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

In both cases, while the participants indicated that in some instances they were not averse to sharing support with others, neither felt that this had been offered to them as a choice – and both commented that it restricted their choice of activities. People with learning disabilities who took part in other focus groups (e.g. people living in rural areas, people with lived experience of mental health problems) also reported similar practices around having to share support against their wishes and preferences.

Adequate Support: The research suggests that some people are not receiving adequate, person centred support. Good quality, adequate support via SDS can be instrumental in improving people's quality of life and plays an important role in helping people 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 people are treated with dignity and respect in all interactions with health and social care professionals and that assessments and support are adequate and tailored to people's requirements and way of life, taking into account all clinical, dietary, religious, cultural, or any other considerations based on protected characteristics and other self-identities. Health and social care staff should consider the possibility of mental health crisis when changing packages and eligibility criteria and be able to arrange reassessments and signpost support services where needed.

Residential Care

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

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

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

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

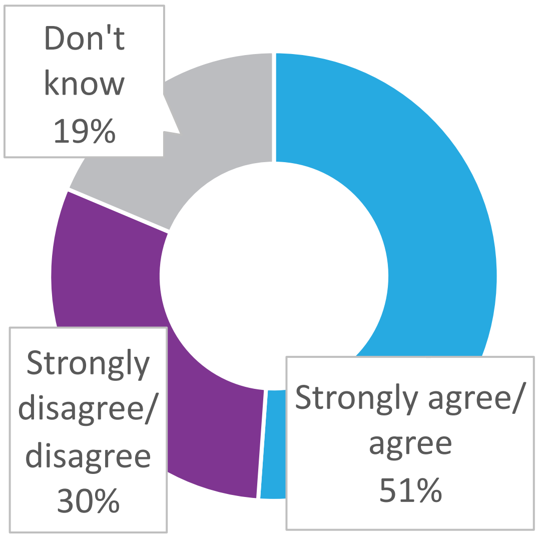
Another person provided the following account:

> *"The local authority adopted a fixed and intransigent position that my needs could only be met in residential care and refused to give any of the SDS options. I was left with a 'discretionary' budget which was not enough to meet even my most basic personal care needs."*

Such actions, while only reported by a minority of participants, are extremely troubling. Several unpaid carers also raised concerns about whether their adult children would continue to be supported via SDS once they were no longer able to provide care – and were particularly worried about the idea of local authorities defaulting to residential care for their adult children. One interviewee stated that this concern means that they “will not rest” until they feel confident that their child is supported within a community setting.

Residential Care: 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, if that is what they want.

Chart 24: “Lack of flexibility in how I can use my personal budget makes SDS more difficult” (Survey)



Flexibility

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

We asked survey respondents to respond to the statement “Lack of flexibility in how I can use my personal budget makes Self-directed Support more difficult for me”. Of the 311 respondents, 159 people (51%) strongly agreed or agreed with that statement, while 94 people (30%) disagreed or strongly disagreed. A further 58 people (19%) stated that they were unsure.

Interviewees and focus group participants expanded on this theme. For example, people reported difficult experiences in obtaining suitably flexible assistance with day to day tasks. One blind participant was told that they could not have help with shopping, because that was outwith the purview of SDS – even though their screen reader struggled with online grocery ordering. They also found shopping stressful if reliant on assistance from shop workers who they did not know and who were not fully trained in how to assist blind and partially sighted people. In practice, they use their PA hours for social engagement, in part, to shop; but this is not officially acknowledged in their outcomes plan. Blind and partially sighted peoples’ experiences of SDS are explored in more detail in a separate thematic report.

When people were given flexibility in how to use their budget to meet agreed outcomes, they spoke positively of the experience. For example, one interviewee stated that:

> *“The care manager structured it in such a way that she maximised the amount that we could get. A*

> *carer was there […] but the way she put the package together, she maximised the amount of hours that [we] were entitled to, to give us a little bit bigger budget that we could use to spread out the care."*

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

> *"It was good at being a family budget because sometimes, 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."*

Some interviewees, who had experienced less flexibility in the way their SDS was arranged, called for more choice to be available to service users – for example, to pay for services outwith the local authority area:

> *"[We need] flexibility. […] Allow money to leave [specific LA] to go to [neighbouring LA] if you're not able […] to provide a service that would be beneficial to somebody both mentally and physically."*

Other people spoke about the importance of support for engaging in activities – particularly sport. As with the blind and partially sighted people who did not want to rely on untrained shop workers for assistance with grocery shopping, several respondents reflected on the benefits of having support from a care worker or personal assistant to use a gym or sporting facilities – and the problems caused when such items were removed from their SDS package due to inflexible approaches to personal outcomes.

One person 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 did 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 with 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 negative impact that inflexible practices around SDS can have on people's quality of life, we did also hear from one focus group participant who felt that a flexible and supported reduction in their SDS had been beneficial to them. That person related how they had originally moved into independent accommodation, and had overnight care seven days a week, plus support in the day. As they became accustomed to living on their own, this support was gradually reduced, following regular consultations between the service user and their social worker. The person stated that the gradual nature of the change was key, taking place "over time until I could live independently", with discussions that were about testing reductions rather than completely cutting a budget. They reported that now they could "never go back to having seven sleepovers – being told to come in at half past ten every night!" and that they were happy with their reduced SDS package and increased level of independence. Other participants in the focus group commented positively on the flexibility of this person's experience, and the careful supported decision making process that prioritised the individual's input, ideal outcomes, and consent.

Flexibility: The research suggests that some people are not able to use SDS as flexibly as they should, which can negatively impact on quality of life and enjoyment of rights to independent living and equal participation in society. Improving universal access to flexible SDS will help reinforce the positive impact of support. This flexibility could be in how people are empowered and supported to use their SDS, but also relates to people's ability to have ongoing conversations with social work professionals, and adjust systems accordingly on a regular basis.

Access to Respite

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

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

Another person described their experience as follows:

> *"It's been fantastic for us, with [Name's] respite, because we started to use [respite venue]. [...] We were just supposed to send [Name] for like Friday to Tuesday but they have [a camp] that runs*

> *for 10-11 days, and they have it for adults and they have it for children, so we have used that. […] As far as we're concerned, [Name's] away on holiday, rock-clambering, away having a great time. And myself and the other members of our family once went to [location] for four nights […]. That was amazing."*

However, many people spoke about problems accessing respite, even when it was included in their personal outcomes plan, and the subsequent difficulties that could cause. One person stated that problems over accessing respite had had serious consequences for their relationship with and trust in their social worker. They 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."*

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

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

Travel Costs

Travel costs – for respondents, personal assistants and care staff – were also repeatedly mentioned as a key concern, especially for people living in rural areas. This was not always linked directly to people's SDS packages, but where people employed personal assistants, the time to travel by public transport to carry out activities was not always acknowledged in care plans. People also indicated that they would welcome more assistance from social work in accessing appropriate travel passes and in dealing with transport problems. Even in cases where decisions lie with the Department for Work and Pensions rather than local authorities, most people tended to reflect on transport issues and SDS without clearly delineating between the two parts of their experience of social support.

One respondent summarised their travel concerns as follows:

> *"I must say it all seems to boil down to the transport issue. If I can get about easily and get help to make long-distance appointments and things and keep long-distance appointments that would make a tremendous difference, really would. And I know transport is a very expensive*

> *thing to provide, I suppose, but, coming back to the point about the bus services, just not organised on a basis that makes it convenient to use."*

Another interviewee from a rural location expanded on this theme:

> *"But there, I have to pay for the transport. If I want to go anywhere outwith [specific town] it's quite a high charge. So […] you say, well I won't have the pleasant journey into the shopping area. But then, if I was taking a taxi it would probably be twice the price, you know, so I'm trying to weigh things up – but the new criteria doesn't pay for transport at all. And there's no housework, there's no traveling expenses [in SDS]."*

A different interviewee reflected on difficulties with sharing transport with another 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 care worker was compounded by the fact that they had 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. Another person reflected on a recent experience with bus travel as a blind person:

> *"And even on the bus this morning – different bus drivers, different routes. The driver when I got on, I heard him going, 'tap, tap, tap, tap'. And I'm holding out my pass and he's going, tap, tap, and I said, 'excuse me what are you tapping at?' And he goes, 'I'm tapping at you to put your pass into the machine'. And I go, 'I'm standing here with a guide dog, what do you think? It's a blind pass I've got.' And then he went, 'OK then, a grumpy man' – as if to say you shouldn't be blind on a bus."*

Finally, transport also emerged as a topic during focus groups, during which people discussed and reflected on the different approaches to travel costs and access taken by different local authorities.

