My Support My Choice:

Blind and Partially Sighted People's Experiences of Self-directed Support and Social Care

Thematic Report, December 2020

Self Directed Support Scotland
the organisation of choice

ALLIANCE
HEALTH AND SOCIAL CARE ALLIANCE SCOTLAND
people at the centre

Table of Contents

List of Charts

Acknowledgements and Dedication

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

About this Report

This report uses data[1] about blind and partially sighted people who participated in "My Support, My Choice: User Experiences of Self-directed Support in Scotland" (MSMC), a research project run by the Health and Social Care Alliance Scotland (the ALLIANCE) and Self Directed Support Scotland (SDSS), funded by the Scottish Government.

This publication is part of a suite of MSMC reports. The national report sets out findings from all research participants and includes additional information about the overall project design and methodology, national context for Self-directed Support (SDS)/social care, and short reports about the experiences of older people and information about SDS, people with lived experience of homelessness, people living in rural areas, disabled parents, parent/guardian carers, and LGBT+ people. Further thematic reports published separately explore the experiences of people with learning disabilities,[2] Black and minority ethnic people,[3] women as users of SDS/social care, and people with lived experience of mental health problems. A further suite of reports focusses on people's experiences in specific local authority areas; at the time of publishing this report, these had been interrupted by COVID-19.

COVID-19

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

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

Executive Summary

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

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

This document is part of a suite of MSMC reports and focuses on the experiences of blind and partially sighted people who use SDS/social care in Scotland. Between November 2018 and February 2020, MSMC heard about the experiences of 75 blind and partially sighted people via a survey, interviews and focus groups. Research took place prior to the appearance of COVID-19 in Scotland, and this report does not reflect people's experiences during the pandemic.

Overall, blind and partially sighted participants reported that SDS had improved their social care experience, however there are some improvements that would respond to people's concerns, build on existing good practice and increase the effectiveness and reach of positive SDS/social care experiences. The views expressed by research participants and analysis of the findings have led to a number of recommendations, many of which echo other independent reviews of SDS.

Poverty and SDS

An estimated 24% of Scottish households with a disabled person live in relative poverty after housing costs, and 56% of blind and partially sighted research participants 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 blind and partially sighted people on low incomes who access or are trying to access social care, given that this can lead to people having to manage without support, negative impacts on mental and physical wellbeing, and demands on family and friends to assume roles as unpaid carers.

Data Gathering and Analysis

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

Overall Experiences of SDS

Blind and partially sighted people gave both positive and negative feedback when asked to summarise their experiences of SDS. However, overall they reported that SDS had improved their social care experience.

Information About SDS

Blind and partially sighted people find out about SDS from a variety of sources, with social workers being the main information point. Blind and partially sighted people recommend that those wanting to know more about SDS should get in touch with social work, independent advocacy and independent advice services as soon as possible. It would be helpful to widen the pool of professionals – particularly in health and education – who are informed about SDS and can encourage blind and partially sighted people to access it.

Blind and partially sighted people reported lower satisfaction levels with the information they received about SDS compared to MSMC research respondents overall. They were also less likely to have had all four SDS options discussed with them during their needs assessment and to feel that all their questions had been answered at their most recent meeting with social work professionals. Some blind and partially sighted participants had not been provided with accessible information or documentation, even after requesting it from social work departments.

Blind and partially sighted people require comprehensive, high-quality and timely information in a range of accessible formants about all four SDS options and the budgets available to them, so they can make informed choices about their care and support. For some blind and partially sighted people, information is best provided face-to-face, more than one conversation may be needed, and people should have access to independent advocacy and support during meetings if they want. Social work professionals should proactively check in with people after assessments and reviews to address any outstanding concerns.

Informed Choice and Control

51% of blind and partially sighted respondents indicated they had enough time to consider their SDS options. While many MSMC participants overall commented on problems caused by long waiting times for assessments or support, more blind and partially sighted people raised this issue during interviews and focus groups than other population groups. Almost all blind and partially sighted interviewees and focus group participants had waited longer than six months for a needs assessment or review following a request for support and many had waited over a year. Targeted measures are required to address these overly long waiting times, which cause unnecessary stress and anxiety and can lead to a deterioration in people’s physical and mental health and wellbeing.

Most blind and partially sighted survey respondents were on their preferred SDS option, however several interviewees and focus group participants reported being offered a reduced choice. And although most survey respondents indicated they fully involved in decisions about their care and support, two-thirds reported that family member or social workers had chosen their support for them. Recommendations include ensuring that all blind and partially sighted people are offered a meaningful choice between the four SDS options and improvements to embed supported – rather than substitute – decision-making.

Good quality, flexible, and adequate support plays a vital role in helping blind and partially sighted people enjoy their right to independent living and equal participation in society. Proposed changes (particularly reductions) in budgets should be clearly communicated to – and discussed with – blind and partially sighted people well in advance and increases in support should be introduced in a timely fashion. It is vital that all blind and partially sighted people are treated with equality, irrespective of when sight loss has occurred.

Travel costs – particularly for blind and partially sighted people living in rural areas – were repeatedly mentioned as a key concern; more acknowledgement and accommodation of them is required in SDS budgets.

Conversations and Relationships with Social Work

Blind and partially sighted survey respondents were evenly split between those who were happy and those who were not about the conversations they have had about their support with professionals. They highlighted that good conversations require effective communication, access to information, prompt decisions and good future planning. Those who were happy with their conversations and enjoyed consistent relationships noted that it's important for social workers to 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.

Blind and partially sighted people were less likely to be happy with the conversations they had about their support with professionals compared to all MSMC research participants overall. Participants reported difficulty obtaining paperwork and documentation concerning their care arrangements – even after repeated requests to social work departments, difficulty obtaining information about how to lodge formal complaints, and that health and social care professionals disregarded their preferences around social care arrangements.

Some blind and partially sighted people shared experiences of discrimination, intimidation and bullying. While these accounts were rare, in contrast to most people's experiences, they were important enough to include within this report. No-one should have to deal with discriminatory, intimidatory or bullying language, attitudes or behaviour from social work professionals, and there are several recommendations aimed at improving policy and practice.

More work could be done to ensure complete transparency across several elements of SDS/social care, including eligibility criteria, needs assessments, budget and support packages, changes to support, participation in decision making and how to challenge decisions.

Impact of SDS on Family/ Relationships

Blind and partially sighted people outlined a variety of ways that SDS has improved family live 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. It is also important for professionals to consider conscious and unconscious gender bias when assessing people's right to access support.

Care Staff Recruitment, Training, and Quality

Blind and partially sighted people report mixed experiences of support worker recruitment, training and quality. As well as the positive impact of good support workers, several participants indicated difficulties finding and retaining personal assistants and care workers that are suitable for their requirements. Respondents would welcome more support to arrange staff recruitment, training and continuous professional development from local authorities and relevant support organisations.

Independent Advocacy and Support

Blind and partially sighted people value and benefit from the provision of independent advocacy and independent advice and support. As well as ensuring that these services continue to be resourced to carry out their vital work, local authority staff should be given more training and information about local independent organisations so they can more routinely refer people to them and recognise the value they bring to their own work. Local peer support networks should be encouraged and supported.

Recommendations

Blind and partially sighted people generally reported that SDS had improved their social care experience and shared several examples of good practice. 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 blind and partially sighted 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 apply for and use SDS/social care.

Information About SDS

3. Blind and partially sighted people need timely 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; large print; Braille).

4. 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.

5. 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.

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

7. Blind and partially sighted 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.

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

9. Social work professionals may require further training in supported decision making and the SDS options.

10. Blind and partially sighted people should be informed about all four SDS options, rather than being given information about a more limited list of options.

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

12. Blind and partially sighted 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.

13. Blind and partially sighted people should always have access to independent advocacy and support for assessments and review meetings, if they desire.

14. Blind and partially sighted people should be promptly provided with all information – in accessible formats – pertaining to their SDS, including Personal Outcome Plans, budget agreements, and decisions about their support package.

15. 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 blind and partially sighted people.

16. Blind and partially sighted 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.

Informed Choice and Control

17. Blind and partially sighted people should be given enough time to choose their preferred SDS option.

18. Targeted measures are required to address overly long waiting times for blind and partially sighted people – for a needs assessment, review, or for support to be put in place.

19. Blind and partially sighted people have the right to expect a reasonable notice period for needs assessments or reviews.

20. More work is needed to ensure all blind and partially sighted people are offered and can make their own meaningful choice between all four SDS options.

21. Improvements could be made to safeguard supported – rather than substitute – decision making by blind and partially sighted people about their care and support.

22. Any proposed changes (particularly reductions) in budgets should be communicated to – and discussed with – blind and partially sighted people well in advance.

23. Increases in support should be implemented in a timely fashion.

24. 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.

25. Blind and partially sighted people need flexible budgets and a focus on outcomes to enable them to live as independently as possible. Flexibility is required in a range of ways: from the flexibility to change SDS option, to being able to choose how and when to spend personal budgets, with different amounts of spend and support at different times of year.

26. Blind and partially sighted people – particularly those living in rural areas – require more acknowledgement and accommodation of travel costs in their SDS budgets.

27. Blind and partially sighted people could benefit from assistance from social workers and third sector organisations in navigating the bureaucratic processes to obtain travel passes.

Communication and Relationships with Social Work

28. 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.

29. Social workers need to have a good breadth and depth of knowledge about SDS and local services.

30. Social workers need to have good listening skills and empathy, and the time and skills to build relationships and trust with blind and partially sighted people accessing SDS and unpaid carers.

31. Blind and partially sighted people should be informed if their social worker changes and have a right to request a new social worker if trust breaks down.

32. Blind and partially sighted 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.

33. Blind and partially sighted 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.

34. 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.

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

36. 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).

37. Work is needed to ensure systematic good practice and consistent transparency across several elements of SDS/social care, including eligibility criteria, needs assessments, budgets and support packages, changes to support, participation in decision making and how to challenge decisions.

Impact of SDS on Family/ Relationships

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

39. Professionals should not assume that family members and friends are able or suitable to provide unpaid care, and 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.

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.

Care Staff, Recruitment, Training and Quality

40. Some blind and partially sighted people need more help from local authorities to recruit and train care staff. Local authorities should work with people who access SDS and unpaid carers to improve systems and processes related to care staff recruitment, training and quality, including diversification of the workforce.

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

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

Independent Advocacy and Support

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

44. Focused efforts are required to ensure blind and partially sighted people are aware of – and can access – independent advocacy and support services.

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

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

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

48. Local peer networks should be encouraged and supported.

Research Participants

MSMC heard about the experiences of 75 blind and partially sighted people. 61 people completed the survey, we interviewed nine people who spoke about their own experiences and the experiences of other members of their household who use SDS, and five people participated in our focus groups (plus one unpaid carer).

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

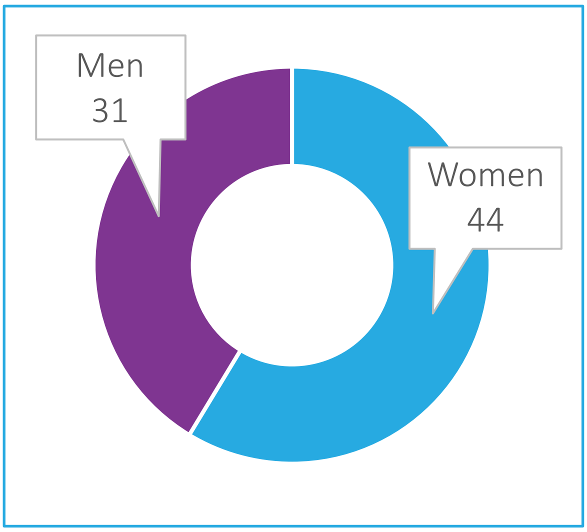
According to the Royal National Institute of Blind People (RNIB), in 2020 there are an estimated 178,000 people in Scotland who are blind, partially sighted, or have experienced some level of sight loss (3.25% of the general population).[4] In 2019 Royal Blind and Scottish War Blinded and Scottish Care carried out a joint research project into blind and partially sighted people’s experiences of SDS. They found that 47% of people surveyed received social care support in some form, but that 65% had not heard of SDS. A further 63% of people surveyed said that they had never had the four SDS options explained to them, and only six out of 23 people receiving SDS felt they had received enough support for their decisions. Most people using SDS (63%) has not been informed of their budget.[5]

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

Gender

Overall, 44 women and 31 men who are blind or partially sighted participated in MSMC.

