My Support My Choice:

People's Experiences of Self-directed Support and Social Care in Glasgow

August 2021

Self Directed Support Scotland
the organisation of choice

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people at the centre

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Acknowledgements and Dedication

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

About this Report

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

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

COVID-19

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

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

Executive Summary

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

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

Between November 2018 and February 2020, MSMC heard from 52 people in Glasgow who received SDS (or had been assessed in the previous 12 months) via a survey and interviews. Research took place prior to the appearance COVID-19 in Scotland. Overall, MSMC heard from 637 people across Scotland via a survey, interviews and focus groups. As the largest direct national consultation of its kind to date, the national report provides vital evidence, analysis and recommendations for improvement to SDS/ social care in the aftermath of the pandemic, based on people's experiences. This report provides analysis of the results from Glasgow within that larger context.

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

Poverty and SDS

An estimated 24% of Scottish households with a disabled person live in relative poverty after housing costs. MSMC found that 86% of research respondents in Glasgow who provided income data lived below the poverty threshold. National and local public bodies should take action to ensure that reductions in SDS budgets and tightened eligibility criteria do not negatively impact people on low incomes who access or are trying to access social care, given that they can lead to people having to manage without support, deteriorating physical and mental health, and demands on family and friends to assume roles as unpaid carers.

Data Gathering and Analysis

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

Overall Experiences of SDS

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

Information About SDS

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

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

This pattern of variable information about the four options continued into people's needs assessments. A minority of people in Glasgow reported that they had "all four options" discussed with them during their assessments. Most people reported that they did not have all their questions answered during their needs assessments.

Just under half of the respondents in Glasgow indicated that they had received information about how much money they could spend on their care and support. However, the same proportion had not received that information, while the remainder were unsure.

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

Informed Choice and Control

Overall, most participants in Glasgow felt they had not had enough time to choose their SDS option. People reported variable wait times for assessments and those who waited the longest also generally reported the highest levels of stress and difficulty in accessing SDS.

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

Similarly, while it is positive that half of the respondents in Glasgow were offered the choice of who would manage their personal budget, it is concerning that just over a quarter reported being offered no choice, and a further fifth were unsure; this also demonstrates that, amongst other things, they were not fully offered all four SDS options.

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

Budgets and waiting times were prevailing themes when respondents in Glasgow discussed ongoing concerns with their needs assessments. Reductions to budgets and support has significant negative impacts on people's mental and physical health. Any proposed reductions in SDS budgets or support should be communicated clearly and discussed with people well in advance of any changes being introduced. Health and social care staff should consider the possibility of isolation or mental health crisis when changing packages and eligibility criteria and be able to arrange reassessments and signpost support services where needed.

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

Communication and Relationships with Social Work

Participants in Glasgow highlighted that good, consistent, trusting relationships with social workers and clear lines of communication are all essential for positive and effective experiences of SDS. A minority of participants reported positive and favourable experiences of assessments and reviews with professionals, providing a range of good practice examples. However, many people outlined concerns about their conversations with social work professionals, including about not receiving full answers to questions raised during assessments and a lack of information about SDS. Some participants shared troubling stories of being treated with disrespect by professionals.

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

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

Care Staff Recruitment, Training and Quality

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

Independent Advocacy and Support

Respondents in Glasgow indicated that they value and benefit from the provision of independent advocacy, independent advice and support services, which need sustainable resourcing to continue their important role. Focused efforts are required to ensure all people are aware of – and can access – independent advocacy and support services. Local peer networks should also be encouraged and supported. Glasgow Centre for Inclusive Living (GCIL) and the Glasgow Disability Alliance (GDA) were mentioned several times as helpful in supporting people to navigate and access SDS.

Recommendations

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

Poverty and SDS

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

Data Gathering and Analysis

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

Information About SDS

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

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

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

6. People should be provided with timelines for each stage of the process for accessing SDS, and transparency about where and when decisions about support are made. Transparency would be improved by sharing more publicly available information in accessible formats.

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

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

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

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

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

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

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

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

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

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

16. Any proposed changes (particularly increases) in care charges should be communicated clearly to - and discussed with - people who access SDS/ social care well in advance of the changes being introduced.

Informed Choice and Control

17. Systems could be improved to guarantee short waiting times – for a needs assessment, review, or for support to be put in place – to help people avoid unnecessary stress and anxiety, and deteriorations in their physical and mental health and wellbeing.

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

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

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

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

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

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

Communication and Relationships with Social Work

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

25. Social workers need to have the time and skills to build relationships and trust with the people accessing SDS and unpaid carers that they are working with.

26. People's opinions (spoken or written) should be recorded and acknowledged during needs assessments and review meetings to demonstrate the level of choice and control exercised over their support.

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

28. 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).

29. 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.

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

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

32. 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.

33. We encourage Glasgow City Council to indicate document publication dates and webpage timestamps. The Council's website could also provide further information on their Equality Impact Assessments and the role these play in SDS/ social care decision making. To strengthen participatory decision making, Glasgow City Council could set out the steps taken to involve people who use support, unpaid carers, and partner organisations in the development of eligibility criteria and the delivery of support. Further details of other engagement with

people with lived experience would support greater transparency.

Care Staff, Recruitment, Training and Quality

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

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

Independent Advocacy and Support

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

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

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

39. Local peer networks should be encouraged and supported.

National and Local Context for SDS/ Social Care

National Context

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

Local Context

Glasgow is the largest city in Scotland, with an approximate population of 626,000 people across over 290,000 households.[8] It is the centre of the "Greater Glasgow" conurbation and is a predominantly urban area, situated to the west of the central belt, with Dunbartonshire to the north, Renfrewshire to the west and south, and Lanarkshire to the south and east. In 2020, Glasgow contained the second highest percentage of areas of deprivation in Scotland, after Inverclyde (although it also saw the largest percentile decrease in deprivation of any local authority in Scotland between SIMD 2016 and SIMD 2020).[9]

Glasgow City Council publishes a range of information for people who access or wish to access SDS on their website (searchable via the search bar on the council website). The relevant page is titled "Personalisation" rather than SDS, with a subtitle "What is Personalisation/Self-directed Support?".[10] This provides people with a definition of SDS, and states that people can manage an SDS budget themselves or let the Council do so on their behalf. Glasgow also published information for unpaid carers, including in a range of languages (Arabic, Mandarin, Polish, Romanian, and Urdu).[11] We welcome the multilingual publication of information for carers – which is unusual in Scottish local authority websites – as an example of good practice.

At time of writing, to obtain more information on how to access SDS, and the eligibility criteria, people are invited to call the Social Care Direct phone number (an 0141 number). There is no option to call a freephone number, which would enable people from low-income households to call without being charged. This consideration is particularly important given the number of people in Glasgow – and respondents to MSMC specifically – who live below the poverty line.

The webpage details the assessment steps and associated paperwork. According to respondents to MSMC, the eligibility criteria used in Glasgow provides support to those people who are at the greatest risk of harm if they are not given support; people assessed as being at "critical" or "substantial" risk. Support is not provided via SDS to people who are assessed as being at a "moderate" or "low" risk levels.