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

People Living in Rural Areas and SDS

Several people discussed the increased costs and difficulties for disabled people, people living with long term conditions, and unpaid carers who live in rural areas – and the difficulties that rural living can cause to the successful implementation of SDS.

Several interviewees reflected on how limited or non-existent access to public transport left them reliant on taxis or personal assistants for transport – and that the requirement to have a personal assistant who can and will drive considerable distances regularly, just to reach their homes, made recruitment more difficult. Others spoke of how they had been forced to opt for Option 1, as the nearest care providers would not schedule their workers to travel as far as their homes. One interviewee summarised their experience of hearing about the limited SDS options available to them in a rural area of Scotland as follows:

> ***"[The social worker] came in and she showed me a sheet which she took away, and she said, 'This is what type 1 care is, type 2, type 3, type 4.' She said, 'but we can discard type 3 and 4 because they're not available here.'"***

People spoke positively about using telecare in some situations, but also expressed reservations about social work departments expecting them to rely on emergency telecare provision in place of regular personal care. This concern was particularly acute for people facing substantial cuts to their SDS budgets.

In some areas people reported that they had been forced to move to a town or village in order to access support via Option 2 or Option 3. Others recounted how social workers had recommended that they consider moving to a new house, to a less rural area. While it is reasonable for social work professionals to offer advice on the different options available to people, the interviewees felt that this did not address the problems inherent in the different cost of housing (either to buy or rent) between rural and urban living, especially for accessible housing – nor of the difficulties for people in leaving established support and social networks.

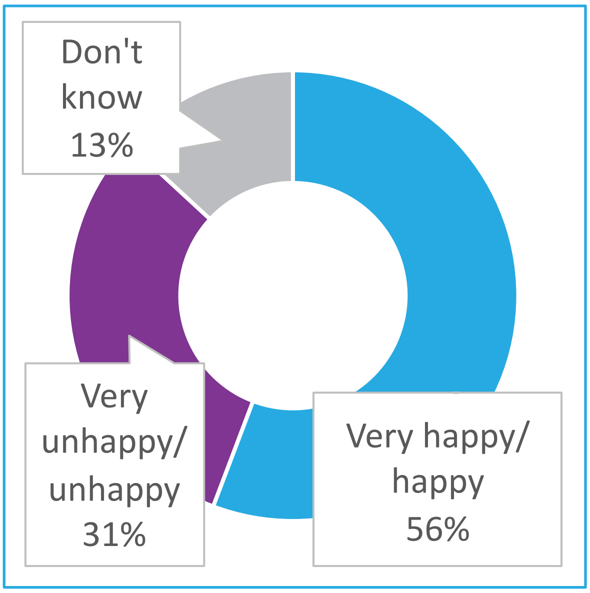
It is important that people should be supported to live independently in a home of their own choosing, irrespective of whether they live in rural or urban areas – with appropriate budget to cover travel costs for carers if required.

Communication and Relationships with Social Work

Good Conversations and Consistent Relationships

The importance of productive conversations in arranging appropriate social care support was highlighted in the 2019 Care Inspectorate thematic review of SDS.[41] 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.

Chart 25: "How happy are you with the conversations you have had about your support with professionals?" (Survey)



Of the 434 people who answered this question, 242 people (56%) were either "happy" or "very happy" with their conversations with social work professionals, 57 respondents (13%) didn't know, and 135 people (31%) were either "very unhappy" or "unhappy".

Older people were more likely to report that they were happy with the conversations they had with social work professionals. 54% of people aged 40 and under were happy or very happy with their conversations with social work, compared to 62% of people 41-64, and 73% of people aged 65 or older. Meanwhile, 29% of people who were 40 years old or younger stated that they were very unhappy or unhappy with their conversations with social work professionals, compared to 26% of people 41-64 years old, and 16% of people aged 65 or older.

Interviewees highlighted that good conversations require effective communication, access to information, prompt decisions, and good future planning.

Survey respondents who were happy with their conversations with social work professionals highlighted the importance of social workers having a breadth and depth of knowledge about SDS and local services. They also praised the listening skills and empathy of their social workers as key to their positive interactions, along with social workers having the time to listen to them and become familiar with their needs. Some key examples of people's positive experiences of conversations with social workers are as follows:

> *"The social worker listened carefully to what me and my mum said about my independent*

living. They asked good questions and had good ideas."

> *"Social worker has great understanding […] she is very approachable, and I can speak to her about any concerns and suggestions. She is very informative and extremely helpful and reliable too."*

> *"Our social worker really took the time to get to know our family and spend time in our home. We never felt she was in a rush to get in and out, or to just tick boxes. She had a really friendly, comfortable and confident manner and is always really available to us to answer questions."*

> *"She was really friendly, very proactive with a common-sense approach. She got where I was coming from and I really respect how honest she was about getting everything I wanted/needed. She was straight with me but very upbeat and determined."*

> *"My social worker was very friendly and helpful, and tried patiently to make things clear to me. She helped to organise a care plan which is flexible and meets my needs."*

> *"They explained […] in a way I could understand."*

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

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). Interviewees and focus group participants reflected on positive experiences during their needs assessments, and summarised their 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."*

> *"It's important that you have a good relationship with your social worker, that you can approach them and say 'Can I do this? Can I use SDS for this?' I think that's one of the most important things. If you haven't got somebody that you can approach easily, then [SDS] might not work as successfully as it worked for me."*

Some people reported that the conversations they had with social work professionals during their needs assessments were collaborative in nature, their input was respected, and that decisions were made promptly. One person recounted a positive experience with a social worker who took a strengths-based rather than deficits approach to the assessment process:

> *"So, we got SDS set up, and we are really lucky with our social worker who guided us through the process to make sure the forms were being filled in properly and appropriately. [The social worker] made sure that it was highlighted that the SDS user was great at some things, even though the everyday stuff is quite a struggle."*

Another person reflected that their social workers encouraged them to think about future planning during their reviews, which they felt was key to the successful implementation of their SDS packages:

> *"I think the advice is to be honest about what you can do and what you can't do. […] It's always difficult. And I was very loath about accepting that there were things I couldn't do, and it was the [social work] assessor like I said who was sort of looking ahead and realising that my complaint with my sight is not going to improve and pointing out to me that what I actually couldn't do. […] She was much more aware than I was willing to admit of what was going to happen in the future. […] And not pretend to be terribly brave, I think that's really important. Maybe not every assessor is as excellent as the one I had."*

> *"But she was quite foresighted because my sight has really deteriorated since. And she kept saying, 'it's better to apply for as much time as we can from the beginning. It's easier to reduce it then to increase the time available.' […] It was very satisfactory from our point of view."*

Several people also spoke warmly in praise of condition-specific teams in their local authority areas (e.g. mental health or sensory impairment teams). One interviewee summarised their experience as follows:

> *"The mental health team in [specific location] is brilliant, they really are good. And I think we are quite blessed with that, because that's not always the case with mental health."*

Another interviewee discussed the attention to care and support demonstrated by their social worker, and the importance of having time to build up relationships and trust:

> *"What made it a good conversation was our social worker. Our social worker used to come at least every couple of weeks and spend time speaking to the SDS user and things like that […]. I think it is because, well, our social worker specifically cared. I mean obviously it's a job and you make an earning, but she cared – there was something different about our social worker."*

A different person 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.”*

People repeatedly referenced prompt communication and easy access to information as key to smooth communication with social work and effective SDS provision. Two interviewees outlined that they appreciated email contact with the social work department and their regular attendance at meetings about their children’s care.

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.”*

Another person echoed this praise, stating:

> *“She signposts to a lot of things. I’ve already given her really good feedback [...]. She is always sort of thinking of us. Some of the things are not relevant when you look into them, but just the fact that she actually gives you the names and the numbers.”*

Other interviewees highlighted that difficult circumstances are often the precursors to engagement with social work, and social workers and service users alike can have to overcome people’s pre-conceptions about the role. One respondent, for example, outlined that her family’s introduction to social work was through an intense application for guardianship for her child. This fraught process included assessments from medical professionals and mental health workers.

Consistency of social workers was also viewed as a positive factor, as it gave people time to build up trust and awareness of people’s needs and individual situations. Social workers being able to take time to get to know people 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.”*

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 people and become familiar with their requirements. These findings also highlight the benefits of consistent relationships with social workers, including having direct and varied lines of prompt communication available. Overall, we would recommend that work to ensure positive conversations and meaningful, consistent engagement with people should continue, with ongoing planning to guarantee high quality practice for all people using SDS – especially around clear and accessible communication.