Chart 1: Respondents' gender

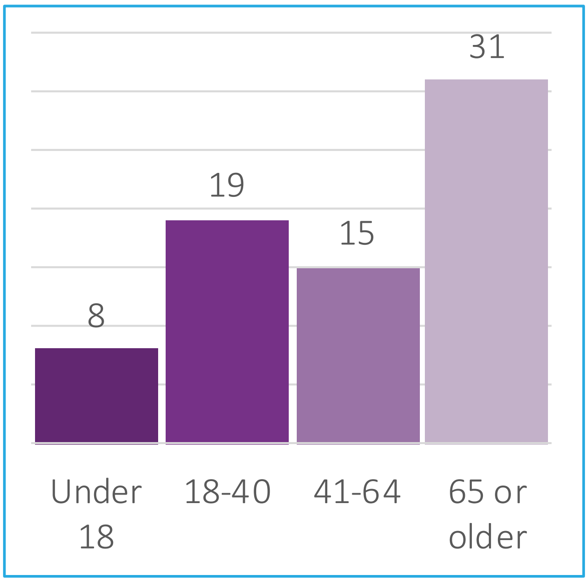


ISD figures are not available for women and men accessing SDS in 2017-28, however they do publish statistics on the number of women and men accessing social care support services more generally – of whom an estimated 45% access SDS – although not every local authority submitted gender disaggregated data. ISD report that in 2017-2018 62% of people accessing social care support were women and 38% were men.[7] Gender disaggregated data of blind and partially sighted people who access SDS is not available on the ISD dashboard.

Age

We asked all participants to share their age. Of the participants who chose to answer the question, eight people (11%) were under 18 years old, 19 (26%) were between 18 and 40 years old, 15 (21%) were between 41 and 64 years old, and 31 (42%) were 65 or older. Two participants did not wish to share their age.

Chart 2: Respondents' age



ISD do not provide an overall breakdown of age groups accessing SDS in 2017-18, although age group data is provided by SDS Option Chosen and Client Group Profile. ISD 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, 77% of people accessing social care support were over 65 years old, 20% were aged 18-64, and 1% were aged under 18 years.[8]

Data on the age groups of blind and partially sighted people accessing SDS for 2017-18 is not available on the ISD dashboard.

Ethnicity

60 blind or partially sighted people who completed the MSMC survey were white, and one person chose not to describe their ethnicity. Most interviewees and focus group participant did not disclose their ethnicity when self-describing themselves, and the majority of those that did described themselves as "white". The spread of respondents

is less ethnically diverse than the Scottish population more generally.

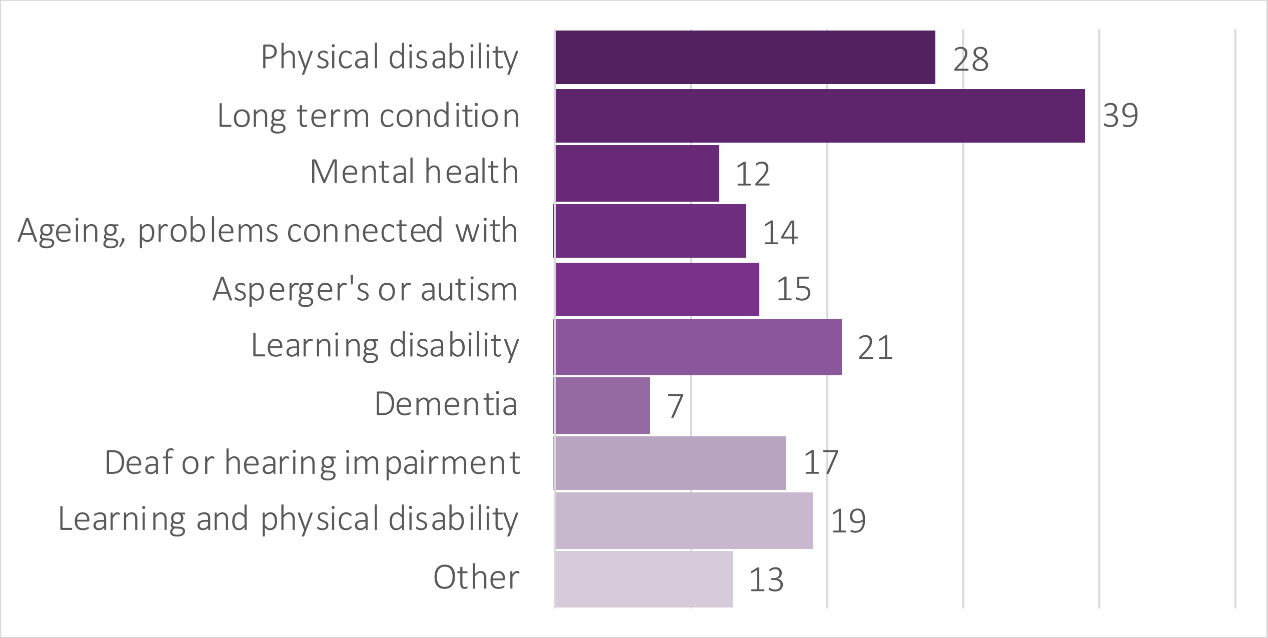
The 2011 Scottish Census indicated that 92% of the population of Scotland identified as "White: Scottish" (84%) or "White: Other British" (8%), with a further 3.3% selecting "White: Irish", "White: Polish", "White: Gypsy/ Traveller" or "White: Other white". The remaining 4.7% of the population identified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

ISD do not provide a disaggregated breakdown of the ethnicity of people accessing SDS for 2017-18. They have some disaggregated data on the ethnicity of people receiving social care support services more generally (of whom an estimated 45% access SDS), using the limited categories of "White", "Other", and "Not provided/ Not known".[10] Not all local authorities submitted data on ethnicity to ISD. Of those local authorities that did submit information, ISD report that in 2017-2018 71% of people accessing social care support were "White", 28% were listed as ethnicity "not provided/not known", and 1% categorised as "Other" (including "Caribbean or Black, African, Asian and Other Ethnic Groups").[11]

Client Group/Disability/ Long Term Condition

MSMC survey respondents who self-identified as being blind or partially sighted lived with a range of conditions, with the majority reporting that they live with multiple conditions. In addition to self-identifying as being blind or partially sighted, 39 people (64%) said they live with a long term condition, 28 people (46%) selected physical disability, and 21 people (34%) described themselves as having a learning disability. Only two people reported that they were blind or partially sighted with no other disability or long term condition.

Chart 3: Client Group/Disability/Long Term Condition in additon to "Blind/partially sighted



Interviewees and focus group participants also discussed their conditions, and – if they were unpaid carers – those of the people for whom they care. Of the nine blind or partially sighted people whose experiences we heard about during interviews and focus groups, several accessed SDS in part because of their sight but also for other reasons.

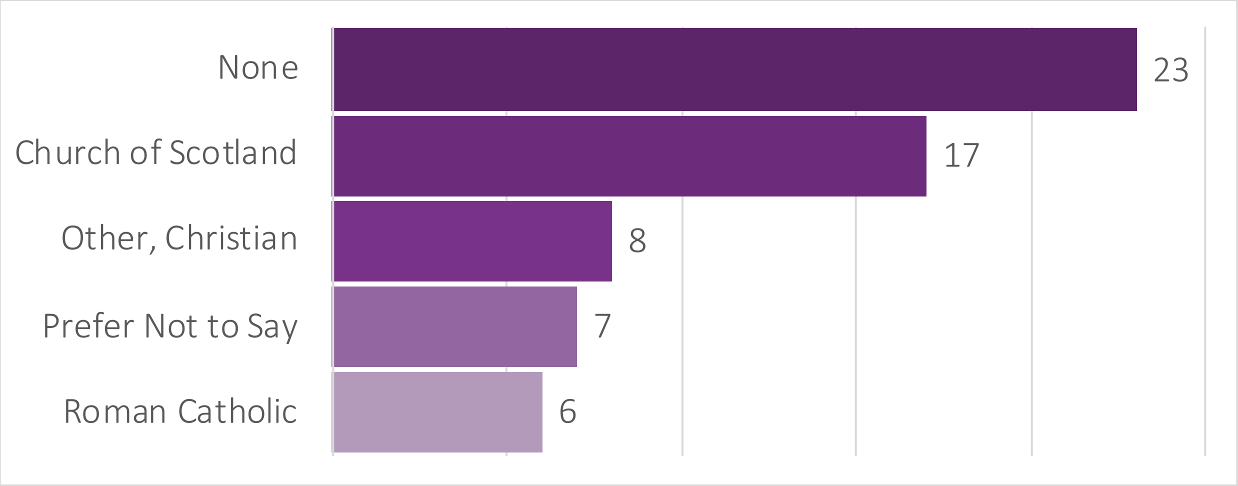
ISD list the following client groups for people accessing SDS in 2017-2018: frail/elderly, physical and sensory disability, learning disability, dementia, mental health, other, and not recorded.[12] These broad categories do not directly align with those tracked in MSMC, and not all local authorities submitted data to ISD. As with MSMC, people could feature in more than one client group simultaneously. Overall, ISD estimate that 47% of people accessing SDS did so because they were "elderly/frail", 35% due to a physical or sensory disability, 10% because of a learning disability, 8% due to dementia, 7% as a result of their mental health, and 17% for "other" reasons. A further 8% did not have their reason for accessing SDS recorded by the local authority (not including those that did not submit data).

Religion

When asked about their religion (if any), 23 (38%) blind or partially sighted people stated "none", 17 (28%) were part of the Church of Scotland, six (10%) were Roman Catholic, eight (13%) described themselves as "other Christian", and seven (11%) preferred not to answer. None of the interviewees or focus group participants explicitly disclosed their religion when self-describing themselves. These results are less diverse than 2011 Scottish Census data for Scotland.

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

Chart 4: Survey respondents' religion



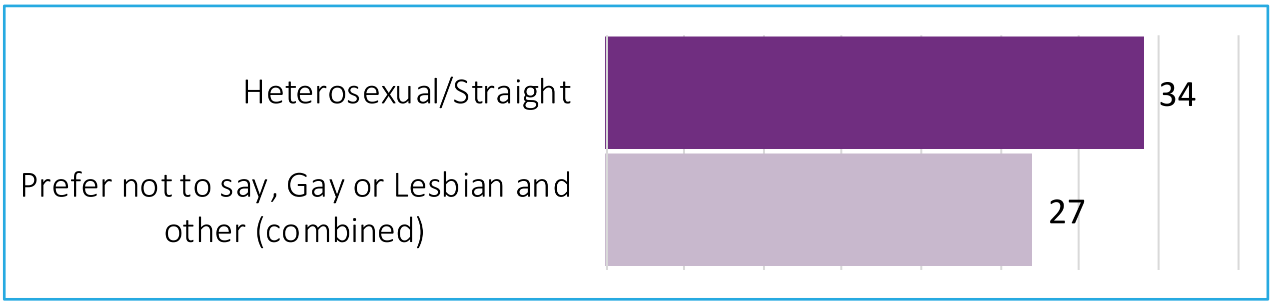
Sexual Orientation

In the survey, 34 (56%) blind or partially sighted people described their sexual orientation as heterosexual or straight, the remainder preferred not to answer the question or represented other groups. None of the interviewees or focus group participants explicitly disclosed their sexual orientation when self-describing themselves. The 2011 Scottish Census did not record data on sexual orientation at local authority level (although the 2021

Scottish Census will do so); as such, we do not have local statistics on sexual orientation available as a comparison.