A further search on Glasgow City Council's website for "direct payment" offers more details on Option 1.[12] Information includes a description of Option 1, how it can be used and managed, who is eligible for direct payments, and what records are required from people using Option 1. There is also a link to the Glasgow Centre for Inclusive Living (GCIL), under "Related Links".

We would encourage Glasgow to publish more information on the four individual options and outline their eligibility criteria online. We would also recommend that the Council webpages on SDS could usefully include direct links to independent support and advice organisations and independent advocacy, as well as other resources for people who are not deemed eligible for SDS.

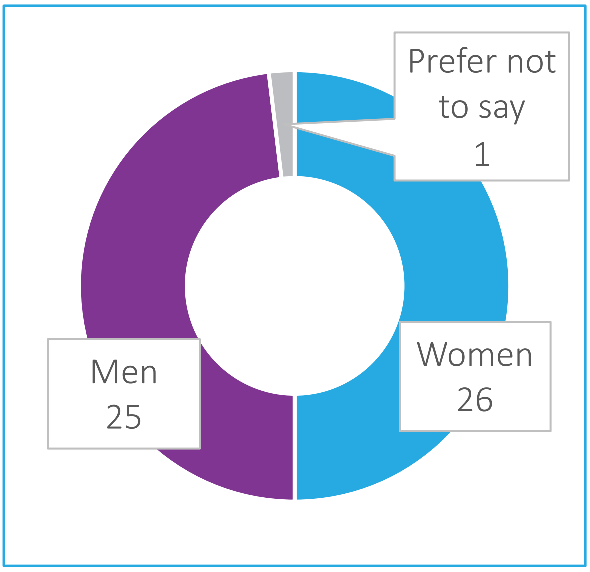
We also recommend that Glasgow City Council indicates document publication dates and webpage timestamps. The Council's website could also provide further information on their Equality Impact Assessments and the role these play in SDS/ social care decision making. Finally, to strengthen participatory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

Research Participants

MSMC heard about the experiences of 52 people who use or were being assessed for SDS in Glasgow. We interviewed 11 people who spoke about their own experiences and the experiences of other members of their household who use SDS (spanning the experience of a total of 12 people who use SDS or who were being assessed for SDS). A further 40 people from Glasgow completed the survey. Throughout this report some participant details (e.g. age) have been changed slightly to preserve anonymity, while maintaining the most important information. Where changes have been made to quotations those alterations are indicated via square brackets (e.g. "My advocate, [Name], was great").

Where possible, we have compared our participant data to local data and figures from Public Health Scotland's (PHS, formerly Information Services Division) 2017-2018 experimental statistics on social care in Scotland.[13] While not comprehensive, PHS have demographic statistics on people using SDS, and accessing social care support services more generally, that is provided by local authorities, including Glasgow. PHS include people who use SDS within their wider discussions of people receiving "social care support", but also include care home residents and people who use community alarms and telecare services (with or without SDS) in that wider definition.

Chart 1: Respondents' gender



Gender

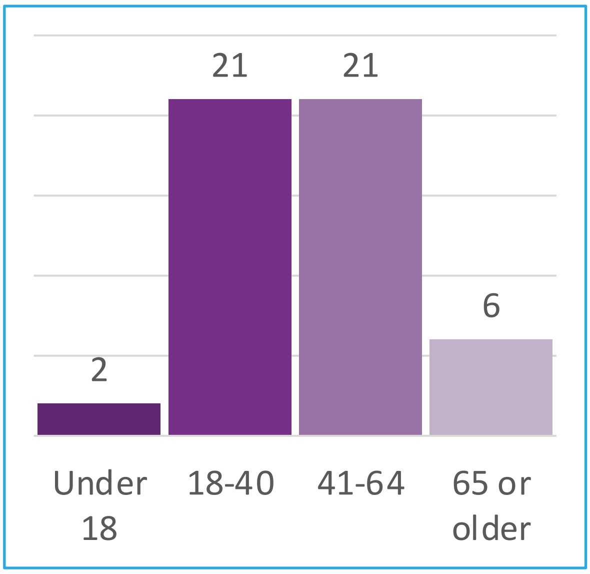
Overall, 26 women (50% of respondents) and 25 men (48% of respondents) participated in MSMC in Glasgow. One person (2%) preferred not to disclose their gender.

PHS figures are not available for the division of men and women receiving social care support services in Glasgow in 2017-2018, as Glasgow City HSCP did not submit disaggregated data across the 19,329 people they supported during that period (which also affects analysis of other protected characteristics for people accessing social care services in Glasgow).[14] Nationally, PHS report that in 2017-2018 38% of people accessing social care support were men and 62% were women (of whom, combined, an estimated 45% access SDS).[15]

Age

We asked all participants to share their age. Of the 50 people who chose to answer the question, two (4%) were under 18 years old, 21 (42%) were between 18 and 40 years old, 21 (42%) were between 41 and 64 years old, and six (12%) were 65 years or older.[16]

Chart 2: Respondents' age



PHS figures on the ages of people receiving social care support in Glasgow are not available for 2017-2018, as Glasgow City HSCP did not submit disaggregated data for that period.[17] In 2016, 62% of the population of Glasgow was under 45 years old (higher than the Scottish average of 53.5%), with the average age expected to increase. The 65 to 74 age group is projected to see the largest percentage increase between 2016 and 2026 (+24.4%).[18] The overall spread of MSMC respondents is slightly younger than 2011 Scottish Census data for Glasgow.[19]