Poor Communication and Relationships

Some people described less positive experiences of communication and relationships with social work professionals. Of the 434 people who answered the survey questions about how happy they are with the conversations they have had about their support with professionals, 135 (31%) indicated they were either "very unhappy" or "unhappy". Some stated that their social worker did not have enough time or knowledge to meet with them and discuss their needs and questions properly. Others indicated more fraught relationships.

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

"I was never told about my options."

"Lack of transparency in terms of having policy and process in public domain; no way to find out what is accurate, everyone seems to be winging it. It also means no recourse to challenge decisions and frankly inaccurate information. […] You have to ask for Easy Read."

"Not being able to speak to the right person at the right time, difficult to get through to departments, and difficult to get consistent information. Lack of clarity, restrictions from management, and overall disempowerment as lack of resources and choice."

"Felt like she wanted to fit me into boxes, not to listen to my individual experiences and struggles. At a review I mentioned I would like to look at other options […] but I was told that no other agency would be able to fit in my hours and that it would be more expensive to go elsewhere. I felt like my interest in exploring other options was ignored."

"Having a fixed view of how my needs could be met and refusing to accept and give effect to my rights as a disabled person to live in my own home and choose the level of risk that I am comfortable with."

"Judgements were made on what we needed when the social worker had never met us nor had she taken the time to get to know us. We were discouraged from the SDS option I wanted."

> *"My care manager was misinformed on SDS, and although saying SDS was person centred they were using the old system. […] My care manager even took the micky out of me and her […] team with someone else and accidentally sent it to me in error, which was scathing and rude."*

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 fell 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?"*

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

> *"She put words into my mouth. She thought I wasn't capable to choose what I wanted [to choose] and what outcomes I wanted. And I said, 'No, I can choose what I want, I've got a voice. Why are you putting things into my mouth?' So, that was the difficult part of it."*

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

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

Several research participants raised issues about problems of accessible communication with social work. One person stated that their social worker is "utterly clueless in how to communicate with me". Another respondent outlined a difficult situation where, during their needs assessment, the social workers did not engage with their views:

> *"[My social worker] did not take into account my communication difficulties and did not take into account my views. At my last assessment […] I was unable to verbalise my answers [and] the care agency answered them on my behalf and between them and the social worker came up with the rating for each question. After the assessment I wrote down my comments but they were not taken into account."*

Another 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."*

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."*

Several respondents reflected that they no longer have a consistent social worker – but when in the past they had had a named person to contact, this had made accessing and adjusting social care easier. One person reflected that staff turnover could cause difficulties and trauma for people:

> *"Every time you see a new person, a social worker, you've got to explain everything again. And I've been doing this since it's kicked in. Quite difficult."*

One respondent reflected further on the difficulties of being assigned a social worker with whom one can then build a good relationship. They stated that:

> *"I was talking to social work and they were saying it's really hard to get a social worker now. It's got to be really bad before you can get one – and this is what will make it harder for people to get Self-directed Support or whatever, unless you already have a social worker and you can bring it up to them. But if you've not got a social worker it is going to be a lot harder to get one because of them being short."*

Some interviewees also experienced challenges with communication and consistency when they had a change of social worker without being notified. One interviewee confided that this has coloured their reactions to engaging with social work:

> *"It's anger and upset. I get angry with them every time they come. I can't help it. And I think it's just because of all the upset*

> *I've had over the years with them. I've had a lot of upset."*

Another person reflected that their relationship with their current social worker "improved over time". They stated that "relationships are very important, and communication makes such a big difference. There has to be continuity with social workers."

Poor Communication and Relationships: Examples of poor communication raise clear concerns about decision making and autonomy; if people's opinions (spoken or written) are not recorded and acknowledged during assessments, then they cannot be said to control or choose their support. The findings invite further work to continue existing good practice and ensure that people'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 people 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 the majority of people's experiences, they were significant enough to include within this report as examples of poor practice and as part of efforts to improve and ensure high quality care for people across Scotland.

Some people recounted difficult attitudes from and interactions with staff in their local social work departments. One focus group participant summarised a wider discussion about stigma as follows:

> *"There is stigma. They stigmatise you there, even with social work and that, […] it's just like people who do nursing or medicine, psychology or something. But the more social workers I've seen […] they don't attach a good bond; they are very negative. They stigmatise you that they are more superior in a way. And the way they talk to you, communicate, lowers you down."*

Black and minority ethnic people stated that when they requested different SDS options they were often labelled as "troublemakers":

> *"I think that ethnic minorities, because their issues are not known, what they would like, they are seen as troublemakers. Because if they demand, they say they want this, and they complain about it, they are seen as troublemakers. Who do you hear from? From the staff, who say, 'oh, they're giving us a hard time, we can't provide support for that.' But nobody is prepared to hear their side of the story. […] You're seen as a troublemaker or not listening, or difficult. […] This is a problem."*

One respondent outlined problems they experienced with social workers, going beyond well-intentioned ignorance or poor training and into discrimination and racism. They summarised that sometimes, in their experience, "it's even more simple; you deal with a social worker who thinks that black people shouldn't be in this country in the first place." They went on to ask: "what mechanism does the department have to detect that, and what role does that have within the service provision?"

A lack of respect for cultural awareness was also highlighted as directly connected to reductions in people's support. One person gave an example of how, during a needs assessment, a disabled Black and minority ethnic person was asked by their social worker about their 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 they were 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 disabled person had their SDS package removed, as the social worked concluded that if they could carry out hair care tasks they 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."

Another respondent recounted difficult attitudes towards blind people from their social work department. When they asked if there was a sensory impairment social work team in their local area (as there is in many local authorities), they received the following response: "A social worker for the blind? […] Don't be so stupid, we don't have one." The same person also recounted the following experience, following a different conversation with their social work department:

> *"I had a word with them somebody from the social work department recently and they said I sound 'too intelligent to be blind.' […] I said to them, 'I hope this phone call is being recorded because that comment alone is distasteful' and I put the phone down on them. I have not heard from them since."*

Another interviewee described an experience of their 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, their 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 their compound health conditions (with letters of support from medical professionals) and the need for more care, as their unpaid carer was no longer able to provide the level of support they 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 they found difficult. The interviewee was expected to take off their 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 they were able to refuse. They feared that if they did not comply then they would be denied the support they needed. They 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 undress in front of the social work professionals in order to demonstrate their process.

They stated that the social work professionals responded to their query by saying, "and what's the problem with somebody seeing you like this?" The interviewee replied that their discomfort with nudity in front of people they did not know stemmed from their 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 they then complied and showered in front of the two assessors. They stated that they were crying throughout the process of showering, but the social work professionals did not allow them to stop, nor did they attempt to reassure the interviewee or make them feel more comfortable.

The needs assessment that this interviewee described was not person centred, did not respect their autonomy or preferences, and at points violated their 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 different interviewee described feeling unsupported by their social worker, who did not seek their input at all stages of the needs assessment, so they requested a change of social worker. Following this request, a more senior colleague then started to attend home visits along with the member of staff the interviewee had expressed dissatisfaction with, which they found "quite intimidating, because it was two against one". The interviewee was then informed that a multi-disciplinary meeting would take place, which they were not allowed to attend. They were also not allowed to read the minutes of the meeting. The interviewee summarised this experience as follows: "I felt like I was being bullied and intimidated in my own home".

A further respondent described their interactions with their social work manager as follows:

> *"But this manager […] I don't have any respect for this person because of the way she treats people, she is very much a bully. She stands behind you and bullies you and pokes you like that with her finger – which I don't approve of at all. She said she can pull my service at any time*

> *and she snapped her fingers at me and said, 'just like that'. […] She told me I have to 'watch my step.' So very nice people."*

The respondent revealed that they are reluctant to request changes to their package, as it means they will have to speak to the individual in question, and that they no longer attend public meetings if they know their social work manager will be present. The physical and verbally threatening behaviour they experienced, and consequent difficult relationship with social work, has adversely affected this person's social care and their civic engagement within the local community.