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

Chart 5: Survey respondents' sexual orientation

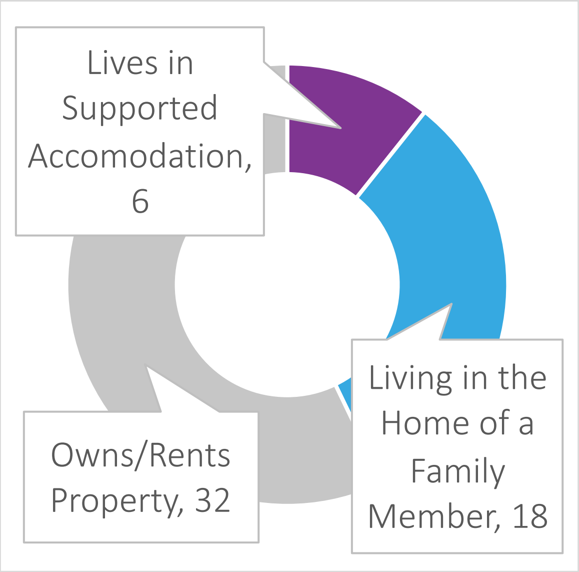


Housing

Among the blind and partially sighted people who answered this question, 32 people either rent or own their own home, 18 people stated that they live in the home of a family member and six live in supported accommodation.

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

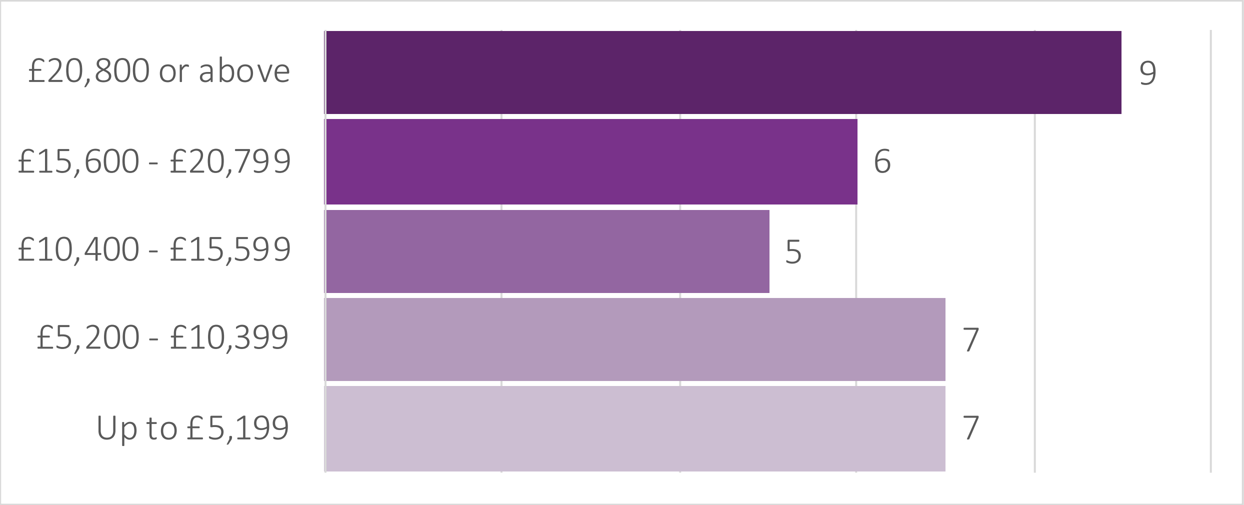
Chart 6: Survey respondents' housing arrangements



Household Income

We asked survey respondents about their household income. We are interested in this information because within Scotland an estimated 24% of households with a disabled person live in relative poverty after housing costs, compared to 17% of the population with nobody with a disability in the household.[13] Survey respondents described their annual household income as follows:

Chart 7: Survey respondents' annual household income



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

According to Scottish Government data, the median household income in Scotland in 2015-2018, before housing costs, was £499 per week (£25,948 per annum).[14] The relative poverty threshold was defined as household income below 60% of the median, which for the same period was defined as £302 per week (£15,704 per annum).[15] Based on this definition, 19 (56%) of the blind or partially sighted respondents who chose to provide details on their household income are living below the poverty threshold. RNIB research has noted that blind and partially sighted people "face greater financial pressures than the UK average".[16]

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

SDS Option

Of the blind or partially sighted survey respondents who shared which SDS option they used, 29 people (56%) indicated they used Option 1, seven people (13%) used Option 2, ten people (19%) used Option 3, and six people (12%) used Option 4.

Figures from ISD indicate that in 2017-2018 there were 8,390 people in Scotland using SDS Option 1, 7,435 using Option 2, 78,054 using Option 3, and 4,257 using Option 4.[17] In some instances, people are logged as being on two options simultaneously (e.g. Options 1 and 3) rather than Option 4, which distorts these figures.

Data on the SDS options chosen by blind and partially sighted people for 2017-18 is not available on the ISD dashboard.

Data Gathering and Analysis

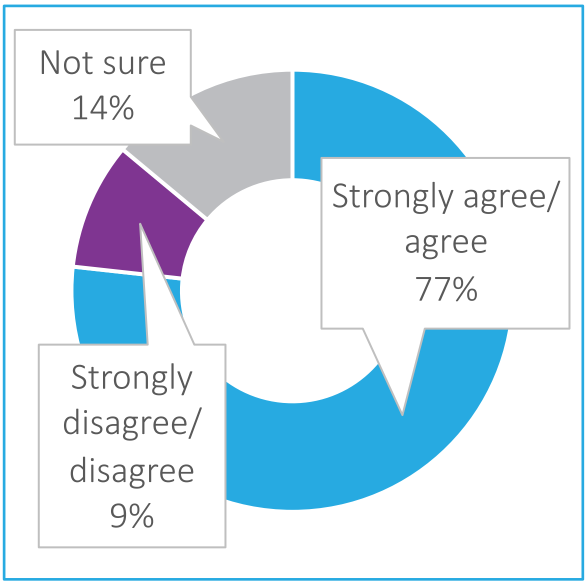
As this chapter demonstrates, there are concerning gaps in SDS data gathering and analysis. Information Services Division (ISD) have reflected on difficulties gathering disaggregated data on people's use of and experiences of SDS/social care in their experimental statistics publication Insights into Social Care in Scotland.[18] They highlight differences in reporting periods for social care data across local authorities, and that some local authorities and social care partnerships were either not tracking or not able to share disaggregated data about SDS and the people using it.[19] Data gaps are also in part due to existing patterns of data collation – leading, for example, to the ISD Social Care Information Dashboard tracking ethnicity via the limited and problematic categories of "White", "Other", and "Not provided/Not known".[20]

Data Gathering and Analysis: Disaggregated data gathering and intersectional analysis is essential to develop fully realised policies and practices that prioritise equal access to SDS/social care for everyone, including blind and partially sighted people, 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, disability, sexual orientation, ethnicity, and religion, as well as socio-economic information like household income and SIMD.

Overall Experiences of SDS and Social Care

We asked survey respondents whether they felt that SDS had improved their social care experience. Overall, 33 blind or partially sighted respondents (77%) stated that they "strongly agree" or "agree" with the statement "SDS would/has improve/d my social care experience". Only four respondents (9%) disagreed with that statement. Six respondents (14%) said that they were unsure. 18 people did not answer this question.

Chart 8: "SDS has improved my social care experience"



Survey participants were also asked to share an overall summary of their experiences and any advice they might have for people considering SDS. One blind 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 blind and partially sighted people's statements about their overall experiences of SDS were positive:

> *"Do it!"*

> *"Go for it."*

> *"Advise them to do it. Just do it."*

> *"SDS plan gives more flexibility and independence."*

> *"Do it. But be determined and stick firm to what you really do need."*

> *"Get it if it helps you to have the support you want and do the activities or work you want to do."*

> *"Fight for it. If they stay flexible with how I can use my funds it is life changing."*

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

> *"It can be a good system, but you do need to be very organised with the paperwork*

and used to dealing with multiple organisations/individuals.”

“It takes time to get everything in place but once it is [it’s] well worth the meetings [and] form filling.”

“Keep your eyes on the outcome that you are hoping to achieve. […] For us, Self-directed Support is the perfect solution.”

However, some blind and partially sighted 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.”

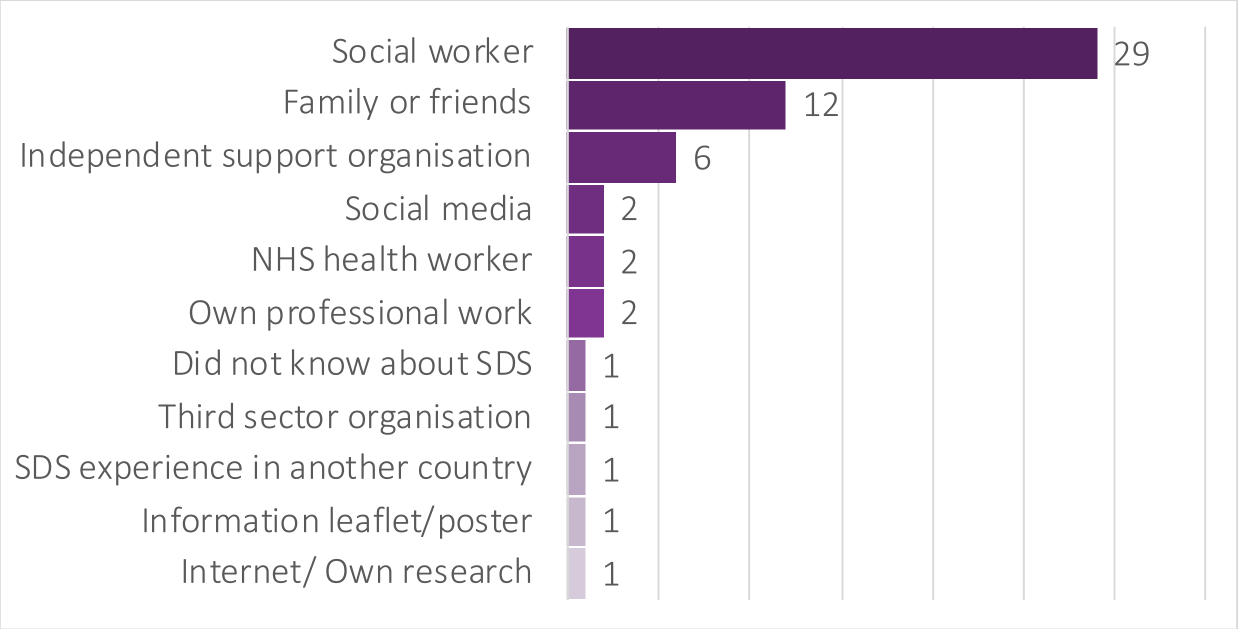
“Don’t do it […] it’s very stressful and time consuming and hard recruiting carers.”

“Don’t hold your breath. Process takes ages, too many long forms with stupid questions. Wait aged for social worker, then pushed into PA option as it’s cheaper for local authorities – that’s if you can meet the criteria.”

“If what we experienced was SDS then I would suggest that [other people] don’t waste their time.”

Information About SDS

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



Finding Out About SDS

We asked people how they first found out about SDS.

29 blind or partially sighted survey respondents (49%) had first heard about SDS from a social work professional. 12 respondents (20%) heard from friends or family members, six from an independent support organisation, two from NHS health staff, two from social media, and two people first heard about SDS through their own professional work (respectively, disability campaigning and local authority work). One respondent learned about SDS from an information leaflet or poster, one from the internet, and one from a third sector organisation. One person knew about SDS from their experiences in another part of the UK. One person did not know 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, an independent support organisation, or a health professional.