Ethnicity

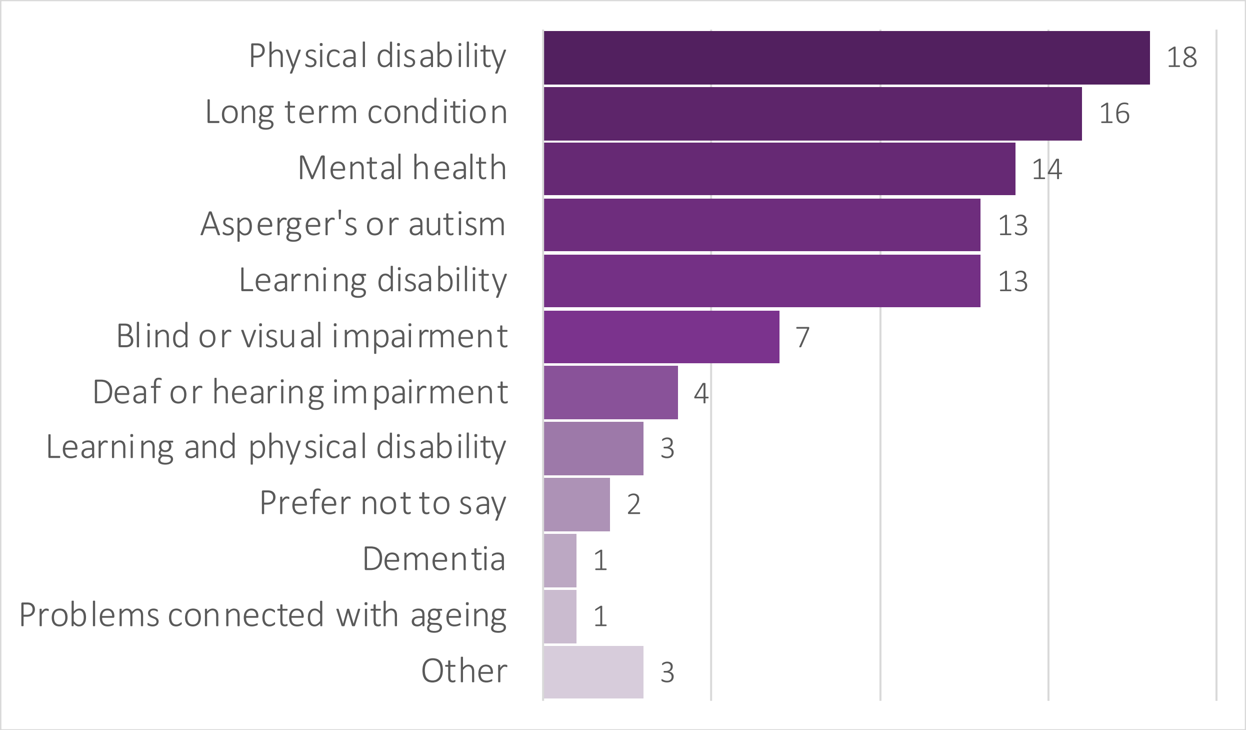
37 MSMC survey respondents in Glasgow identified as white, one survey respondent identified as "Asian, Asian Scottish, or Asian British", and one as "Mixed or multiple ethnic groups". One person chose not to describe their ethnicity. Most interviewees did not disclose their ethnicity when self-describing themselves, and the majority of those that did described themselves as "white".

The 2011 Scottish Census indicated that 82.7% of the population of Glasgow identified as "White: Scottish" (78.6%) or "White: Other British"

(4.1%), with a further 5.7% selecting “White: Irish” (1.9%), “White: Polish” (1.4%), or “White: Other” (2.4%). The remaining people identified as being part of minority ethnic groups: 8.1% of the population identified as “Asian”, “Scottish Asian”, or “British Asian”, and 3.5% as belonging to “other ethnic groups”. The overall spread of MSMC respondents is slightly less ethnically diverse than 2011 Scottish Census data for Glasgow.[20]

PHS figures on the ethnicity of people receiving social care support in Glasgow are not available for 2017-2018, as Glasgow City HSCP did not submit disaggregated data for that period.[21]

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



Client Group/Disability/ Long Term Condition

MSMC survey respondents in Glasgow self-identified as living with a range of conditions, with the majority reporting that they were living with multiple conditions. Of the 38 people who provided further details, 18 (47%) selected physical disability, 16 (42%) said they live with a long term condition, and 14 (37%) selected “mental health.”

Interviewees also discussed their conditions, and – if they were unpaid carers – those of the people for whom they care. Their reasons for accessing SDS were broadly in keeping with survey respondents’. Of the 12 people whose experiences of SDS we heard about during interviews, 11 accessed SDS because of their own conditions, and one person had found that there were no suitable support services available in their area, so had ended the process.

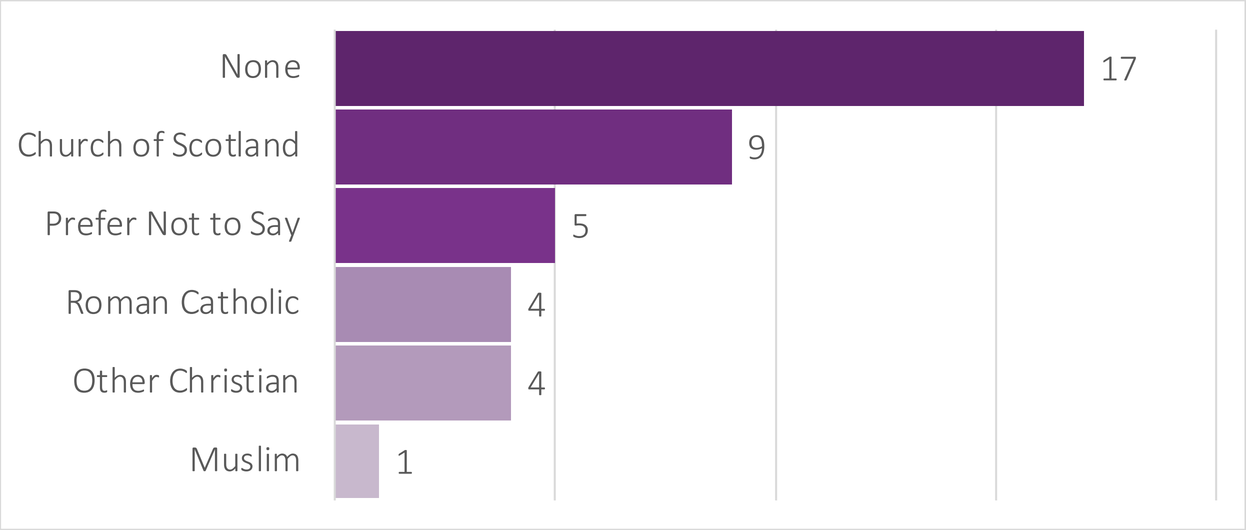
PHS figures on the client groups of people receiving social care support in Glasgow are not available for 2017-2018, as Glasgow City HSCP did not submit disaggregated data for that period.[22]

Religion

When asked about their religion (if any), 17 survey respondents (43%) stated “none”, nine were part of the Church of Scotland (23%), four were Roman Catholic (10%), four described themselves as “other Christian” (10%), and one was Muslim (3%). Five people (13%) preferred not to answer.

Most of the interviewees did not choose to explicitly disclose their religion when self-describing themselves. The overall spread of MSMC respondents is slightly less religiously diverse than 2011 Scottish Census data for Glasgow.[23] Data about people’s religion is not available on the PHS dashboard.

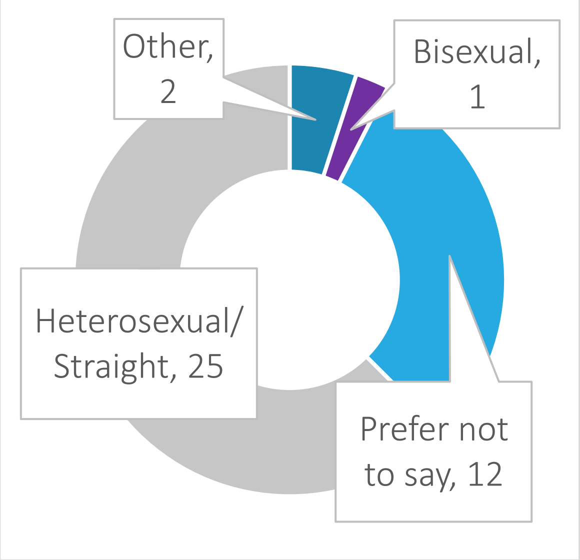
Chart 4: Survey respondents’ religion



Sexual Orientation

25 survey respondents described their sexual orientation as heterosexual or straight, two people selected “other”, and one person was bisexual. A further 12 people preferred not to disclose their sexual orientation. The 2011 Scottish Census did not record data on sexual orientation at local authority level (although the 2022 Scottish Census is expected to do so); as such, we do not have local statistics on sexual orientation available as a comparison. Data on people’s sexual orientation is not available on the PHS dashboard.