Another person recounted how their social worker attempted to insist that they move from 24/7 support to a combination of paid carers and telecare. They pointed out that telecare was not possible for them, due to their rural location (any mobile carers driving to the service user would take a considerable amount of time to arrive) and their physical range of movement. They recalled their interaction with their social worker as follows:

> *"And they were both virtually shouting at me, the social worker […] saying I was quite capable of pressing a button. And she then said, 'I spoke to you on the phone earlier, you answered the phone, how did you manage to do answer the phone when you can't press a button?' I said, 'but I've got a carer, and she places the phone on my shoulder and I speak into the phone that's on loud speaker – that's how it works. […] But [phone company] who provide that system will not guarantee it and will not put in emergency numbers because they can't guarantee it's 100%.' So she wouldn't believe that, so I said, 'fine, I'll phone up [phone company representative]' […] and he explained that we cannot put in emergency numbers, and it cannot be used as emergency equipment. […] The phone call ended, she put the phone down, and she said to me, 'there you are now, nothing wrong with your phone, you can use it.'"*

These examples of discriminatory, intimidatory and bullying interactions pose clear problems, in terms of the treatment of disabled people, assumptions made and respect for people's choices.

Overall, several respondents stated that they would welcome more empathy and respect during their interactions with social work. Furthermore, a small but significant 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 people 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 people spoke warmly of their social workers and the transparency of process, saying "there was no problem", they had copies of all agreements and paperwork, and that when they queried sections of the plan their social worker "was quite happy to agree to some changes".

One key theme around transparency was the need for greater clarity on eligibility criteria for accessing SDS. While some local authorities share eligibility criteria publicly (either in information leaflets or via local authority websites), this is not the case across Scotland. One person reflected that they wanted to access SDS, but when they requested an assessment they were informed that "you're a category 4". When the respondent asked for further information on what the categories meant, they were 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.

One interviewee summarised their perspective as follows:

> *"And, obviously, they said there is a waiting game, it's a case of prioritisation, [...] but it'll basically be determined by who is a higher priority as to who is to be funded first."*

Another person was blunter about the prioritisation of different disabled people and people living with long term conditions, stating: "I don't think they treat blindness like a disability."

A different person reported problems with their social care support after their local authority changed the eligibility criteria for support. They were informed by their social worker at their last review that the criteria had changed, and their support package would now be reduced. They reflected that:

> *"You try to be careful with everything and then suddenly it's all up in the air because the criteria has changed. Now when you change the criteria, it's like, just taking a bag of feathers and shaking it all out – but you can't get all that back in can you?"*

Concerns about transparency of process were often synonymous with the ability to make active choices about care and sharing of documentation. Respondents summarised their difficulties with opaque processes as follows:

> *"I asked for information regarding the agreement, the criteria [for] using family members [as PAs], and the flexibility regarding how the funding can be used. No information given."*

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

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

Another interviewee also highlighted transparency as a problem during their last assessment. Their needs had increased rather than reduced, but their package was cut substantially (by more than half). They highlighted a lack of information about why their package was reduced:

> *"They didn't explain why, I still don't know why. […] They broke it down in their theory about how long it is to take you to do this and everything else. But there is no logic to it, you couldn't do it if you were able-bodied, never mind being disabled. […] They are not interested in giving me any explanation."*

Another person recommended asking an independent person to attend meetings with health and social care professionals to ensure transparency of practice:

> **Respondent:** *There are other resources involved because people […] can't just write their own notes when you've not got anybody attending. It's difficult.*
>
> **Interviewer:** *Would you recommend as a service user to have someone present?*
>
> **Respondent:** *Yes. Because your notes and [social work's] notes are completely different, […] and you are not allowed to have copies."*

A different person shared how they were given "very little information" about SDS or what to expect from a needs assessment prior to it taking place. They stated that they were "not given anything in the form that I could read". Instead, their social worker "decided it was up to him to read things out to me and not for me to make my own informed decision". The individual felt that this reduced their autonomy and denigrated their intelligence. Since that needs assessment the person has been able to access SDS but with similarly limited information, and their hours were reduced by 40% from the original package – although as no paperwork was shared with them, they are unsure if this reduction in support is an issue with their provider or with the final SDS package:

> *"I am meant to be getting five hours a week, but I get three. […] The money was awarded seemingly from [specific local authority] […] but I don't know where that money has gone and nobody is willing to speak to me about it."*

Another person reported a similar experience in terms of difficulties with the terms of their support package and budget, and unclear communication. Their package was recently increased to include support for social engagement as well as help with household tasks and was also supposed to include travel costs. However, those hours have not manifested during the time they have accessed SDS.

Furthermore, when the individual has asked their local authority for clarification, they have not received satisfactory responses. They summarised their experience as follows:

> *"So anytime I open my mouth and ask I get shouted at. I don't know where that money has gone, and I would love to see all the paperwork trails. This is why I've gone down this [Option 1] route myself because I can actually manage, hopefully, manage my support the way I want it."*

Another strong theme was that people were not always provided with a clear calculation and break-down of how SDS budgets are assessed and decided on, based on information from needs assessments/ reviews. One interviewee stated:

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

The interviewee went on to comment that a clearer explanation of process is also needed, and more attention paid to ensuring that service users understand and agree with everything that they sign off on in the assessment process. They stated that:

> *"I've felt that that is where the biggest bit of influencing, if you can put it that way, […] is filling in that needs assessment, because I don't think it gets explained properly. And at the end, some things they'll just sort of say, 'Well now that we've finished that […] I've got enough information from what you're telling me, I'll go back to the office and fill that out'. And you don't know what's filled out. You don't what generates the budget but they*

> *do, so you're influenced at that juncture as well, and at the end of it they sort of give you, 'Right, that's the assessment I'll send it out, I'll fetch this out, now I just need you to sign that off.' And the important bits to us are really belittled by them to get it all through and on a place that they really want it to be."*

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.

Another interviewee commented that locating properly accessible information about SDS in the public domain is similarly difficult. They stated that:

> *"It's actually finding the information on the local authority's website in the first place to see how you can initialise that in the first place and who the contact is. It is getting the proper and accurate information that I struggle with. Because if you ask [social work] they are not willing to give you the proper information that you should have access to in the first place."*

Respondents felt that transparency of process was particularly important when specific types of support are declined, or care arrangements need changed:

> *"When somebody declines [a type of support], and they know their need, there should be in the process why it was declined. The person should be signing, the person who declines. They should be able to see the reason of decline, rather than… it becomes very easy for [social work] to say they declined, they don't need to say why they declined, they can manage. But they don't manage."*

For many research participants, particularly people with learning disabilities and people who are blind and partially sighted, concerns about transparency of process were often synonymous with issues with accessible information. One person stated that they had requested assistance with accessible paperwork and struggled to get assistance from social work. This made them nervous about entering a contract for SDS. They described their experience as follows:

> *"And because the literature [social work] have explaining what they do is in very small print, I asked for somebody to come and read it aloud. And every time there was a section that sounded to me a bit awkward, the reply was, 'Oh, don't worry about this, we'll take care of that.' But in actual fact, they don't and the responsibility is the user's. […] And I have got some legal experience, and I just didn't like the sound of it. Normally, things go fine, but when they don't, it could be quite serious. […] I just didn't like the sound of it."*

Finally, when one person requested the appropriate contact details to lodge a complaint, they were not given these:

> *"I have to go through the support services manager that I have to get the information [on] who her boss was – so she was the person I was making the compliant against. […] She gave me the incorrect*

person's name, so I still don't know who her boss' name was, because I ended up speaking to a chap who had nothing to do with that side of social work. […] He said, 'I think you have the wrong number or the wrong department'. And I said, 'this number was given by a support worker manager so surely this is the right number?' Wrong name, wrong number. I don't have the right contact. She refused to give it to me."

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. People should not have to resort to Freedom of Information requests or court action to acquire information about their SDS/social care.

Impact of SDS on Family/Relationships

Respondents identified a range of ways that SDS had enhanced their lives, including a beneficial impact upon family relationships. However, the picture is mixed, with some people reporting that SDS had 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.

The following quote illustrated one interviewee's reflections on the impact of SDS on their family life and relationships:

> *"Well, the impact on the family [...] they're extremely happy for me now. Whereas years ago I was just cooped up in the house, doing nothing apart from waiting for somebody to come and pick me up to take me to the voluntary work and all these other meetings and things like that, having to rely on somebody (this was long before Self-directed Support even happened). And of course having to depend on my [partner] all the time, but now [they're] depending on me, because my [partner] has had [a health condition] for a good ten years now and it's beginning to get worse."*

Another person, an unpaid carer, stated that:

> *"It's taken the pressure off. […] I work two days a week and I'm now thinking of looking for something else more than the two days a week because I feel I can. Whereas before it was very tight, we couldn't. Which gives me more self-worth; I think that I can go and do something for me. I can do more."*

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

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

Another interviewee highlighted that having support in place for their children enabled them to pay attention to their own health needs:

> *"Basically, being able to attend appointments that I need for my own health. Even though sometimes still I struggle to get to some of them, but it gives me that flexibility, whereas before I couldn't do any of that."*

However, not all respondents were positive about the impact of SDS on family life. Those that highlighted problems tended to centre these concerns around budget cuts, which led to increased care responsibilities for friends and family as unpaid carers.