One interviewee, an unpaid carer, highlighted that their knowledge of SDS came through their professional work. They reflected that while SDS has been beneficial to the blind 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:

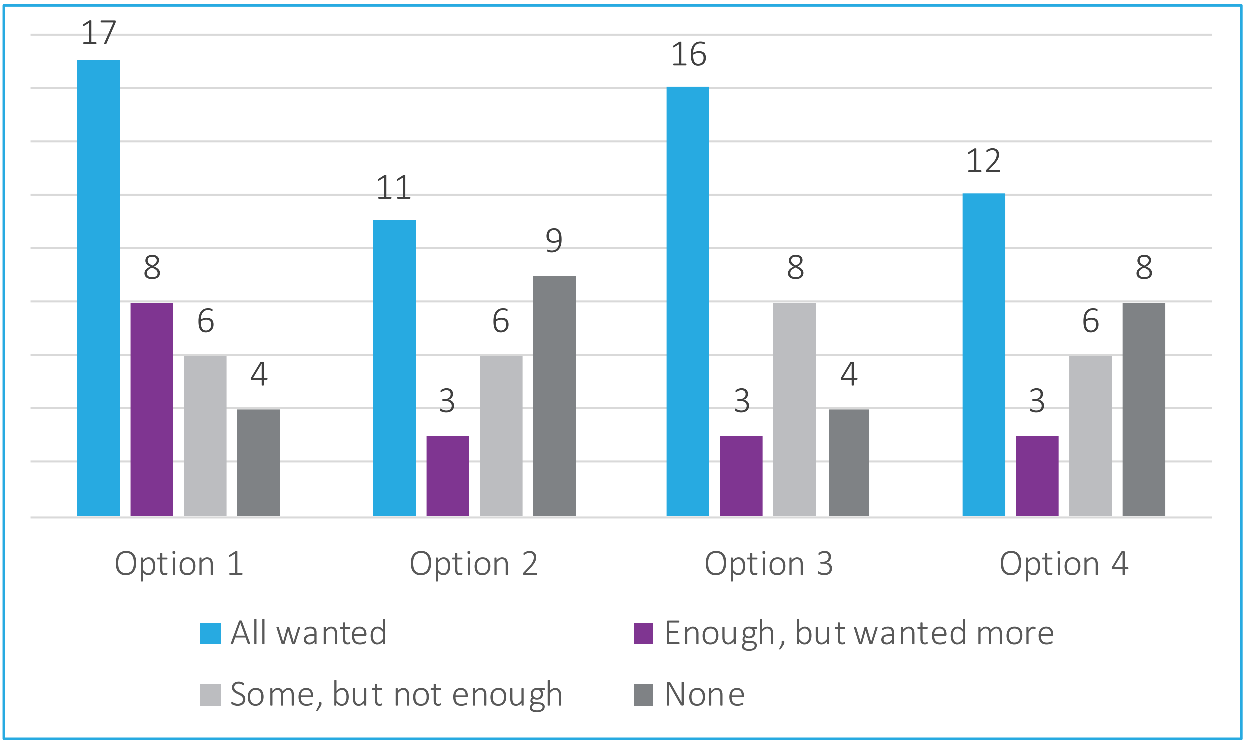
> *“I think certainly the GP could be more proactive […] I think they have had a very hands-off approach to a lady at [specific age] that had hardly been to the doctors in her life and their family has never ever phoned before, but they’re phoning being concerned about her, her very low mood and her 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: Overall, the results indicate that it would be helpful to widen the pool of professionals who are informed about SDS and can encourage blind and partially sighted people to access it. Making more use of health and education professionals would be particularly valuable, as well as building on the existing expertise of social workers, independent advice and support organisations. Greater use of health professionals in the process would also help to strengthen the integration of health and social care.

Information and Preparedness Before Assessments

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

Chart 10: Information received before discussing support



As the chart indicates, across all four SDS options a large minority – or, with Option 3, a small majority – of respondents received "all the information [they] wanted" (respectively, 49% (Option 1), 38% (Option 2), 52% (Option 3) and 41% (Option 4)). However, it is concerning that the majority of people across three of the options either had no information or were left wanting more in advance of their needs assessment.

Of the respondents who felt they needed more information before meeting with a professional to discuss their support, 29% stated that they either received "some, but not enough" or no information at all about Option 1, while a further 23% said they had received "enough" information "but wanted more". With Option 2 (which had the lowest satisfaction levels across the options), 52% reported that they had either "some, but not enough" or no information, with 10% receiving "enough, but wanted more". For Option 3 (the only option where most people received all the information they wanted), 39% of respondents still said that they had either "some, but not enough" or no information, and 10% of had "enough, but wanted more". Finally, 48% of respondents said they had received either "some, but not enough" or no information about Option 4, while 10% received "enough, but wanted more".

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 advice and support organisation for providing them with appropriate information (several were mentioned by different participants). One focus group participant stated that they were given incomplete information about the four options – a common experience for blind and partially sighted people:

> *"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."*

A different participant shared how they were given "very little information" about SDS or what to expect from a needs assessment prior to it taking place. Furthermore, 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 participant felt that this reduced their autonomy and denigrated their intelligence.

Several respondents reported that they struggled to access large print or Braille versions of documents and information leaflets – even when social work professionals knew that they required documents in accessible formats. Some participants also raised concerns about advance information on eligibility criteria. While some local authorities shared eligibility criteria publicly (either in information leaflets or via local authority websites), this is not the case across Scotland.

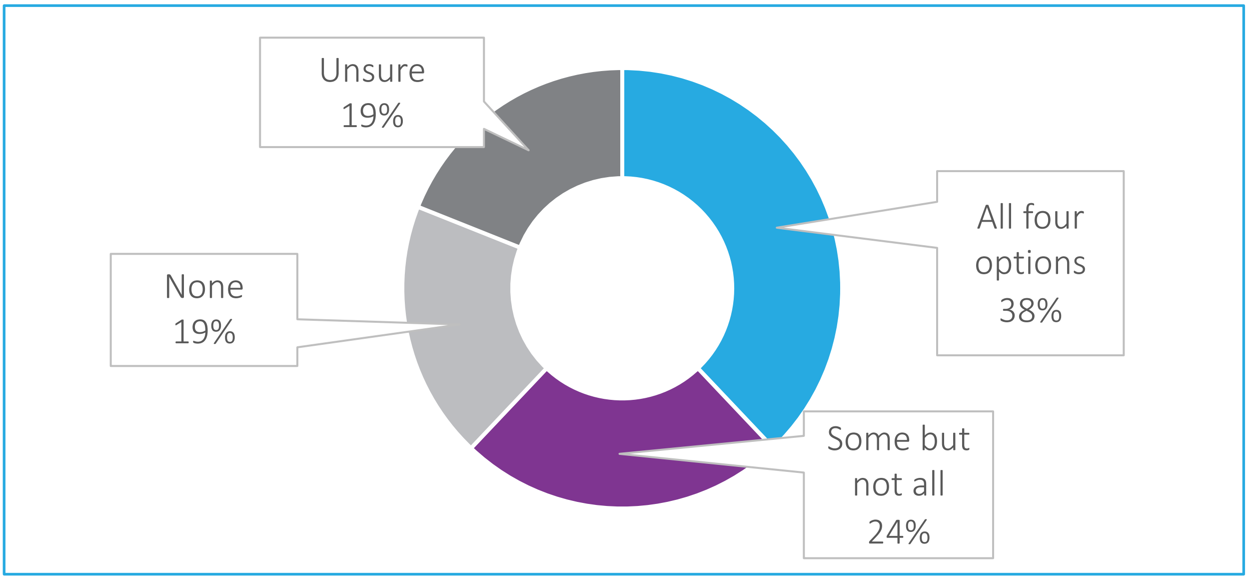
Information and Preparedness Before Assessments: These findings indicate that blind and partially sighted people still require better advance information and support to feel prepared for their needs assessments. Comprehensive, high-quality information in a wide range of accessible formats should be pro-actively provided to people about the different options, carers' assessments and support plans. Overall satisfaction with advance information about all SDS options could be improved for blind and partially sighted people, particularly Option 2. The benefits of earlier, high-quality, accessible information include early intervention, before people reach crisis point, and reduced demands on staff time because people are better prepared for discussion and assessments.

Information During Assessments

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

Of the 58 people who answered this question, 38% stated that the professional discussed "all four options" with them. However, 24% also reported that "some but not all" options were discussed with them, and 19% stated that "none" of the options were discussed. A further 19% stated that they were "unsure" which options were discussed with them during that meeting. Three respondents chose not to answer this question. These findings indicate that more work needs to be done to fully outline and discuss the four options with blind and partially sighted people during their needs assessments and reviews.

Chart 11: Discussing SDS options with professionals

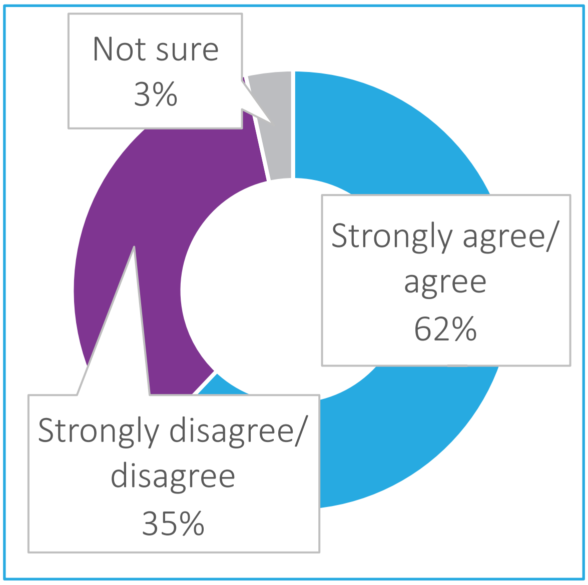


Some interviewees and focus group participants reflected on positive experiences during their needs assessments. One participant related that the sensory impairment team in their local social work department are excellent, and several respondents spoke highly about individual social workers and the positive impact that constructive and thoughtful needs assessments had made to their lives.

However, the majority of blind and partially sighted interviewees and focus group participants recounted more mixed experiences with their needs assessments or review. Several reported that the needs assessment conversations they had with social work professionals were rushed, and many stated that social workers did not explain the process around SDS properly to them in a way they could understand.

In the survey, we asked respondents a series of questions about their interactions with social work professionals. When asked whether they agreed with the statement "The person I met with explained things clearly to me", 36 blind and partially sighted people either "strongly agreed" or "agreed" (62%) with the statement, while 20 people (35%) disagreed or strongly disagreed, and two people were unsure. Three people did not answer this question.

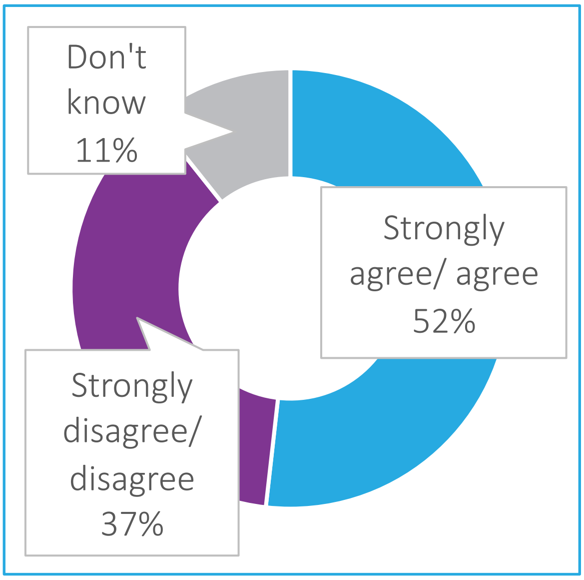
Chart 12: "The person I met explained things clearly to me"



We also asked participants 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 social work professional. Of the 56 blind and partially sighted respondents who answered this question, 29

(52%) strongly agreed or agreed, while 21 (37%) strongly disagreed or disagreed. A further six people (11%) said that they did not know.