Chart 5: Survey respondents’ sexual orientation



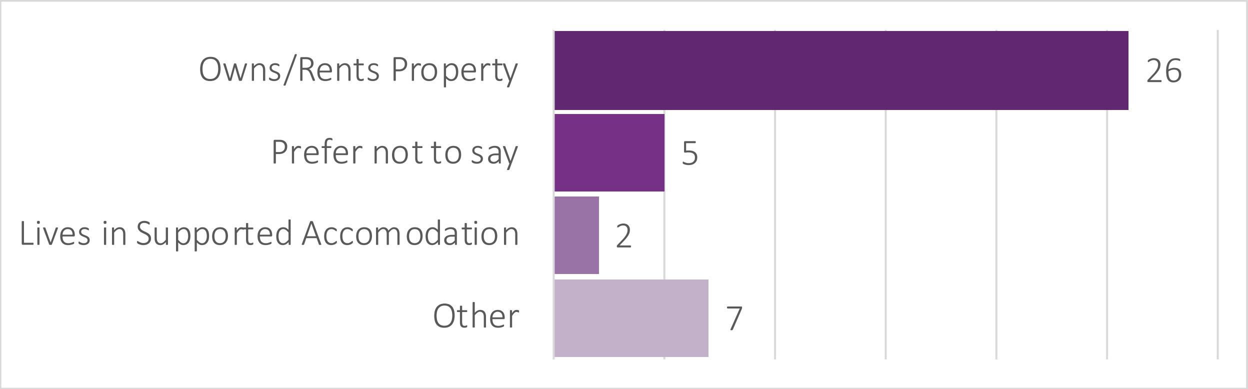
Housing

26 survey respondents (65%) either rented or owned their own home, five people (13%) reported

that they lived in the home of a family member, two (1%) lived in supported accommodation, one stated that they live in a "council house", and one person described their living situation as "homeless living with a friend". Five people selected "prefer not to say" (13%).

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

Chart 6: Survey respondents' housing arrangements

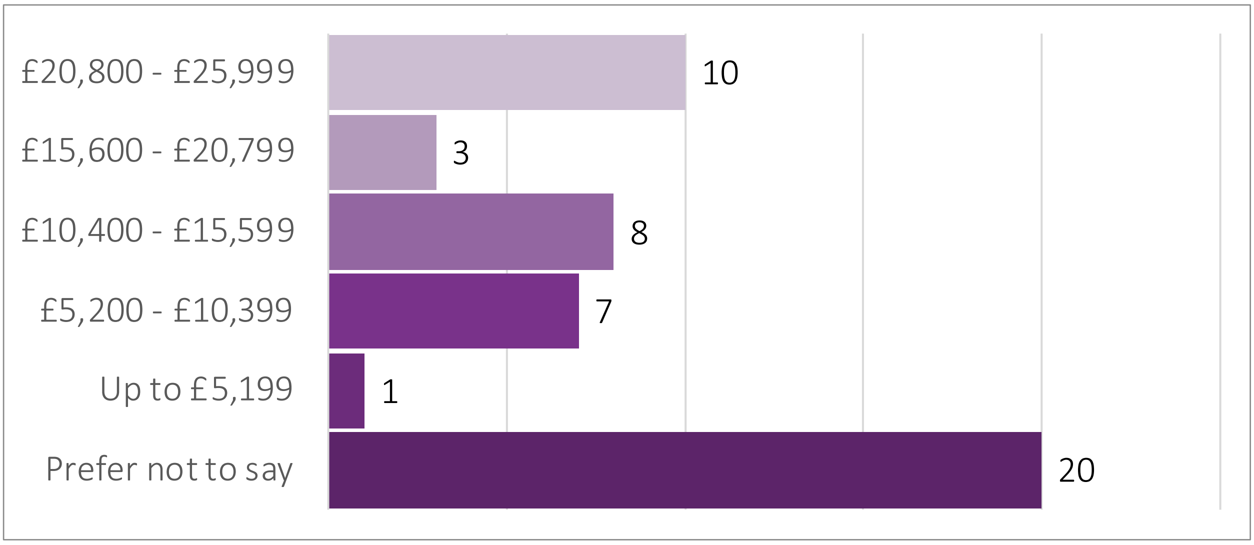


Household Income

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

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

Chart 7: Survey respondents' annual household income



According to Scottish Government data, the median housing income in Scotland in 2015-2018, before housing costs, was £499 per week (£25,948 per annum).[25] 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).[26] Based on this definition, 16 (86%) of the respondents in Glasgow who chose to provide details of their household income are living below the poverty threshold. Data on the household incomes of people accessing SDS is not available on the PHS dashboard.

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

SDS Option

Of the 34 participants in Glasgow who shared which SDS option they used, 16 people (47%) indicated they used Option 1, eight people (24%) used Option 2, four people (12%) used Option 3, and three people (9%) used Option 4. Three people (9%) stated that they did not know what option they used.

Figures from PHS indicate that in 2017-18 there were 648 people in Glasgow using SDS Option 1, 1,1553 using Option 2, 1,597 using Option 3, and no data was available on people Option 4.[27] In some instances, people are logged as being on two options simultaneously (e.g. Options 1 and 3) rather than Option 4, which distorts these figures.

Data Gathering and Analysis

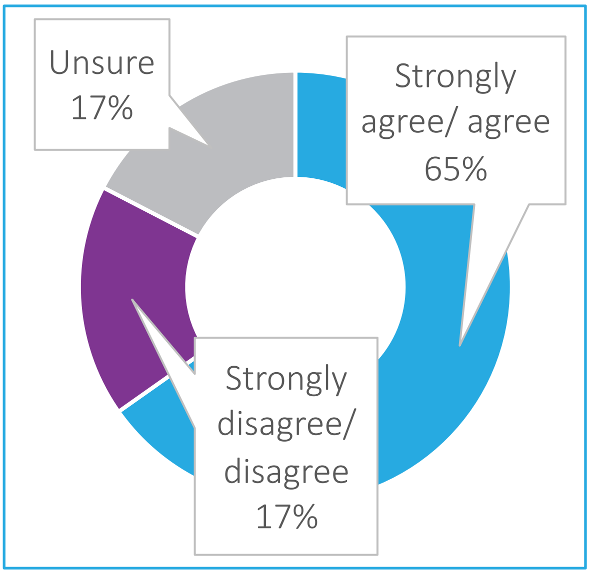
As the chapter on research participants demonstrates, there are concerning gaps in SDS data gathering, analysis and reporting across Scotland. PHS have reflected on difficulties gathering disaggregated data on people's use of and experiences of SDS/ social care in their experimental statistics publication Insights into Social Care in Scotland.[28] 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 in 2017-2018 (including Glasgow).[29] Data gaps are also in part due to existing patterns of data collation – leading, for example, to the PHS Social Care Information Dashboard tracking ethnicity via the limited and problematic categories of "White", "Other", and "Not provided/ Not known".[30]

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

Overall Experiences of SDS and Social Care

We asked survey respondents in Glasgow whether they felt that SDS had improved their social care experience. Of the 23 people who answered this question, 15 (65%) stated that they "strongly agree" or "agree" with the statement "SDS would/has improve/d my social care experience". Four people (17%) strongly disagreed or disagreed, and four (17%) were unsure.