Several people shared the negative impacts of when there was not enough support in place to meet the needs of an SDS user. These issues were particularly acute when social workers assumed that family members would be able to provide unpaid care without properly assessing whether that was feasible or desirable for the people involved.

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 said 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."

Another respondent was particularly concerned with the gender bias displayed by their social worker during their last review. They summarised their experience as follows:

> *"I had three hours per week home help until [specific year] at which point I got married and they told me, 'oh well you have a wife and she's a female wife so why would you need anyone else to help? […] She can do it for you as well as working full time, helping with childcare and everything'. So that's all there is really."*

Other people recounted problems with accessing SDS as disabled parents. One respondent summarised their experiences as follows:

> *"I don't think many people I've talked to have had experiences where their position as [a] 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."*

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

Parent/Guardian Carers' Experiences of SDS

Throughout MSMC, we heard from many people who are parent/Guardian carers for children under 18 and adults. Of those unpaid carers we spoke to, very few accessed SDS with a carers budget, and the majority were not aware that it was possible to access SDS as an unpaid carer. None of the participants in the focus group held with parent/Guardian carers had been offered an assessment for a carers' SDS budget.

There was considerable confusion as to whether unpaid carers could employ family members as PAs – with variance in practice within individual local authorities as well as Scotland as a whole. Several people reported that employing a family member (not a Guardian) as a PA is actively discouraged by some local authorities, even following difficulties recruiting PAs or arranging support via Options 2 or 3.

Some interviewees praised efforts by their local authorities to hold SDS information sessions for parents/Guardians. However, they reported that the exercises and discussions demonstrated people's confusion about "measurable outcomes" and the process of accessing SDS. One interviewee stated that they and their partner are "both extremely well-educated people, and we can't make our way through this minefield". They also pointed out that often parents need support themselves, particularly if they have learning disabilities, mental health problems, or are dealing with personal challenges around the stress of combining unpaid care with work.

Parents whose children use SDS report widespread difficulties with transitioning from children's social services to adult social services. Many reported a break in service provision over several months, and a negative impact on family life and their adult children's independence and opportunities.

Finally, many parent/Guardian carers we heard from stated that there was an explicit or implicit assumption from social work professionals that they would provide unpaid care indefinitely – even in instances where their adult child stated that they wished to be supported to live independently in their own home.

The research indicates that further work should be done to ensure all carers are informed about – and can access – carers assessments and budgets. Improvements could also be made to information systems about SDS generally for carers, guidance on employing family members as PAs, and on systems when people transition from children to adult services. Social work professionals should not assume that unpaid carers will be able or wish to continue in that role, and respect disabled people and people living with long term conditions' preferences when it comes to housing and support arrangements.

SDS and Mental Health

Some respondents – particularly those who had experienced problems with needs assessments or reviews – reported that accessing SDS had been a stressful experience. In some cases, people 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 the people for whom they cared.

One interviewee summarised the positive impact of SDS on their 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[42] – 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.

A different interviewee reflected that the person for whom they care accessed SDS because of their mental health, and that before they accessed SDS the person was "increasingly getting worse" and "couldn't cope any more". After their SDS package was approved and appropriate support was put in place, the SDS user "was much more able to speak to people" about their mental health problems and support needs, and their quality of life improved. This change also resulted in a reduction in stress for family members who provided unpaid care, and an improvement in their health.

The experiences of people with lived experience of mental health issues who use SDS/social care are explored in more detail in a separate thematic report.

Several other interviewees concluded that once appropriate support was in place SDS had improved their mental health and/or the mental health of the people for whom they cared. One interviewee summarised the impact of SDS on their 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."*

Another interviewee, an unpaid carer, highlighted the improvements to a service user's mood, after setting up more personalised care arrangements through SDS:

> *"Oh yes, it's massive. Even when [Name] meets people in the street and the guys are out with [them], I've had people say to me 'what a difference, what a huge difference'. [Name] is brighter, [they're] alert, [they're] doing more stuff. […] [Name's] chosen what [they] want to do rather than just sitting at home and thinking, 'OK, let's do this because that is what my [parent] likes.' [They're] getting choice, getting much more control of [their] life, [they're] getting to choose."*

Another respondent summarised the impact of SDS as follows:

> *"It meant that I could be independent and have my own home. You know, be part of the community and be able to look after my house, get out and about and be involved with everything. I didn't feel so isolated because I was getting out to groups and things. The benefits of physical health because I'm getting out and doing exercise and increasing my physical ability. Mental health because I had people to talk to, help with health like eating property, healthy diets and make sure I'm up to date with everything."*

SDS and Mental Health: If adequate, person centred support is provided, there are clear benefits of SDS to people's mental health and relationships. However, poorly conducted SDS processes and reductions in support can have a negative impact on people's mental health. Health and social work/care professionals 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.

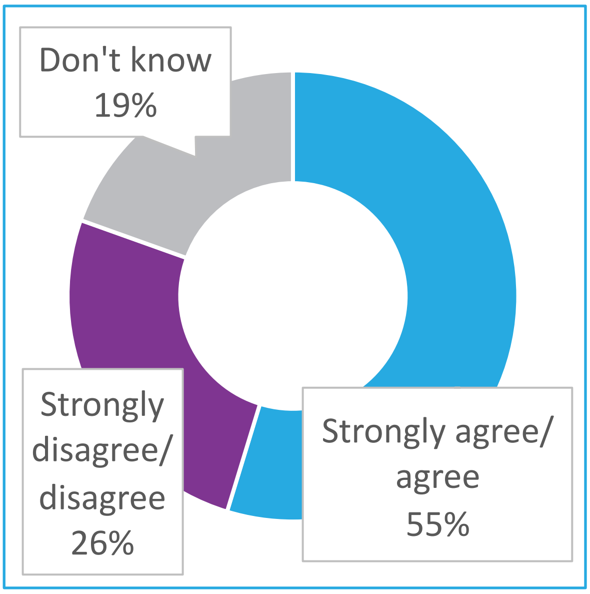
Care Staff Recruitment, Training and Quality

Throughout MSMC, care staff – personal assistants (PAs), support workers, and agency staff alike – were mentioned as a key element of people'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 307 people who answered this question, 168 (55%) either "strongly agreed" or "agreed", while 79 (26%) disagreed or strongly disagreed. A further 60 (20%) were unsure.

Chart 26: "Lack of a regular personal assistant (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, personal assistants who are appropriate to their requirements, as the following quotes demonstrate:

> *"We started advertising and it took a while. We were struggling to get many applicants – and those who were applying we didn't feel were for [Name]."*

> *"If the situation got worse and I needed more care, how would I find it? Because obviously you have got to arrange your own support. […] The two people I have are brilliant and lovely, but it did cross my mind that if I needed to get more support, where I would find the right people to do it? That I think could be a downside [of Option 1], if you're stuck and can't get somebody who is able to do it."*

> *"The only thing I've been given choice about was the cooking; […] I was told that I could have the money for the cooking, but I didn't get any help finding anybody. I had to go for years to find somebody who was advertising and where to look so I found someone who said that she was willing."*

For another interviewee's family, finding the right person for the household was essential. Sometimes, as they explained, the recruitment process would fail to attract suitable candidates for the PA role to the interview. One interviewee commented that they have found it increasingly difficult to recruit suitable personal assistants over the last few years. They went on to assert that:

> *"The amount of people that waste your time is unbelievable! They*

> *apply, and they sound good, and you phone them, and you have a chat, and you think I quite like them. And […] then they don't come for interview. Or they come and then they spend a few shifts, they shadow your PAs, watching, and then they disappear. They've got no reason, or they don't come back, or they give you some excuse. And you think I've just wasted weeks with you! That is really annoying. And you get to the point now where you're a bit cynical with everybody."*

Another person reflected on recruitment as a blind person. They requested help from a third sector organisation with interviews in order to get a sighted person's opinion of potential employees' body language:

> *"Interestingly, for a few other PAs, when I went through the interview process… Since I'm totally blind I'm not able to read body language […] so I asked a girl from [third sector organisation] to sit in an interview and give me her opinion at the end."*