Chart 13: "All my questions were answered"



From the survey responses, more than half of people felt that social work professionals provided good information and answered all their questions – even if an important minority also wanted more information. One interviewee 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."*

Information During Assessments: Social workers and other professionals play an important role in informing, influencing and implementing decisions about social care, and they are often many people's first port of call for information about SDS, including eligibility criteria, waiting times and available support. The research indicates that further work is needed to ensure that blind and partially sighted people are fully informed about the four SDS options during assessments and all questions are answered. For some blind and partially sighted people, information is best provided face-to-face, more than one conversation may be needed, and people should have access to independent advocacy and support during these meetings if they want. Blind and partially sighted people should have timely access to information in a range of accessible and inclusive communication formats in advance of and during meetings. Social work professionals may require further training in supported decision making and the SDS options, and should ensure sufficient time is allocated for meetings.

Outstanding Concerns and Appeals

We asked survey respondents whether they have any concerns that were not addressed during their last assessment. Of the 58 blind and partially sighted respondents who answered this question, 29 people (50%) had no concerns, 19 people (33%) had outstanding issues that were not addressed by social work, and 10 people (17%) were unsure.

Of those survey respondents with unaddressed concerns, budgets, delays in implementing care, and a lack of information about SDS (and social security entitlements) were the main issues – with people highlighting that these issues had direct and negative impacts upon their health and the health of the people for whom they care. People also noted the need for a strengths-based rather than deficits-based approach to assessments. Two people who had been the victims of crimes reported that they did not feel their safety concerns were addressed during their needs assessments. Interviewees and focus group participants also highlighted key outstanding concerns about their support, specifically around transparency of process, accessible information, budgets, and waiting times.

Blind and partially sighted survey respondents offered some comments on their outstanding concerns:

> *"Flexibility of my care […] was not addressed. Choice was limited."*

> *"How my support workers would get training. […] What would happen to my SDS if my family wasn't around."*

> *"When it would start, […] when it would be reviewed, what it involved, what happens is staff [are] off sick / enough staff to cover, can the staff drive the car."*

> *"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 suffer [from specific condition] and have psychological issues relating to being a victim of abuse. There was no attempt to find a way to put some form of care support in place or put me in the direction of places. 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."*

> *"My personal safety at home, risks to me following a crime committed against me, how I actually felt."*

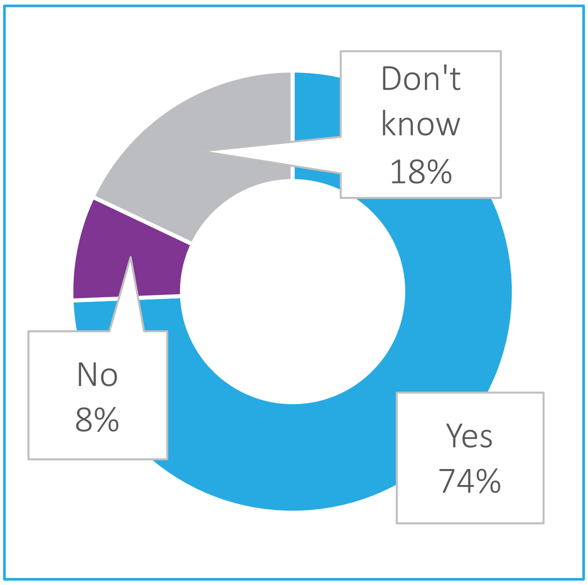
We also asked survey respondents whether they were in the process of appealing the decision made in their last review or needs assessment. Of the 361 people who answered the question, 25 people (7%) indicated that they are in the process of appealing the outcome of their last social care assessment or review, of whom four were blind or partially sighted.

Outstanding Concerns and Appeals: The research invites further work to strengthen and embed existing good practice to ensure that blind and partially sighted 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 39 blind or partially sighted people who answered the question, 29 (74%) said yes, they had been told how much money they could spend, while three people (8%) said they had not been told how much money was available to them. A further seven people (18%) stated that they did not know if they had been given a budget. That most people had received information about how much money was available to them is a positive finding. However, it is concerning that around one quarter of respondents had either not received that information or were unsure.

Chart 14: "Have you been told the amount of money you can spend on your support?"



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

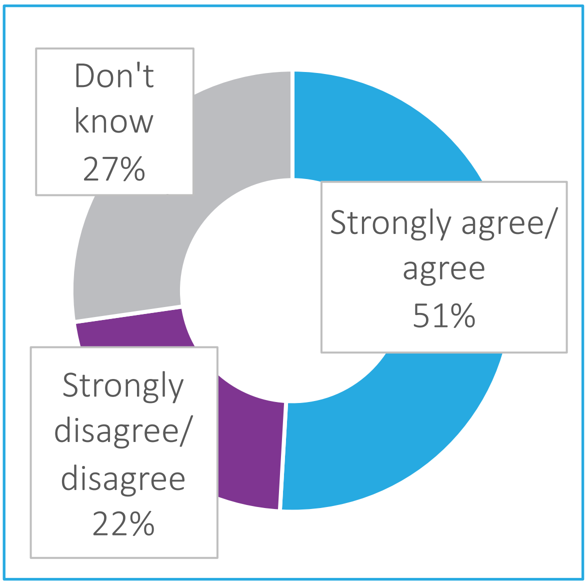
Information About Budgets: Blind and partially sighted people must be provided with accessible information about the budget available to them in order to make informed decisions about their care. People may want to take part in several conversations to support informed decision making about care charges,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

Informed Choice and Control

Time to Consider Options

We asked survey respondents whether they agreed with the statement “I had enough time to choose the option of SDS that suited my needs.” Of the 55 blind and partially sighted respondents who answered this question, 28 (51%) either agreed or strongly agreed, 12 (22%) either disagreed or strongly disagreed, and 15 people (27%) stated that they did not know.

Chart 15: Enough time to choose SDS option



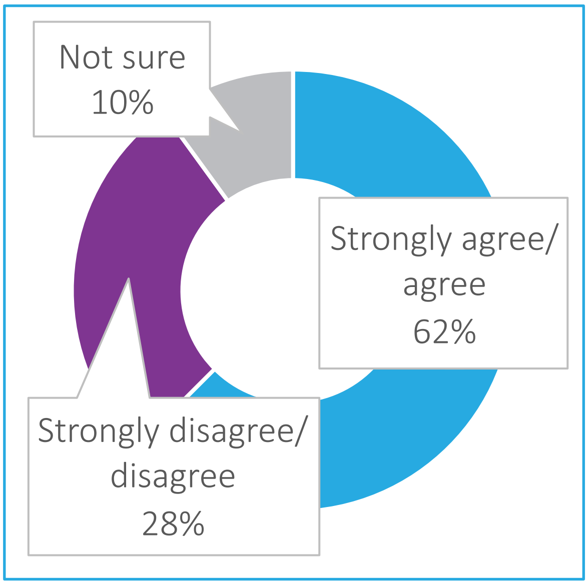
Overall, around half of all blind and partially sighted participants who answered this question felt that they had enough time to choose the SDS option. However, one fifth would have liked more time before deciding – a result that has strong overlaps with those people who wanted more information before deciding.

Time to Consider Options: The research indicates that more work could be done to ensure that blind and partially sighted people have enough time to choose their preferred SDS option. There is also a correlation between the time people are given and the need for clear, prompt and accessible information so that people can 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 40 blind or partially sighted people who answered, 25 (62%) either strongly agree or agreed with that statement, while 11 (28%) disagreed or strongly disagreed. Four people (10%) stated that they were unsure.

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



Interviewees and focus group participants also appreciated short waiting times for a response or decision from social work. While many MSMC participants overall commented on problems caused by long waiting times to access needs assessments or support, more blind and partially sighted people commented on this as an issue during interviews and focus groups compared to other population groups. Almost all blind and partially sighted interviewees and focus group participants had waited longer than six months for a needs assessment or review, following a request for support, and many had waited over a year. 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 participant 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."

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. Very few people had support in place within the same 12-month period as their initial contact with social work. During that period, family members reported concern about how to provide support, especially when the service user was living with increasing sight loss and needed corresponding increases in support. One person reported 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 decisions on whether they could access SDS:

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

Eventually, the individual in question did obtain a suitable SDS package – but the prolonged wait period caused substantial stress to the people providing unpaid care, and deterioration in the individual's physical and mental health. Had decisions been quicker, those adverse consequences for the interviewees may have been reduced. The unpaid carer also reflected that had they known how long it would take to access SDS, their family member would have selected another option which would have enabled a quicker provision of support via Option 3 – even if care was then less tailored.

Waiting Times: The research indicates that targeted measures are required to address overly long waiting times for blind and partially sighted people. Delays – whether for a needs assessment, review, or for support to be put in place – compounded by barriers to accessible information and alternative support, cause unnecessary stress and anxiety and can lead to a deterioration in people's physical and mental health and wellbeing. Timely support can help blind and partially sighted people avoid reaching crisis point, and the potential for more invasive and expensive intervention later.

Choice Over SDS Options and Support

We asked survey respondents if they were on their preferred SDS option. Of the 42 blind and partially sighted people who answered this question, 39 people (93%) were on their preferred option, with the remaining respondents either unsure (two people) or not on their preferred option (one person).

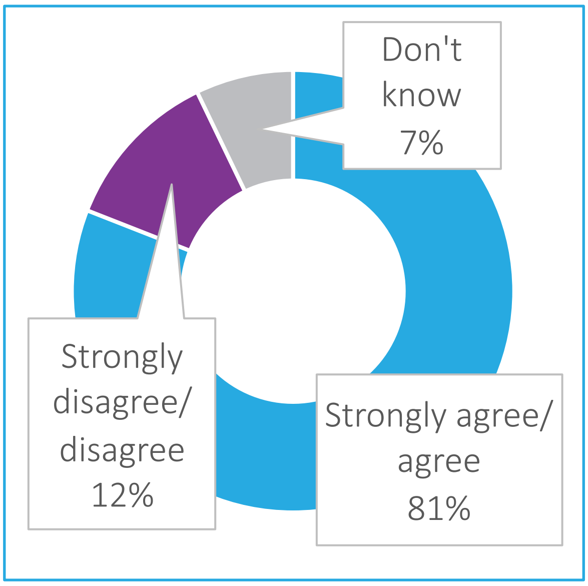
The people who were on their preferred option described how support arrangements enable them to do a diverse range of activities. These include (but are not restricted to): personal care, assistance with household tasks and shopping, respite breaks, access to educational facilities, and support with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

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 42 people who responded, 34 (81%) strongly agreed or agreed with that statement, while five people (12%) disagreed or strongly disagreed. A further three people stated that they did not know (7%).

These figures indicate that blind and partially sighted survey respondents are more likely to be on their preferred SDS option and feel involved in decisions about their care and support compared to MSMC survey respondents overall.