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



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

> *"Go for it! Make sure that a social worker is in place early."*
>
> *"Learn all you can, never think you can't do it. […] Think of all the aspects of care you will need not only now but in the future and secure it in your funding from the start. […] It isn't all plain sailing and sometimes a struggle, but the best thing in my life I have ever done."*
>
> *"Do it. But be determined and stick firm to what you really do need."*
>
> *"I think it's worth trying. But be prepared for it to take time and energy."*
>
> *"If it doesn't work out there's no shame in that; you come back and try one of the other options. Things change over time as well. I'd say give it a go and try and get the balance between having a vision about what you would actually like, in line with the reality of what you might actually be able to do."*
>
> *"I appreciate the people that help me, in social work and in Glasgow Centre for Inclusive Living."*

One interviewee spoke eloquently of the positive impact SDS had had for their adult child, enabling them to have more independence and choice:

> *"[Name] has complete freedom and my whole plan was for [them] to have freedom in every aspect of [their] life, what with [Name] being an adult and having a right to decide things."*

Another interviewee reflected that SDS provided them with both independence and a safety net if their health deteriorates:

> *“I’m independent given that I’ve got help. […] It gives me a level of confidence. […] Now, I’ve got no plans for this, but say the day came that I did have a fall or something, the SDS [care workers] would be coming in anyway, and of course they’re at the end of the telephone. So is 999, but it would be nice to avoid that!”*

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

> *“[Have] a good filing system! It sounds really quite simple, but I’m aware that I brought my professional, my working experience to doing this, and knowing how to write letters and file things, and how to keep everything in order has helped enormously – and it’s not something that you get lessons in.”*

> *“Make sure all your needs and not just hours of support are all recorded in the care/support plan, as you may be left to self-fund your care needs that are not recorded.”*

> *“Be sure that you have all the relevant information about what [you] are entitled to and don’t just accept what you’re offered without sitting down and getting a support plan organised, options offered and explained, and copies of any minutes relating to the person requiring care.”*

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

> *“It’s not worth the bother.”*

Some interviewees highlighted that while SDS had previously enabled them to live a full and independent life, cuts to their care had limited their ability to fully participate in their local communities. One person summarised their situation as follows:

> *“I’ve got not enough hours to do what you got to do. Because SDS is supposed to be a tool that allows you do what you want to do. And if you’ve got not enough hours to do that, you can’t do that. Doing what you want to do doesn’t just include getting up in the morning and getting fed.”*

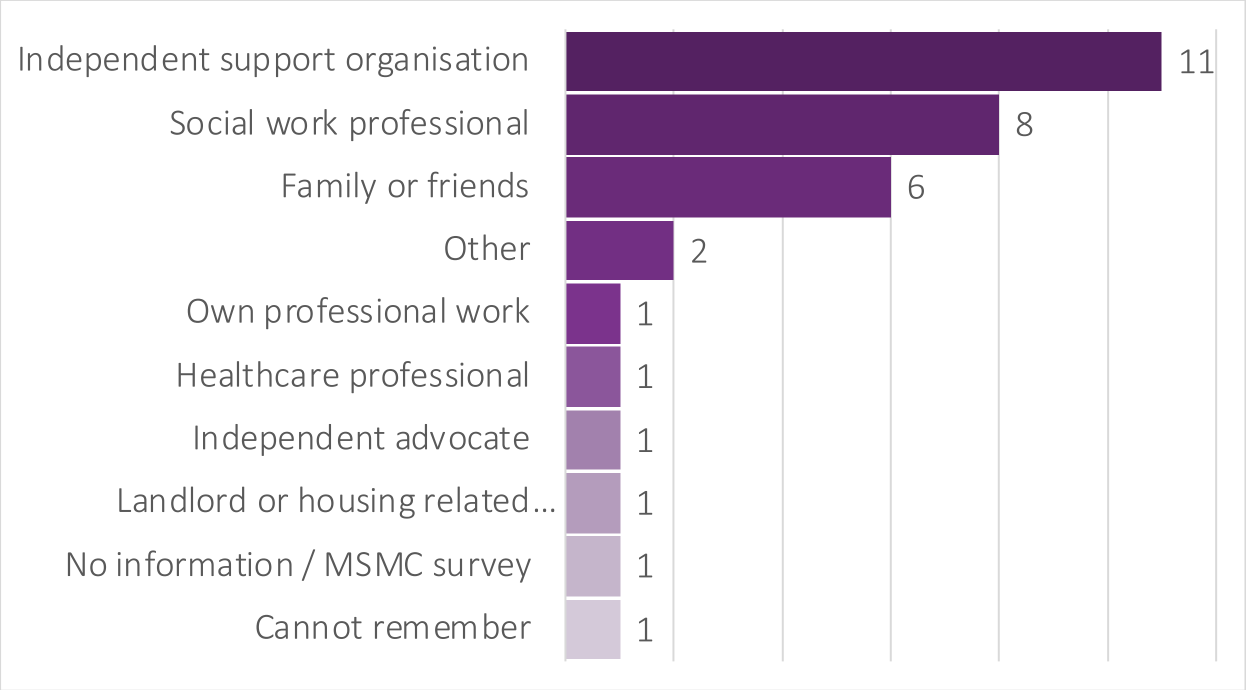
Information About SDS

Finding Out About SDS

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

11 (28%) survey respondents first heard about SDS from an independent support organisation, eight (20%) from a social work professional (e.g. a social worker/social work assistant or an occupational therapist), and seven (18%) from social media. A further six people (15%) heard from friends or family members, one from NHS staff, one from an independent advocate, one from a landlord or housing related professional, and one from their own professional work. Two people heard from an unspecified "other" source, and one person could not remember.

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



One survey respondent reported that they had never received information about SDS. Some interviewees also said that they had not had SDS fully explained to them, even though they used SDS, and had done for some time.

Among the interviewees, social work and people's workplaces were the most common method through which people first heard about SDS. Three interviewees heard about SDS for the first time through their professional employment, and three heard from social work. This was followed by people hearing from friends and family, an advocacy organisation, social media, and a SDS information event run by third sector organisations. The interviewees who found out about SDS via their employment worked in the social care or education sectors.