Other people indicated that they would have welcomed more assistance from their local authority or third sector organisations with interviews:

> *"I did approach my local carers centre to see if they have a bank of PAs that perhaps are looking for work. They said they didn't, but they could assist with putting up an ad[vert] and help with a room for interviewing and they certainly could help with contracts and employment and job descriptions, etc."*

> *"I mean, there wasn't even any help with, 'we could help you write a job advert', or 'we've got somebody who could come and sit in on interviews with you', there was nothing like that. So, we were kind of left high and dry doing it ourselves."*

Some people commented specifically on difficulties recruiting people who could understand and respect the needs of Black and minority ethnic people, and their specific cultures (and, more broadly, the limited number of Black and minority ethnic carers and social workers in Scotland). Key comments are as follows:

> *"I think that social work should employ ethnic minority support workers. My [spouse] suffers dementia, […] I look after my [them], but I never feel as if I have a break at all. […] I'd like somebody from an ethnic minority group. I've tried to find a support worker, but my [spouse] won't accept that. I'd like an ethnic minority one, a [specific ethnic group] one. You've got to know the person, but they come in for a few hours. It's very difficult. I tried to get the service but social worker says it's impossible, nobody wants that kind of job."*

> *"Also, when looking for carers, and something we haven't really touched on, is having carers from your own community, who can speak your language – especially if you can't speak the language. There is a lack of ethnic minority community carers. And some people will refuse because they cannot understand, they want to interact with somebody for ten minutes. The only person they see all day! And if that's the case, they come, open the fridge, they make them a sandwich – and they hate eating cold food!*

> *And I think there are multiple issues with that as well."*

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

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

One interviewee highlighted that they felt the key problem around recruitment was respect for the care sector as a whole and commensurate pay. They summarised their perspective as follows:

> *"I think [we need] recognition that care work is really important and is essential. […] I think if it was better pay and it was more secure and the hours were better than I wouldn't be so afraid that my personal assistant would leave."*

Problems with high turnover of staff, especially those employed through agencies, was also a key theme when it came to factors that made SDS challenging for people.

One interviewee shared that their child was supported by twenty-four staff members in a short period – which was problematic in terms of enabling the family and child to build good relationships with care workers and experience high quality care. The interviewee, who uses Option 2, requested a change of care provision following a series of problems with staff. They were 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. They requested two or three regular care workers, who they and their child could know and trust (and was the original arrangement for their care); this request was turned down by the agency. They recounted how high turnover of staff affects communication and the standard of service delivery, and summarised their 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."*

Several research participants spoke of the benefits of being supported consistently by one or two trusted people, and problems with high staff turnover were reported across Scotland.

Staff Training

Another important care consideration for research participants is personal assistants who are qualified to carry out the specific specialised personal care they need, with appropriate medical training. Some people 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 respondents 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 people commented on their priorities regarding care staff. Interviewees summarised the following important characteristics in a support worker:

> *"The person that is doing care work has got to be quite sympathetic, quite understanding, and have a good working knowledge of life skills."*

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

> *"We are not looking for someone who has 20 certificates saying, 'I am a carer'. We are looking for someone who would be able to care […] in a way that is appropriate. Our personal assistant didn't have any care qualification, but that wasn't an issue for us. People find it really hard to find appropriate care. Sometimes they have to look at it realistically of what they want, and you have to look at what the [SDS user] needs."*

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 [personal assistants] 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."*

Others highlighted that it takes time to build up relationships with support workers. One respondent highlighted that an established support worker can also assist during assessments and discussions with health and social care professionals:

> *"Support workers […] know about you and your mental health. When I went for a consultation, I probably forgot loads of stuff with my mental health. […] I might say some stuff and my support worker will be with me. […] I'll say I can't cook, and he'll say what I've been going through before all that […] and what you have been through prior to your mental health."*

Care Workers and Risk

Several people commented on their consciousness of the potential risks of being reliant on care workers – even those who currently had good working relationships with trusted people. One person, 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 care needs 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.[43]

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

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

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

> *"And staff forget. And how I say that is because one of them has offered to give me a cuddle. And I'm thinking, 'in your professional role that is not allowed because I'm not allowed to touch you.' […] I did say to my support staff, 'the only person that gets to do that is my mum.' And she went, 'that's the best cuddle that you can ever receive.'"*

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

Care Staff Recruitment, Training and Quality: Some people would welcome more support from their local authority to arrange PA recruitment, training and continued professional development. It is also evident that some people would welcome improved access to suitably trained and high calibre care workers. While some people are comfortable with the role of employer and have experienced good, long term, working relationships with their support workers, this experience is not universal. This suggests that local authorities should continue to work with people accessing SDS/ social care to find ways to improve systems and processes – particularly around difficulties with recruitment, training, and staff retention within the wider social care sector. This support and acknowledgement of variable practice is particularly important when social care and social work professionals are discussing care arrangements with people who have had poor experiences in the past – whether that be difficulties with individual care workers, or as the victims of crime. People have the right to feel safe – particularly in their own homes – and social care workers and professionals across the sector should do all they can to support service users to feel safe, secure, and independent.

LGBT+ People's Experiences of SDS

We heard from a range of disabled people and people living with long term conditions who are LGBT+ during MSMC. People reported that recruiting PAs and working with new support workers could be more difficult for LGBT+ people. One person spoke of their awareness that some people would not be accepting of their sexual orientation, and the difficulties in knowing whether care workers would treat them appropriately if they disclosed their sexuality.

One interviewee reflected on the difficulties of being LGBT+ and disabled in a rural area, with restricted opportunities to meet partners or people who they knew would be accepting of their sexuality. They highlighted the need for more accessible LGBT+ events and venues for people of all ages, stating:

> ***"In the general, that there's not that much in [specific locations] for LGBT people. And if there is, then it's at the college, […] you've got to be a student. There's no way around about it. You've […] got to be a student at the college to attend LGBT events."***

Some people spoke positively of the support they had received from their social workers. One interviewee sought help from their social worker in finding accessible LGBT+ events and support groups in their local area and praised their efforts to help them. This example of good practice is in keeping with recommendations and findings from a report from Stonewall/University of Bristol, which stated that "there is a need for more targeted support and information for LGBTQI+ Disabled People as well as more information for their PAs".[44]

Finally, two people stated that their families' reactions to their sexual orientation was directly linked to their need to access SDS and housing support, as they were made homeless after coming out to family members. Once homeless, it was frequently more difficult for people to access SDS – not least because of the difficulties in providing a fixed address.

LGBT+ people should not experience discrimination or inequality due to their identity when accessing social care. SDS assessments should take a whole person approach and incorporate sexual orientation and gender identity.

Independent Advocacy and Support

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.

Survey respondents spoke positively of the benefits of independent advocacy and independent advice and support organisations. One interviewee said that a local independent advice and support organisation was the key to "unlocking Self-directed Support [...] and I can't thank them enough for that." People recommended getting in touch with independent advocacy and independent support and advice organisations as early as possible. Some of their key comments and advice statements are as follows:

> *"Get independent advocacy and help to ensure that you are listened to."*

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

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

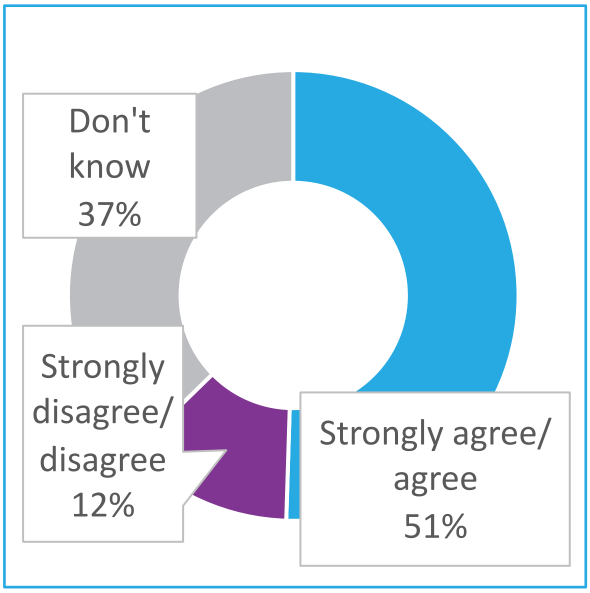
> *"See if there is an independent organisation nearby that can help with information as it's very confusing in the beginning. Use a payroll company. Join a support group online for help and advice."*

> *"Seek help from an independent support organisation who provide information and support for people looking to get SDS as they are knowledgeable about the processes in your area and get support in place."*

> *"Go online. Really get to understand it. Use an advocate and get help to cope with the whole process."*

Independent Advocacy

Chart 27: "Access to independent advocacy makes SDS easier for me" (Survey)



We asked survey participants to respond to the statement "access to independent advocacy makes SDS easier for me". Of the 303 people who answered that question, 153 (50%) "strongly agreed" or "agreed" with that statement, and 37 (12%) disagreed or strongly disagreed. A further 113 (37%) said that they were unsure.