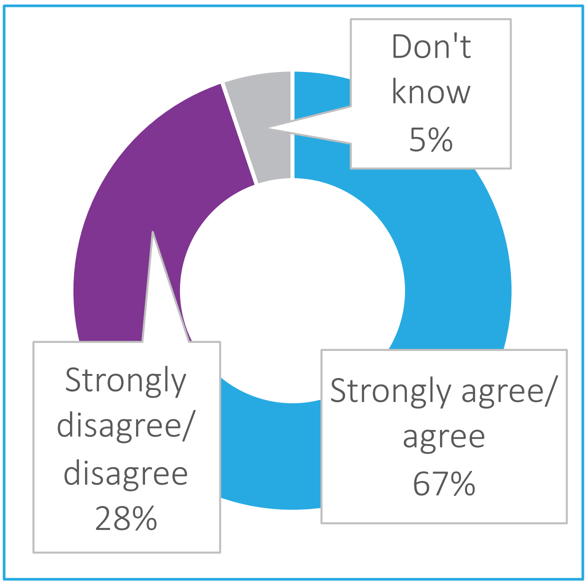
However, several blind and partially sighted interviewees and focus group participants stated that they were offered reduced choice, without all four SDS options being offered. One respondent summarised their experience as "a binary choice I had, either local authority or direct payment, that was it." They did 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.

Chart 17: "I am fully involved in all decisions about my care and support"



In the survey, we asked people to respond to the statement "I had a say in how my help, care or support was arranged." Of the 58 blind or partially sighted respondents, 39 people (67%) either strongly agreed or agreed with that statement, while 16 people (28%) disagreed or strongly disagreed. A further three people (5%) stated that they did not know.

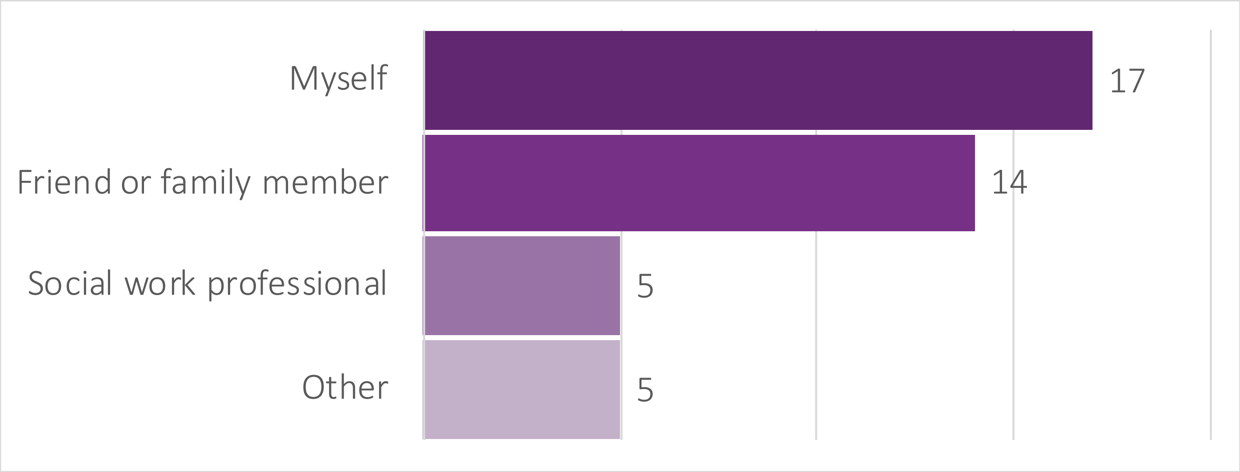
Chart 18: "I had a say in how my help, care or support was arranged"



We also asked survey respondents who chose the way that their support is arranged now. Of the 41 blind and partially sighted people who answered this question, 17 people (41%) said that they chose the way their support was arranged, and 14 people (34%) stated that a friend or family member chose how their support was arranged. Five people (12%) said that a social worker chose for them. A further five people selected "other"; and of those who provided further details, one stated that the decision was share between themself and their social worker, one reported that their legal guardian chose how their support was arranged, and one person said they "had to adapt my choice to suit [their] provider."

These findings indicate that while over a third of blind and partially sighted people are free to choose their own support arrangements, one third had their care and support chosen by friends or family members and a small proportion had the choice made for them by a social worker. These findings invite further work in supported decision making for blind and partially sighted people.

Chart 19: Who chose support arrangements?

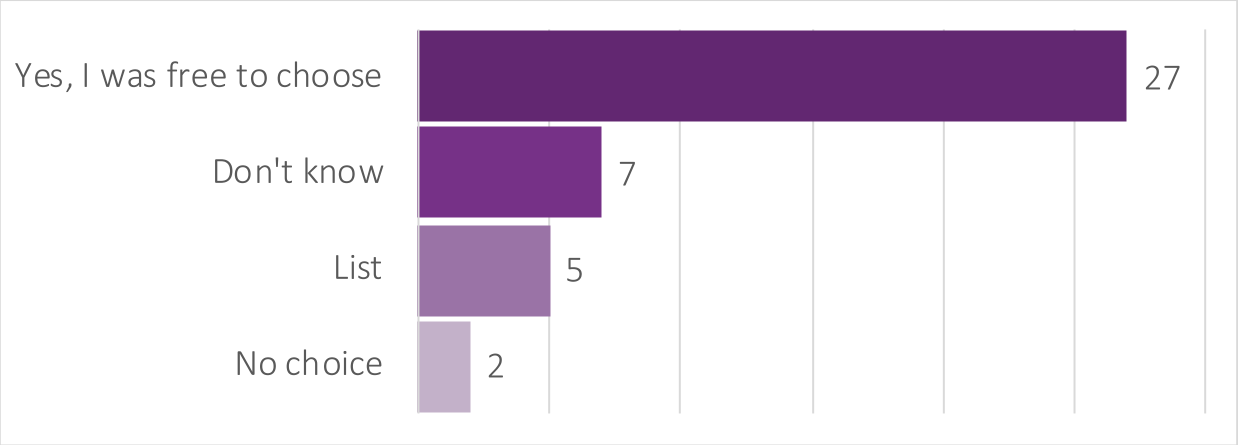


Choice Over SDS Options and Support: The research suggests that work is needed to build on good practice and ensure that blind and partially sighted people are offered a meaningful choice between all four SDS options. Although most people indicated they were happy with their support, improvements could also be made to decision making. While family and friends, and 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 blind and partially sighted people. Staff could be given more training about how to support decision making rather than lead it, and on co-production methods more broadly.

Budget Management

We also asked survey respondents whether they chose who manages their personal budget, and if so, who they chose to manage. Of the 41 blind and partially sighted people who answered this question, 27 (66%) said that they were free to choose whom they wanted to manage their personal budget. Five people (12%) were able to choose from a set list of providers given to them by a social work professional. Two people (5%) stated that they were not given a choice. Finally, seven people (17%) were unsure of whether they had a choice.

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



Of the 27 people who were given free choice of who would manage their personal budget, five selected the local authority, two people chose a third sector provider organisation, three chose a private care agency, and one selected an independent support organisation. A further 14 people (52% of those who were free to choose) selected an individual person (this response could include themselves). Two people were unsure who they chose to manage their budget.

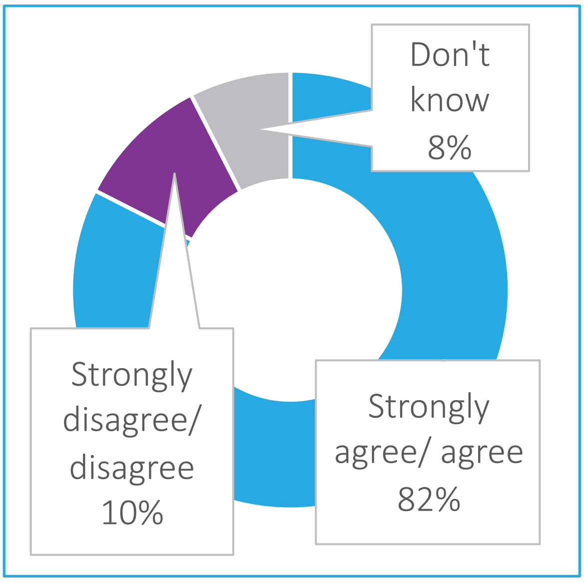
Of the five people who chose from a list, two selected the local authority, one chose a third sector provider organisation, one chose an individual person, and one was unsure who they chose. Of the two people who said that they were not given a choice and the seven who were unsure, none provided details of who manages their budget.

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

Adequate Support

We asked survey participants to respond to the statement "Enough budget to meet my outcomes makes Self-directed Support easier for me". Of the 40 blind and partially sighted people who responded, 33 (82%) either strongly agreed or agreed, while four people (10%) disagreed or strongly disagreed. Three people (8%) were unsure.

Chart 21: "Enough budget to meet my outcomes makes SDS easier for me"



Several blind and partially sighted interviewees and focus group participants spoke warmly of the contrast between earlier, more rigid arrangements for social care support and SDS. For example, one person was "originally sent [...] to a day centre, which wasn't really designed for someone with a visual impairment; I stared there all day doing nothing" – but that since the implementation of SDS they had much more control and independence.

One participant reflected that they wanted to access SDS, but when they requested a review they were informed that "you're a category 4". When the respondent asked for further information on what the categories meant, 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 try to put us off basically" and assumed family or friends would be able and willing to provide unpaid care.

Another participant also 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?"*

One person spoke about how they accessed SDS but had been offered very limited information about their budget. When their hours were reduced recently by 40% the lack of paperwork meant that 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. […] I feel that […] people who say they are blind are not getting support that they need because there are too many excuses."*

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 and budget have not manifested during the time they have accessed SDS:

> *"I've never seen [the full hours of support] in five years […] even though it has been awarded and it's been approved and all the paperwork has been done."*

Several people spoke in detail about the impact on their physical and mental health of substantial reductions to their SDS budgets and support – particularly around support for social engagement. Several people 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 or outcomes. Focus group participants discussed their experiences as follows:

> *Respondent 1: I just feel it is off-putting [to use a gym without support] because you are going and you can't see on the treadmill and you are trying to set it and things and I find it difficult. And you're trying to concentrate and your eyes are wobbling everywhere and you end up pressing wrong buttons and you think, 'you know what this is just too much hassle.' And I used to love years ago going and doing like, you know, the kettle bells and just the weights and things – and now you can't see the size of the weights and picking up something that is far too heavy and that's not the right size. You need to take somebody along who is sighted just to help you, you know.*
>
> *Respondent 2: I think a lot of people that are visually impaired miss out on this and it should be an enjoyment.*
>
> *Respondent 3: I used to. I loved the gym. I did it with […] someone from [specific local authority] and she would take me to the gym, and I loved it. But then that […] stopped.*
>
> *Respondent 4: Then when you went back to the gym and they said if she wants assistance £12 per time. That's somebody from there. […] And no disrespect, [but] I've seen kids come in with learning difficulties and they're one to one – somebody takes them round. And I think, "why are they treated any differently to someone who can't see?" You know, no disrespect, I*

> *know they are entitled to get help and they've got other difficulties.*
>
> *Respondent 2: The difference though is people forget that if you're blind you're more familiar with your own home. You know where your chairs are because you placed them there yourself. […] I don't even think they have a clue regarding visual impairment. The thing is if you are familiar, they say "oh you're really good around the house, you know where you are going". No, it's because it is familiar. […] People don't understand that when you are out and about you still need to get support.*

Finally, some blind and partially sighted respondents raised queries about unequal provision of support – within social work and the third sector alike – for people who experienced sight loss later in life compared to people who were blind or partially sighted since birth or childhood, and encouraged greater support for the latter group. One participant summarised this perspective as follows:

> *"Everything seems to be aimed at elderly people losing their sight rather than people who are born visually impaired. That is why it is all about sight loss."*

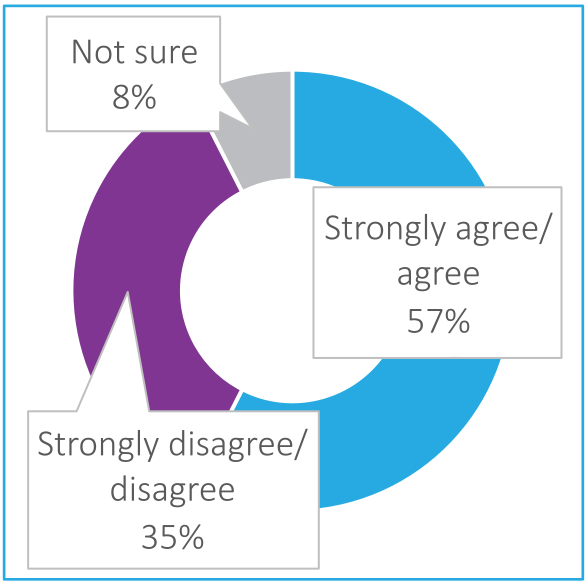
Adequate Support: The research demonstrates the importance of good quality, adequate, person centred support for blind and partially sighted people. It plays an important role in helping people enjoy their right to independent living and equal participation in society and can be instrumental in maintaining and improving health, wellbeing and quality of life. Any proposed changes (particularly reductions) in budgets should be communicated clearly to – and discussed with – blind and partially sighted people well in advance. Increases in support should be introduced in a timely fashion. Social care professionals should consider the impact on people's mental and physical health when changing packages and eligibility criteria and be able to arrange reassessments and signpost support services where needed. It is vital that all blind and partially sighted people are treated with equality, irrespective of when sight loss occurs.