All three interviewees who found out through a social work professional outlined that this contact was initiated by them contacting social work to seek support. One interviewee described their experience as follows:

> *"I called up social work because I was working to see if there was a facility available to help me more getting out and about […] so I just contacted them and they had mentioned the personalisation package and it was them that kind of started the ball rolling with that."*

A second interviewee reflected on the gap between SDS legislation and communication with the wider public, and the need for more information sources:

> *"There was a consultation and a draft bill was created. There was a debate […] and it passed its first reading. It went to Committee and there was space for stage two amendments. They heard evidence from disabled people's organisations, and it all went through; people who know absolutely nothing about disability thought 'sounds good to me', and they all voted it through. Except that I had no idea that it even existed. I've been ill for 33 years and I did not know that this existed until I got to the point of phoning the Council and saying, 'what services can I have?' And they immediately said, 'Have you applied for SDS?' And I was like, 'What is that?'"*

The interviewee who heard about SDS from their friend commented that they "always knew from other friends that lived independently; my friend always done it, she'd done it from leaving school, so she had quite a bit of knowledge." The Glasgow Centre for Inclusive Living (GCIL) was also mentioned as an organisation that provided people with useful information about SDS.

Other interviewees suggested that they would have welcomed more information from health workers, and that integrated information sharing would have made their experience easier. One interviewee stated explicitly that "joint working between social work and health services, especially GPs, needs to be improved"; another stated that "integration of social work needs to improve so that personal information is gathered sensitively and without unnecessary repetition."

One person reflected on their experiences of integrated engagement between their GP and social worker as follows:

> *"Well, it's definitely not happening from our GP practice anyway. […] I mean I have said to her I'm trying to get more support and she said 'well that's good'. But that's about the extent of the conversation around the support. They certainly have not pushed anything or asked to link in or asked who we were linking in or whatever within social work, not at all."*

Finding Out About SDS: The research indicates that many people in Glasgow had good experiences finding out about SDS from social work professionals and local independent support and advice organisations (specifically GCIL). There are some people in Glasgow who require improved access to information about SDS, and it would be helpful to widen the pool of professionals who are informed about SDS and can encourage people to access it. Making more use of educational professionals, hospital staff, GPs and other community health practitioners would be valuable in increasing the range of sources of information for people, as well as building on the existing expertise and resourcing of social workers and independent advice and support organisations.

Information and Preparedness Before Assessments

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

As the chart indicates, across the SDS options, most respondents in Glasgow did not receive “all the information [they] wanted” (respectively, 47% (Option 1), 53% (Option 2), 44% (Option 3) and 43% (Option 4)). It is concerning that among the 17 people who responded to these questions, most people for Options 1, 3 and 4, and a large minority of people across Option 2, either had no information or were left wanting more in advance of their assessment. The detail of those who wanted more information is as follows:

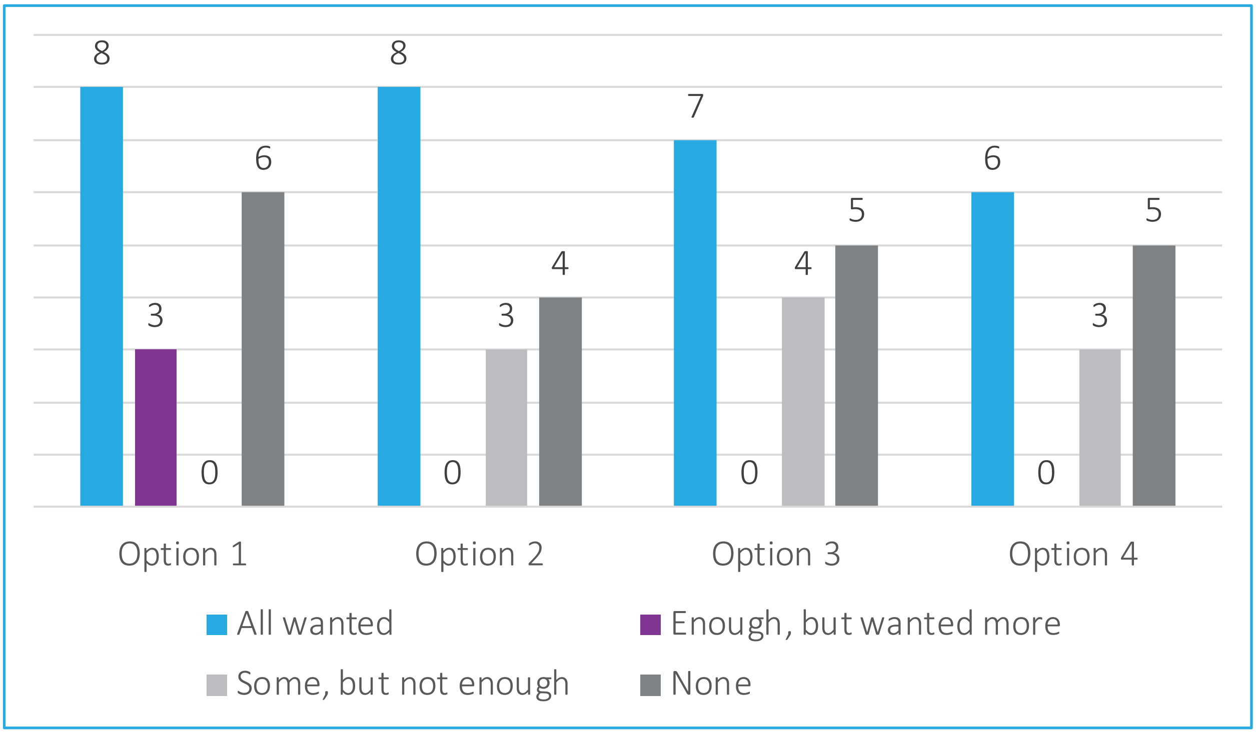
Option 1: 35% of respondents said that they received no information, and 18% received “enough but wanted more”.

Option 2: 47% of respondents reported that they had “some, but not enough” or no information.

Option 3: 56% of respondents said that they had “some, but not enough” or no information.

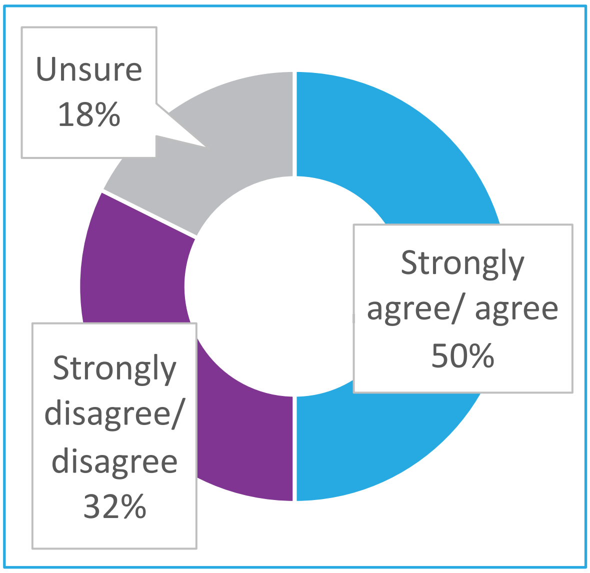
Option 4: 57% of respondents said they had received “some, but not enough” or no information.