Analysing responses by SIMD quintile, it is evident that people living in the most deprived areas of Scotland were more likely to find that access to independent advocacy made SDS easier for them than people in more affluent areas.

58% of people living in SIMD quintiles 1 and 2 strongly agreed or agreed that access to independent advocacy made SDS easier for them, in comparison to 45% of people in SIMD quintiles 4 and 5. However, it is worth noting that this variance was not due to a substantially larger number of people in quintiles 4 and 5 reporting that independent advocacy was not useful, but because more people in affluent areas were unsure whether or not independent advocacy would be helpful (44% selecting "don't know" from quintiles 4 and 5, compared to 36% of people from quintiles 1 and 2).

While most people find access to independent advocacy makes SDS easier for then, we found that older people are less likely to know about these services and find them useful. 55% of people who were 40 or younger agreed or strongly agreed that access to independent advocacy made SDS easier for them, and 54% of people aged 41-64 reported the same. In contrast, only 46% of people who were 65 or older agreed or strongly agreed with that statement, and while only 9% disagreed or strongly disagreed, 45% of that age group stated that they "didn't know", and were generally less likely to have accessed those services.

Commenting on the importance of independent support, one interviewee said:

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

When good relationships were established, collaboration led to effective support planning and implementation of SDS options. One interviewee described the positive outcome of a meeting between their social worker, the interviewee, and an independent advocate, despite initial apprehension from the social worker:

> *"But I still felt that they were ticking boxes along the line of, "well for my job I've got to cover this, this, this and this." Which […] that's what she's employed to do as such, but it does come over as a different kind of experience. But we did have a meeting here with social work and […] advocacy when we were getting more into the detail of things. So, [the social worker] was open and she did come to that and […] it was a good meeting. I think she was apprehensive when she arrived but at the end she actually did say, 'this has turned out to be a really good meeting', because it gave her a better idea of what we wanted."*

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

Other people brought up the value of independent advocacy in accessing SDS. One summarised their advice to others on this count:

> *"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."*

Another interviewee had experienced a significant reduction in their support hours following a recent review, and sought assistance from independent advocacy:

> *"I phoned the [social work] duty care manager about it. I said to myself, 'What am I going to do? Because I can't manage on that.' I said, 'I need somebody, I can't go out on my own, I can't go to appointments or anything. I have to have someone with me, because of [medical details]. I'm in a powered wheelchair, and there's an attendant control on the back. I can't go out on my own.' And [the duty care manager] said 'Just use your contingency fund to cover that, and we'll get you reassessed.' I got the advocacy in and they're going to get it all sorted out and try and get my hours reinstated. [...] They're actually fighting it for me."*

Meanwhile, some respondents 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, people 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 person 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."

Another respondent stated that advocacy and peer support is "critical" for Black and minority ethnic people accessing social care. They stated that:

> *"I've just helped somebody who'd had their funding removed because of the social worker's report [...] you need somebody there. [...] The matter ended up at the tribunal, and the tribunal decision was based on the – had to negate the social worker's report, because the social worker's report meant that the funding was stopped. And therefore, it is critical that you have some sort of advocacy*

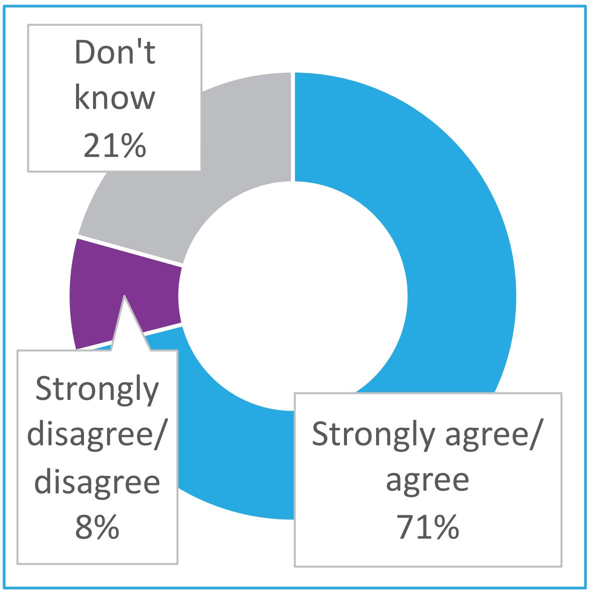
> *in order to ensure that the social worker's decision[s] are valid."*

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

When asked whether access to independent information and support made SDS easier for them, people responded in a positive fashion. 223 people "strongly agreed" or "agreed" with that statement (71%), and 26 people (8%) "disagreed" or "strongly disagreed" with that description of independent support and advice organisations. A further 65 people (21%) said that they were unsure.

Chart 28: "Access to independent information and support makes SDS easier for me" (Survey)



When asking people whether access to independent advice and support services made SDS easier for them, a similar age trend to that found with independent advocacy was evident. 81% of people who were 40 years old or younger either agreed or strongly agreed that access to independent advice and support services made SDS easier for them. In comparison, that finding decreased to 73% in the 41-64 age group, and 62% for people who were 65 or older – with 29% of respondents in the latter group stating that they "didn't know", and were generally less likely to have accessed those services.

Survey respondents, focus group participants, and interviewees all commented on the value of independent advice and support in accessing SDS. Several people highlighted that they had benefited from the involvement of independent advice and support services during their needs assessment and reviews. One survey respondent recommended that people "seek help from an independent support organisation who provide information and support for people looking to get SDS as they are knowledgeable about the processes in your area and get support in place."

One interviewee stated that based on their experience they would recommend that people who want to access SDS should get in touch with independent support and advice services. They reflected on their experience of SDS prior to the involvement of independent professionals as follows:

> *"I think my biggest advice would be to get professional advice. So something like [local independent advice and support organisation], or an advocate, or something; get somebody who that's their*

> *speciality, to support and advise you. Because I've found that going it alone you tend to get pushed back – and it shouldn't be like this, but the system is a case of who shouts loudest gets the most. And I've had the experience of just being pushed further and further back, because you're just patiently waiting. […] And not everyone can make phone calls; like I can't make phone calls, I suffer with anxiety and things. So I have to rely on somebody else to make those calls for me, and they just build up, with how many people you've got to phone around, and everything. […] And it just keeps getting longer, and longer, and things get pushed back, and other things take priority. And then health goes downhill, so that has to come first. It's just a vicious cycle."*

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

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

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 person summarised their experience of support from a third sector organisation as follows:

> *"And any problems that we've had […] have been ironed out, so we've got no problems at all; [local third sector organisation] are very, very good."*

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."*

Another respondent made the following statement about their experience of third sector organisations and social care:

> *"I'd like you to put in the report that sometimes we get better care from the voluntary sector than from the government. I am more likely to phone charities than social work if I need even an answer or an explanation. There's so much rhetoric about*

> *equality, about diversity – but the gap between the aspiration and delivery is huge.”*

Peer Support

Several people 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.”*

Often, peer support can be an essential network for people – as outlined by one interviewee:

> *“I’ve got a friends network on Facebook. What you’ve got to remember is that in 30 years we’ve all got to know each other through the schools, the clubs, the residential places, the day centres. Carers get to know each other. […] So I’ve got quite a lot of good friends that happen to be carers that you met through caring, and we all support each other but we also have each other to moan at you know we can rant at each other as well and cry and battle and fight. […] We have got a saying that carers are all in a circle and they’re all holding a scarf in each hand, so everybody’s holding the scarves and if anybody drops the scarf, somebody else has got to help them pick it up.”*

Independent Advocacy and Support: People 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 and health and social care partnership 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. Focused efforts are required to ensure older people, Black and minority ethnic people, and people from all socioeconomic backgrounds are aware of – and can access – independent advocacy and support services. Local peer support networks should also be encouraged and supported.

Endnotes

1 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 MSMC survey language among the people surveyed and to allow comparisons to be made with other available data.

2 Throughout this report we have used the phrase "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.

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Appendix: Research Documentation

Survey and Interview Questions

Survey

An online version of the MSMC survey can be found here: https://sdsscotland.formtitan.com/MSMC_survey#/ [Link disabled after survey closed on 14 February 2020].