Flexibility

Many blind and partially sighted 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 40 blind and partially sighted people who answered this question, 23 people (57%) strongly agreed or agreed with that statement, while 14 (35%) disagreed or strongly disagreed. A further three people (8%) stated that they were unsure.

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



Blind and partially sighted interviewees and focus group participants expanded on this theme. Some 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.

Flexibility: The research suggests that some blind and partially sighted people are not able to use SDS as flexibly as they should, which can negatively impact on quality of life and enjoyment of their right 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.

Travel Costs

Travel costs – for blind and partially sighted people, personal assistants and care staff – were 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. Blind and partially sighted 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].”*

This interviewee’s and other respondents’ reservations about public transport is also connected to variable and sometimes poor service provision – both in terms of frequency and travel staff training around accessibility. One 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.”*

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

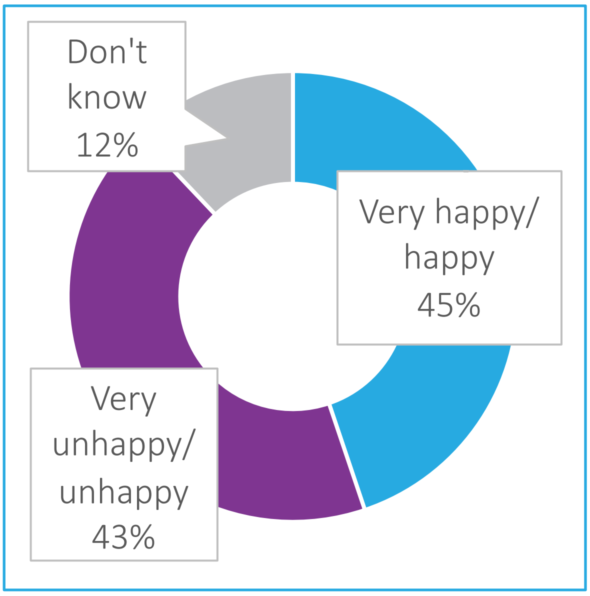
Communication and Relationships with Social Work

Good Conversations and Consistent Relationships

The importance of productive conversations in arranging appropriate social care support was highlighted explicitly in the 2019 Care Inspectorate thematic review of SDS.[21] As such, we asked survey respondents to rate how happy they were with the conversations they had about their support with the professionals with whom they spoke (e.g. social workers/ social work assistants, occupational therapists), on a scale of one to five.

Of the 58 blind and partially sighted people who answered this question, 26 people (45%) were either "happy" or "very happy" with their conversations with social work professionals, seven respondents (12%) didn't know, and 25 people (43%) were either "very unhappy" or "unhappy".

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



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 comments about blind and partially sighted people's positive experiences of conversations with social workers are as follows:

> *"A feeling of mutual trust and respect."*

> *"I need communication support and this was available."*

> *"Care and attention taken over my wishes and requirements."*

> *"My concerns were listened to and very helpful results were given by friendly, caring people."*

> *"[Social worker's name] is a great communicator and has not rested until a good outcome has been achieved."*

> *"Supportive tone of professional helped [me] to feel comfortable discussing my care needs."*

> *"Feeling that I was being listened to, knowing that the support worker wanted what was best for me."*

> *"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."*

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

Many blind and partially sighted 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 also reflected on positive experiences during their needs assessments. One person reflected that their social worker encouraged them to think about future planning during their review, which was key to the successful implementation of their SDS package:

> *"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 than to increase the time available.' […] It was very satisfactory from our point of view."*

Other people commented that in addition to carrying out assessments their social workers signposted them to local community groups centred on supporting blind and partially sighted people, as well as counselling and befriending services. These suggestions – even when the individual chose not to use all of them – were viewed positively and as part of a constructive relationship.

Some blind and partially sighted people reflected that they no longer had a consistent social worker – but when in the past they'd had a named person to contact, this had made accessing and adjusting social care easier. Two focus group participants also discussed wider patterns of consistent support (no longer current practice in their local authority at the time of speaking with them):

> *Respondent 1: Certainly, growing up every blind person or partially sighted person would automatically get a visit from a welfare officer […] every year regardless of whether you needed it or not.*

> *Respondent 2: That's right, to update your details. They used to visit you at the house to make sure you had all the equipment you need or whatever and going into education or anything, they were really good.*

Good Conversations and Consistent Relationships: These findings highlight the benefits of good conversations and consistent relationships with social workers, including direct and varied lines of prompt communication. 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. Overall, we would recommend that work to ensure positive conversations and meaningful, consistent engagement with blind and partially sighted people should continue, with ongoing planning to guarantee high quality practice for all those using SDS – especially around clear and accessible communication.

Poor Communication and Relationships

When asked to rate how happy they were with the conversations they had about their support with the professionals with whom they spoke, 25 blind and partially sighted people (43%) were either "very unhappy" or "unhappy". Blind and partially sighted people were less likely to be happy with the conversations they had about their support with professionals compared to MSMC research respondents overall.

Some blind and partially sighted people stated that their social worker did not have enough time or knowledge to meet with them and discuss their needs and questions properly. Others indicated more fraught relationships.

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

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

> *"The social worker has no experience of SDS. She is very good at listening to what we need etc. but doesn't know the first thing about SDS or how it works. Her managers, who we have never met, just dictate stuff to her – some of which seems barely legal."*

> *"Not easy to get my point over for what I needed. Not easy to understand."*

> *"Social worker made us feel like we are 'lucky' for our SDS, they made us feel like thieves. […] Social workers are bullies and intimidating."*

> *"Arrogant social worker, lacking in empathy, never prepared, always late, cancelled a lot. Social worker spoke too fast, didn't check I understood – it was very stressful and too long for me, so I couldn't concentrate. The social worker is always in a hurry."*

> *"Felt she didn't care, wasn't interested, and even though I was in crisis there was no emergency back-up plan available or tried to be."*

Several blind and partially sighted people reported difficulties in obtaining further information from their social worker – and the importance of receiving answers to their questions. Again, future planning was highlighted as a particularly important concern for people experiencing sight loss. Key comments are as follows:

> *"They did not listen to the difficulties I was having, [and] then ignored all correspondence to plan my future."*

> *"Very uninformative, no answers to questions, not very well explained so we still don't know what [SDS] is or how it functions. It also means we can't figure out a suitable care plan so my partner can return to work. Felt very misunderstood with my condition and needs."*

> *"Presently the social worker does not keep in touch and keep me informed with what is happening. I contacted social work over seven weeks ago saying I was in crisis and couldn't cope and nothing has changed. No communication leaves me feeling unimportant and that we don't matter, whilst I'm at my wits end."*

> *I asked for information regarding the agreement, the criteria using family members [as PAs],*

> *and the flexibility regarding how the funding can be used. No information given.”*

> *“When you just find out you’re partially sighted, it’s all new and you’re not really prepared to ask the right questions and you don’t really know what to do. As it gets worse, you don’t really hear from anyone; there’s no follow up.”*

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

One person had not had a review in several years, and then received an email from their social worker stating that they would be carrying out an assessment at the respondent’s home on a specific date. When the respondent replied that that date was not convenient due to another appointment, and that they would prefer to meet in a public place, they were told that they did not have the right to change the time or venue of the review. Furthermore, the respondent informed the social worked that they “would like to take in a person to be with me” they were told that would not be possible. The respondent summarised their position on this issue as follows:

> *“I said ‘it’s my right to take someone in with me.’ And I’m still adamant that I am taking somebody else in with me. I felt that if I took somebody else in with me they could actually sit and listen and that way it was a case of it’s not going to be my word against theirs anymore because there’s a third party, it’s not just a case of me being manipulated.”*

Poor Communication and Relationships: Examples of poor communication, inconsistent relationships, and inflexible processes raise clear concerns about people’s experiences of SDS and their decision making and autonomy; if blind and partially sighted people’s opinions (spoken or written) are not recorded and acknowledged during assessments, then they cannot be said to control or choose their support. These findings highlight the importance not only of good communication and sustained and trusting relationships with social workers, but the need for transparency and access to independent advocacy and support.

Discrimination, Intimidation and Bullying

Some blind and partially sighted 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 important enough to include within this report as examples of poor practice and as part of efforts to improve and ensure high quality care for blind and partially sighted people across Scotland.

One interviewee was blunt 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."

One respondent described 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.

A different 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."*

One person summarised their experience in asking for further detail about their support arrangements 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."*

The person went on to outline a further interaction with their local social work department, when during a period where they were snow-bound their care workers could not access the house, so the participant ran out of food. When they requested emergency assistance they "got laughed at over the phone by the person from [specific local authority]", who stated that "I've got a four-wheel drive; I managed to get out OK" and that the participant should "just get your neighbours to help". When the participant pointed out that they could not reach their neighbour's house due to snow drifts they received no further help or advice.

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

When one blind person requested the appropriate contact details to lodge a complaint, they were not given the appropriate details:

> *"I have to go through the support services manager that I have to get the information 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."*

Discrimination, Intimidation and Bullying: No-one should have to deal with discriminatory, intimidatory or bullying language, attitudes or behaviour from social work professionals, and blind and partially sighted 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 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 proactively 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

Blind and partially sighted 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 worked "was quite happy to agree to some changes".

For many blind or partially sighted people, concerns about transparency of process were often synonymous with problems with accessible information. 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 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."*

Transparency: The research indicates that while there are examples of good practice, this is not consistent across all areas and more work could be done to ensure 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. As demonstrated elsewhere in this report, blind and partially sighted people require timely access to information in a range of accessible formats in order to fully participate in informed decision making about their care and support.

Impact of SDS on Family/Relationships

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

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

Focus group participants discussed this topic in the following exchange:

> *Respondent 1: And a lot of things aren't taken into account. […] I've got my husband, but he's out working full time and I think really their attitude is "well you've got your husband as your carer". But I didn't marry a carer I married the man that I love.*
>
> *Respondent 2: I think [Respondent 3] you were highlighting the*

> *same thing that your wife will do all the support.*
>
> *Respondent 3: Yeah, exactly – "why would you need anybody else, because you've got a wife?" and it really does change the dynamic of a relationship if that is the expectation. You know, suppose my care needs were more intimate I wouldn't want to have my wife helping me with all these sorts of things, you know.*
>
> *Respondent 4: And it is discriminatory in itself […] because men by themselves get supported but if you are a blind person like myself I don't get any support. I don't get anything at all.*

Other blind and partially sighted people recounted problems with accessing SDS as disabled parents. One person summarised their experiences as follows:

> *"I don't think many people I've talked to have had experiences where their position as parent has been considered as well as their position of what you need for you. I think a lot of people who use support services – not everybody, but a lot of people – are elderly, have dementia, or have severe disabilities. A lot of them aren't married with children. And some people just weren't really able to process a disabled woman with a baby."*

While almost all blind and partially sighted research participants 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 blind and partially sighted fathers of young children versus that offered to blind and partially sighted mothers of young children. Of the blind and partially sighted parents we spoke to, only the mothers were offered support with household tasks and childcare as part of their SDS packages; with fathers, it was assumed that their female partners could carry out that work (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."*

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. 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.