Chart 10: Information received before discussing support (Survey)



We also asked survey respondents whether they felt prepared for their needs assessment. Of the 47 participants who answered the question, 17 (50%) strongly agreed or agreed, 11 (32%) disagreed or strongly disagreed, and six (18%) were unsure. While it is encouraging that half of respondents in Glasgow felt prepared for their assessment, it is concerning that nearly a third felt unprepared and the rest were unsure.

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



Some interviewees in Glasgow had been fully informed about the options prior to their assessments, but others had not been told about all four options when they started the process of accessing SDS. Those that felt well prepared for their initial assessment usually credited an independent support and advice organisation for providing them with appropriate information (including

GCIL and GDA), or their own research and professional knowledge.

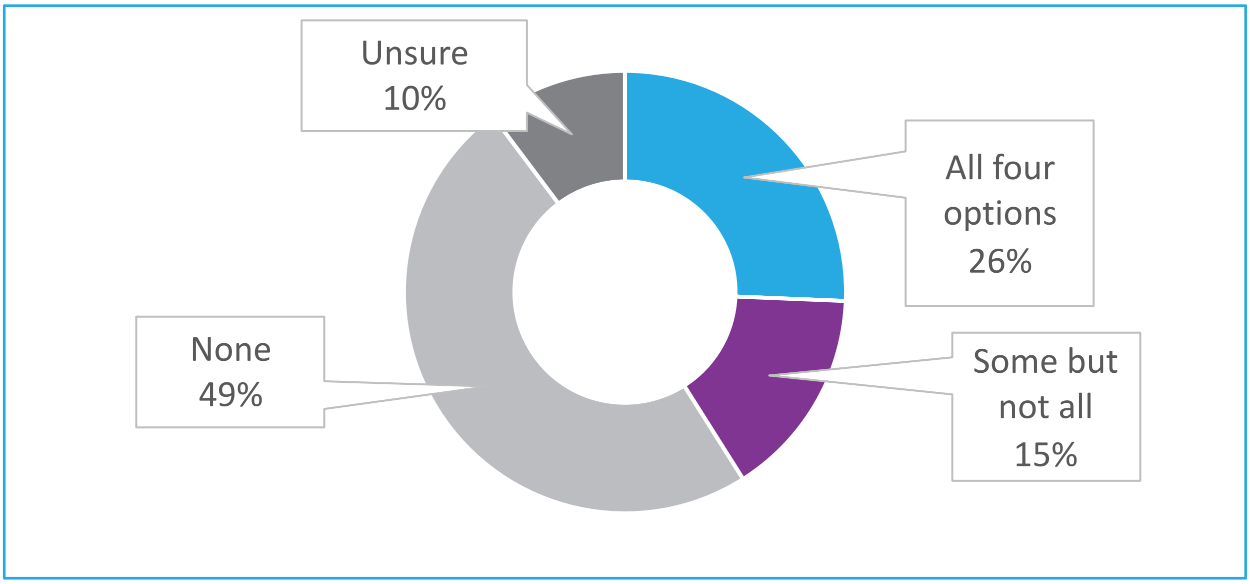
Information and Preparedness Before Assessments: The findings indicate that improvements could be made to ensure everyone in Glasgow has adequate information in advance and feels prepared for a needs assessment. Comprehensive, high-quality information in a wide range of accessible formats should be proactively provided to people about the four SDS options, carers' assessments and support plans, and what to expect of a needs assessment, and made available through a variety of sources (e.g. GP practices as well as more detailed information on Glasgow City Council's website).

Information During Assessments

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

Of 39 survey respondents, 10 (26%) stated that the professional discussed "all four options" with them, six (15%) that "some but not all" options were discussed, and 19 (49%) that "none" of the options were discussed. A further 4 respondents (10%) indicated that they were "unsure" which options were discussed with them. That 64% of respondents had only some or none of the options discussed with them indicates that more work is needed in Glasgow to ensure that all four SDS options are outlined and discussed with people during needs assessments and reviews.

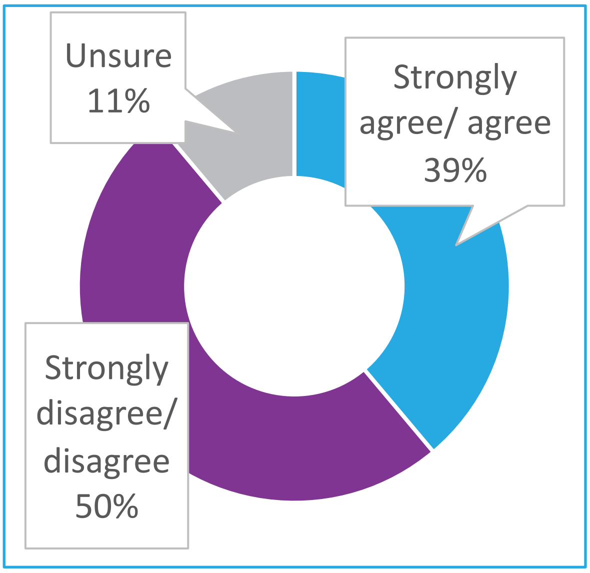
Chart 12: Discussing SDS options with professionals (Survey)



Some interviewees reported that they had not had all four options discussed with them during their needs assessment – including one person who was attempting to move options, with limited support from their social worker. One person reflected that although they now know about all four options, when they first started accessing SDS they "didn't really understand […] which probably caused a bit of friction."

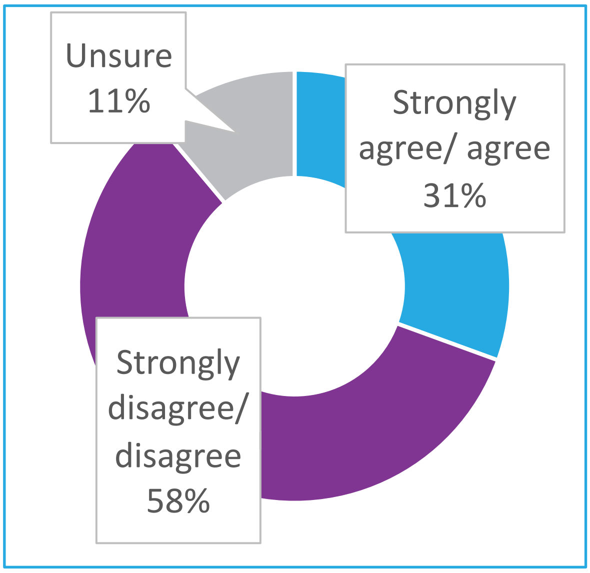
In the survey, we asked whether people agreed with the statement "The person I met with explained things clearly to me". 14 respondents (39%) strongly agreed or agreed, 18 (50%) disagreed or strongly disagreed, and four (11%) were unsure. While nearly two fifths of respondents in Glasgow agreed that the person they met explained things clearly to them, the finding that the majority of people disagreed or did not know indicates that work is needed in this area.