To obtain a .PDF version of the print survey, or a copy in another format, please contact the research team (contact details on the final page of this report).

Interview Questions

Interview Topic Guide: Self-directed Support User

Opening script introducing study to participants:

Thank you for taking the time to speak to me today. Can I check that you received the project information and consent sheet? Do you have any questions about the project or this interview?

Our conversation should last up to an hour. Can I ask for your consent to take part and to confirm that I have your permission to record our conversation?

You can withdraw at any time and you don't need to answer a question if you feel uncomfortable. In the project report, you will be anonymous and if specific information from your interview is mentioned, it will be under a pseudonym.

(Action: obtain signed consent sheet from participant)

1. Can you tell me about yourself, such as where you live, if you live with anybody, your age and the nature of your impairment?

2. Can you remember how you found out about Self-directed Support for the first time?

3. When did you complete your needs assessment or re-assessment and how long did you wait until you received a decision?

4. How is your support arranged now? Prompts:

    I get the money to spend on the support I choose (Option 1, also called a Direct Payment)

    I choose the support I want and somebody else arranges it (Option 2, also called an Individual Service Fund)

    The council arrange my support (Option 3)

    Some of the above options combined (Option 4)

5. Can you describe your experience of applying for Self-directed Support? Prompts:

    Did the professional who carried out your needs assessment provide information on the four options for SDS?

    What form of information was provided, such as leaflets/websites?

    Did you receive support or advice during your needs assessment from any individuals or organisations?

Was the information provided relevant and did it meet your expectations?

6. Did you have any questions during your needs assessment? If yes, can you recall what these questions were?

7. Did you feel that you had a good conversation during your needs assessment and if yes or no, can you explain your answer?

8. How much do you have for your estimated or indicative budget?

9. How do you spend your budget?

10. What factors are challenging for you with Self-directed Support?

11. What factors make Self-directed Support easier for you?

12. How has Self-directed Support changed your life?

13. What would your advice be to other people considering using Self-directed Support?

14. Would you like to mention anything else related to your experience of applying for or managing Self-directed Support?

(Action: leave debrief sheet with participant)

Interview Topic Guide: Self-directed Support Applicant

Opening script introducing study to participants:

Thank you for taking the time to speak to me today. Can I check that you received the project information and consent sheet? Do you have any questions about the project or this interview?

Our conversation should last up to an hour. Can I ask for your consent to take part and to confirm that I have your permission to record our conversation?

You can withdraw at any time and you don't need to answer a question if you feel uncomfortable. In the project report, you will be anonymous and if specific information from your interview is mentioned, it will be under a pseudonym.

(Action: obtain signed consent sheet from participant)

1. Can you tell me about yourself, such as where you live, if you live with anybody, your age and the nature of your need for support?

2. How are your support needs being met at the moment without access to Self-directed Support?

3. Can you tell me what you know about Self-directed Support?

4. When did you complete your needs assessment or re-assessment and have you received news on the outcome? If you received a decision not to award, do you plan to appeal the decision and can you describe how you will do this?

5. Can you describe your experience of applying for Self-directed Support? Prompts:

Was it easy to get a needs assessment? How long did it take?

Were there any barriers to getting an agreement for an assessment to take place?

Did the professional who carried out your needs assessment provide information on the four options for SDS?

What form of information was provided, such as leaflets/websites?

Were people made aware of or referred to other sources of support by the social worker? Did you feel that you were listened to and your needs understood?

6. Did you have any questions during your needs assessment? If yes, can you recall what these questions were?

7. Did you feel that you had a good conversation during your needs assessment and if yes or no, can you explain your answer?

8. After your needs assessment how much did you have for your estimated or indicative budget?

9. How did you plan to spend your budget?

Have you developed a support plan?

If so, who helped you with this and what did you include in this?

Were there any difficulties in agreeing the support plan?

10. In what ways do you feel Self-directed Support would change your life?

11. What would your advice be to other people considering applying for Self-directed Support?

12. Would you like to mention anything else related to your experience of applying for Self-directed Support?

(Action: leave debrief sheet with participant)

Information Pack and Consent Sheets

My Support My Choice: user experiences of Self-directed Support in Scotland

Interviewee Information and Consent Sheet

“My Support My Choice” is a partnership project between Self Directed Support Scotland and the ALLIANCE.

The “My Support My Choice” research has its origins in a 2016 pilot study conducted by Self Directed Support Scotland (SDSS) which explored service users’ experiences of Self-directed Support in three local authority areas in Scotland. The literature review for “My Support My Choice” indicates that little is known about how disabled people and their families feel about the various options available under Self-directed Support nor, the journey through which disabled people and their families undergo in order to access suitable support. Following on from the SDSS 2016 pilot study, “My Support My Choice” will examine user experiences of Self-directed Support across nine local authority areas in Scotland and the research questions are:

1. Are new and re-assessed social care users being given all of the relevant information about options available to them under SDS, and is this done in a way that is supportive and accessible?

2. Are people aware of and able to access advice and support from other agencies to help them to make an informed choice and to set up their preferred arrangements?

3. Are people able to access care and support arrangements that are flexible and tailored to meet their own personally-defined outcomes?

4. To what extent are people able to obtain non-conventional forms of social care?

You will have the opportunity to go through this information sheet with one of the project team and to ask them any questions you may have.

About the research

We have been funded by the Scottish Government to carry out a study which will examine users experiences of Self-directed Support across nine local authority areas in Scotland. A survey will be distributed to users of Self-directed Support and their families/carers. As well as this, we would like Peer Researchers to assist with interviews involving users of Self-directed Support in order to find out disabled peoples' views and experiences. Ten interviewees will be selected from each of the five local authority areas. Interviewees will be invited to take part in an interview lasting approximately an hour.

The study also includes a literature review to examine the latest research evidence base, as well as the collection of new data that will help us to understand current practice. As part of the research we will also be carrying out local feedback sessions with practitioners in each case study local authority. We aim to encourage discussion concerning the implementation of best practice in relation to Self-directed Support.

What is your involvement in the research?

You are invited to take part in a face-to-face interview that will last approximately an hour. We are keen to hear the experiences of social care users and their families/carers of applying for and managing Self-direct Support. We would like to speak to households who have completed a needs assessment or social care review in the past 12 months.

Interviews will take place in an accessible public building with access to a private room, for example a local disability related organisation. Please feel free to suggest a suitable venue where you feel comfortable. Your participation will be voluntary with all travel expenses reimbursed by Self Directed Support Scotland.

What will happen to the information that you provide?

We would like to audio-record the interviews, but we will ask for your consent to do this. If you would prefer not to be recorded, we will respect this and we will ask to take notes instead.

Audio recordings will be transcribed for analysis by the research team. Both the audio recordings and the anonymised transcripts of interviews will be kept on a secure, pass-word protected server at Self Directed Support Scotland. The recordings will be deleted upon completion of the study. Anonymised transcripts of the interviews will be kept for three years (until 2021) in order to inform the National Strategy on Self-directed Support in Scotland. The storage and use of data follows the rule set out by the European Union General Data Protection Regulation.

Will the research benefit you?

The research may not benefit you directly but we hope that our findings will provide a better understanding of user experiences of Self-directed Support in Scotland. We also hope that findings from this project will develop an evidence base for future best practice at both local and national levels.

Further information

Should you wish to discuss the study further prior to making a decision the team can be contacted via e-mail or telephone: [Principal Researchers contact details]. If you have any concerns about the conduct of the research, you can contact the Project Manager [name and contact details].

Consent Form: Interviewees & focus group participants

Please initial the boxes in the right column if you agree with the statements below:

1. I confirm that I have read and understood the information sheet and I have had the opportunity to ask questions.	
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.	
3. I agree to take part in the above research.	
4. I understand that the information I provide will be collected and anonymised with a view to include in a project report for the research funder, but may also be subsequently used in academic presentations and/or papers about this project to inform the development future guidance on this topic, as well as promotional/campaign materials from all research partners.	
5. I agree that information I provide can be used on the terms above.	
6. I understand that all unprocessed information will be accessed only by the project team and that data will be securely stored and later disposed of by 2021 in accordance with the European Union General data protection Regulation.	
7. I give consent for my interview to be audio-recorded.	

Participant Name:	Signature:	Date:
Researcher Name:	Signature:	Date:

Please keep this copy for your records. We will ask you to sign another copy and to confirm each of the statements prior to your interview.

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

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