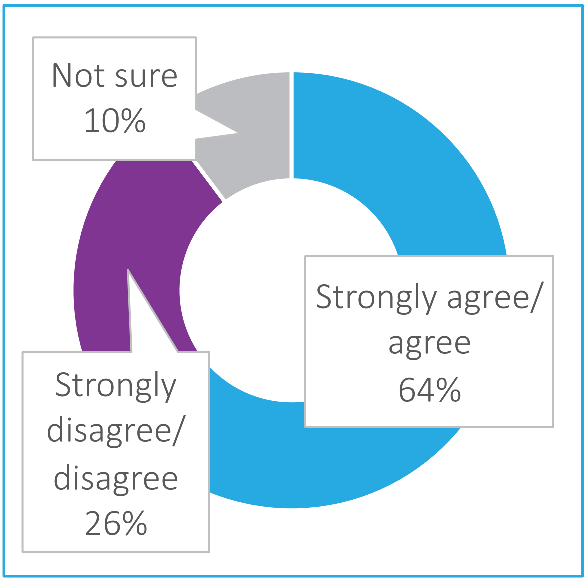
Care Staff Recruitment, Training and Quality

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 39 blind and partially sighted people who answered this question, 25 (64%) either "strongly agreed" or "agreed", while ten people (26%) disagreed or strongly disagreed. A further four people (10%) were unsure.

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



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

One 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."*

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."*

Overall, many MSMC 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 people is PAs 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 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 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.

Care Workers and Risk

Several blind and partially sighted 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 blind research participant 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.[22]

Care Staff Recruitment, Training and Quality: Some blind and partially sighted 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 blind and partially sighted 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 SDD/social care to find ways to improve systems and processes – particularly around difficulties with recruitment, training, and staff retention within the wider social care sector. This support and acknowledgement of variable practice is particularly important when social care and social work professionals are discussing care arrangements with people who have had poor experiences in the past – whether that be difficulties with individual care workers, or as the victims of crime. People have the right to feel safe – particularly in their own homes – and social care workers and professionals across the sector should do all they can to support service users to feel safe, secure, and independent.

Independent Advocacy and Support

Blind and partially sighted research 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.

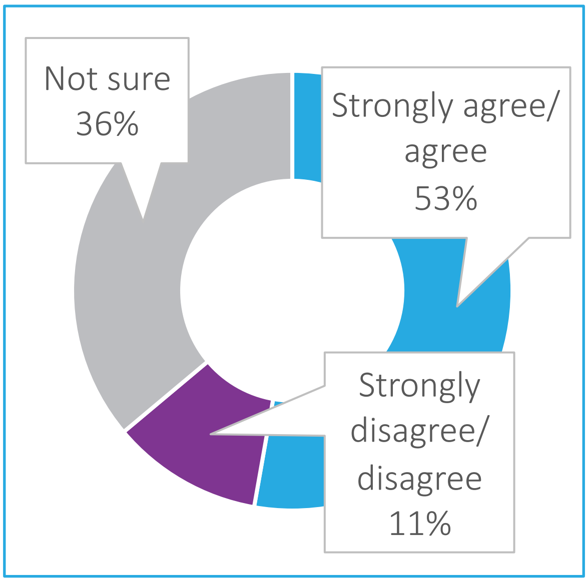
Blind and partially sighted survey respondents spoke positively of the benefits of independent advocacy and independent advice and support organisations. People recommended getting in touch with independent advocacy and independent support and advice organisations as early as possible. Some of their key comments and advice statements are as follows:

> *"Get independent advice and speak to other people who have it."*
>
> *"Go online. Really get to understand it. Use an advocate and get help to cope with the whole process."*
>
> *"Get advocacy support and know what you're entitled to […] with support."*

Independent Advocacy

We asked survey participants to respond to the statement "access to independent advocacy makes SDS easier for me". Of the 36 blind and partially sighted people who answered the question, 19 (53%) "strongly agreed" or "agreed" with that statement, and four people (11%) disagreed or strongly disagreed with that description of independent advocacy. 13 people (36%) said that they were unsure.

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



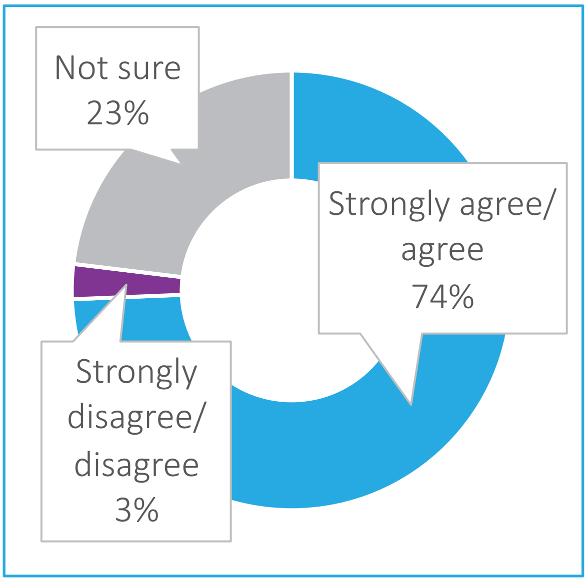
Survey respondents and focus group participants noted that confidentiality and time to build up trust was important to the success of independent advocacy. Several blind and partially sighted people highlighted that they had benefited from the involvement of independent advocacy services during their needs assessment and reviews. One person recommended that people should "speak with others in your area who have gone through the process [and] ask for an advocate." Various forms of advocacy were mentioned, including local user-led service organisations, independent advocacy, solicitors, national legal aid organisations and carers' centres.

Notably, when asked how they had found out or would seek information about independent advocacy organisations, blind and partially sighted interviewees and focus group participants responded that they would carry out their own research – either online, or by calling organisations like Citizens' Advice (for those who were more comfortable with using the phone rather than the Internet). No one stated that they would have asked their social work department for recommendations or expected social workers to signpost them to independent advocacy organisations. Very few blind and partially sighted research respondents had been directed to independent advocacy or independent support and advice organisations by their social work professionals (although those that had been spoke warmly in praise of both their social workers and the support offered by the relevant organisations).

Independent Advice and Support

When asked whether access to independent information and support made SDS easier for them, blind and partially sighted survey people responded positively. 29 people "strongly agreed" or "agreed" with that statement (74%), and only one person (3%) "strongly disagreed" with that description of independent support organisations. A further nine people (23%) said that they were unsure.

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



Survey respondents, focus group participants, and interviewees all commented on the value of independent advice and support in accessing SDS. Several blind and partially sighted people highlighted that they had benefited from the involvement of independent advice and support services during their needs assessment and reviews.

Peer Support

Several blind and partially sighted 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.

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

Endnotes

1 To support readability, the ‘N’ number is not reported for all survey question responses.

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

3 Throughout MSMC we have used “Black and minority ethnic people”. While the project partners are aware that this is a potentially contested term, the interviewees and focus group participants contributing to the research project most commonly self-described their ethnicity as “white”, “Black”, “minority ethnic” or “Black or minority ethnic”; as such, we have followed their preferred terminology. Where participants refer to the experiences of specific groups, we have kept those references unique.

4 Royal National Institute of Blind People (RNIB), Sight Loss Data Tool (2020). Available at: https://www.rnib.org.uk/professionals/knowledge-and-research-hub/key-information-and-statistics/sight-loss-data-tool.

5 Royal Blind and Scottish Care, Self-directed Support Research: Survey Report (2019). Available at: https://www.royalblind.org/node/36278.

6 ISD Scotland, Insights into Social Care in Scotland: Support provided or funded by health and social care partnerships in Scotland 2017/2018 (11 June 2019). Available at: https://beta.isdscotland.org/find-publications-and-data/health-and-social-care/social-and-community-care/insights-in-social-care-statistics-for-scotland/.

7 ISD National Services Scotland, Social Care Information Dashboard. Available at: https://scotland.shinyapps.io/nhs-social-care/ (‘ISD dashboard’).

8 ISD Scotland, Social Care Information Dashboard. Available at: https://scotland.shinyapps.io/nhs-social-care/ (ISD dashboard).

9 2011 Scottish Census, Ethnicity, Identity, Language and Religion (2011). Available at: https://www.scotlandscensus.gov.uk/ethnicity-identity-language-and-religion.

10 ISD dashboard.

11 Ibid.

12 Ibid.

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

14 Ibid., p. 1.

15 Ibid., p. 12.

16 RNIB, Understanding Society: comparing the circumstances of people with sight loss to the UK population (2019), p. 2. Available at: https://www.rnib.org.uk/professionals/knowledge-and-research-hub/research-reports/general-research/understanding-society.

17 ISD dashboard.

18 ISD Scotland, Insights into Social Care in Scotland: Support provided or funded by health and social care partnerships in Scotland 2017/2018 (11 June 2019).

19 Ibid., pp. 6, 48-60.

20

21 Care Inspectorate, Thematic review of self-directed support in Scotland: Transforming lives (2019). Available at: https://www.careinspectorate.com/images/documents/5139/Thematic%20review%20of%20self-directed%20support%20in%20Scotland%20June%202019.pdf.

22 See ‘Outstanding Concerns and Appeals’.

Glossary

Budget / Hours / Package

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

Charging Policy

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

COSLA

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

Direct Payment

See “Option 1”.

Disability

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

Eligibility Criteria

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

Guardian

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

Health and Social Care Partnership / HSCP

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

Independent Advocacy Service / Independent Advocate

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

Independent Living

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

Independent Living Fund / ILF

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

Independent Support Organisation

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

Integration Joint Board / IJB

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

Impairment

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

Local Authority / LA

Local council (32 across Scotland). Key local authorities likely to be mentioned in MSMC interviews are Dumfries and Galloway, Fife, Glasgow City, Highland, Moray, North Lanarkshire, Scottish Borders, South Lanarkshire and Stirling.

Needs Assessment

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

Option 1 (also called “direct payment”)

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

Option 2

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

Option 3

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

Option 4

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

Occupational Therapist / OT

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

Personal Assistant / PA / Support Worker

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

Personalisation

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

Physical Impairment / Physical Disability

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

Reablement

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

Respite

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

Self-directed Support / SDS

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

Sleepovers

The provision of care and support services overnight.

Social Care

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

Support Plan

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

Support Worker

See Personal Assistant / PA.

Unpaid Carer

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

About the Project Partners

ALLIANCE
HEALTH AND SOCIAL CARE
ALLIANCE SCOTLAND
people at the centre

About the ALLIANCE

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

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

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

The ALLIANCE has three core aims; we seek to:

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

Self Directed Support Scotland
the organisation of choice

About Self Directed Support Scotland

Self Directed Support Scotland represents organisations run by and for disabled people, our members support over 31,000 people across Scotland with their social care choices. Together we work to ensure that SDS is implemented successfully so that people have full choice and control over their lives. We do this by:

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

The ALLIANCE

Phone: 0141 404 0231

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

Twitter: **@ALLIANCEScot**

Website:
www.alliance-scotland.org.uk

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

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

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

Registered in Scotland No.307731.
Charity number SC037475.

Self Directed Support Scotland

Phone: 0131 475 2623

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

Twitter: **@SDSScot**

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

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

SDSS is supported by a grant from the Scottish Government.

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

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

Self Directed
Support Scotland
the organisation of choice

ALLIANCE
HEALTH AND SOCIAL CARE
ALLIANCE SCOTLAND
people at the centre