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



In the survey, we also asked people to respond to the statement "All my questions were answered", regarding their meeting with a professional. Of the 36 respondents, 11 (31%) strongly agreed or agreed, 21 (58%) strongly disagreed or disagreed, and four (11%) said that they did not know. Interviewees indicated similar experiences. While nearly a third of respondents in Glasgow indicate that all their questions were answered, the finding that the majority of people disagreed or did not know indicates that work is needed in this area.

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



Several interviewees reflected on positive experiences during their needs assessments and reviews. One interviewee stated that they appreciated having assistance from both their Independent Living Fund (ILF) assessor and their social worker. Most of their questions were around whether funding would be granted (which it was) and relevant timeframes.

However, other interviewees recounted more mixed experiences. One participant recounted that their care manager recommended that ten hours of support should be removed from their package. The interviewee could not understand this approach, as their identified support needs and outcomes remained unchanged. They did not feel their questions about why their care package was being reduced were answered.

Another interviewee was surprised that social support was excluded from their SDS package during a needs assessment, and stated that they were unable to receive satisfactory answers as to why social needs were no longer acknowledged. They summarised their experience as follows:

> *"I think the questions I had was 'OK, you're in the house and you're helping me because of my physical disability, getting me to and from work and things, but what about social life?' And that doesn't seem to factor into my hours."*

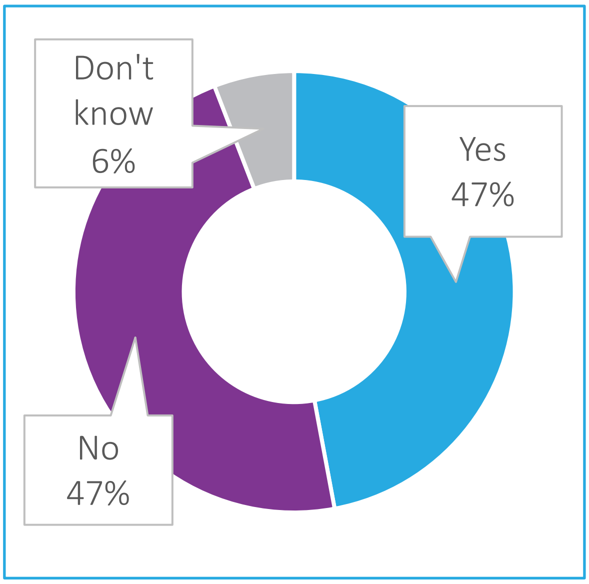
Overall, interviewees indicated that their questions to social work professionals covered a range of concerns, including how support package decision making processes worked, expected wait times, and explanations for reductions in care support.

Information During Assessments: Social worker professionals play a significant role in informing and influencing decisions about social care, and they are often many people's first port of call for information about SDS, including eligibility criteria, wait times and available support. The research indicates that there are positive examples of good practice in Glasgow. However, further work is needed to ensure that everyone is fully informed about all four SDS options during assessments, all questions are answered, and that social work professionals consistently practice supported, rather than substitute, decision making. Information in a range of accessible formats, access to independent advocacy and support should be easily available to all. For some people, information is best provided face-to-face, and more than one conversation may be needed. Enough time should be allocated to ensure meetings are not rushed and people's questions are answered.

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 17 respondents, eight (47%) said yes, eight (47%) said no, and one (6%) said they did not know if they had been given a budget.

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



Nearly half of respondents in Glasgow received information about how much money was available to them. However, it is concerning that an equal number of people had not received that information. It is vital for informed decision making that people are given full information about their personal budgets.

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

Outstanding Concerns and Appeals

In the survey we asked if people had any outstanding concerns that were not addressed during their last assessment. Of the 37 respondents, 14 (38%) had no concerns, 15 (41%) had outstanding issues, and eight (22%) were unsure.

Of those respondents with outstanding concerns, the main issues were budgets, eligibility criteria, delays in implementing care, and a lack of information about SDS. Respondents highlighted that these issues had direct and negative impacts upon their health and the health of the people for whom they care.

Many interviewees also highlighted outstanding concerns about their support, specifically around transparency of process, accessible information, budgets, and waiting times. Of those respondents with unaddressed concerns, insufficient budgets, difficulties getting approval to access short breaks (even when short breaks were included in people's outcomes and budget) and problems arranging suitable support were the most frequently mentioned issues. Several people also reported that they did not receive enough information about their rights, budget, and services. Respondents also highlighted issues with inadequate support options for their specific needs in their local area, which left them either without meaningful choice of providers or without any support. Others indicated that they were not on their preferred SDS option but had been unable to change. One respondent stated that their needs were acknowledged at their assessment, but they were not offered SDS and their social worker pressured them to move to residential care:

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

Other participants also reported that inadequate budgets led to SDS users using personal contributions to supplement their essential care costs. One respondent commented that budget cuts had reduced their support by "more than 50%", which "made it totally unworkable compared to before" and left their support at "life and limb". Respondents argued that instead of costing labour at the lowest common denominator, the best value for money should be viewed in terms of quality of life for service users, prioritising their individual choices. One interviewee summarised their experience as follows: "They had an agenda to cut it. They know the needs-based scenario of it. They're just cutting it [...] regardless."

Interviewees also suggested that decision makers needed to "consider the impact of contribution payments". Another interviewee recounted issues with costs which were not included within the SDS budget and indicated that they were not provided with clear information about what housing adaptions were covered by SDS, what was covered by other funds, and what they were expected to pay themselves. They found that contested costs included: furnishing a spare bedroom for personal assistants (PAs) who were providing overnight support, installing safety equipment, and paying for driving lessons for a PA (as part of their training budget, as a skill that would help with their ability to support the SDS user). They would have appreciated greater clarity from the outset, as well as the opportunity to participate in discussion forums attended by representatives of the local authority/ health and social care partnership and people who access services, to discuss the logic behind their choices and direct them to other sources of funding and support if appropriate.

Other participants were frustrated with the difficulties in receiving support for variable long term conditions, and particularly how variable support needs are assessed against eligibility criteria. One respondent who receives SDS summarised their experience as follows:

> *"They have tied the criteria to reduce eligibility. […] It's a financial issue. […] Anyone with low or moderate needs is to be signposted to other sources of support. That's it. […] There is no obligation on any local authority for what those sources are, the diversity of them, what they cover, their availability or their cost. Nothing. That is totally unregulated, which means it's up to your individual council to decide."*

Another interviewee recounted how a family member provides them with support as an unpaid carer; because of this support, they have been classed as being "at the top end of moderate, but never substantial" under the eligibility criteria. However, the interviewee has significant concerns about how they will be able to live once their family member is no longer able to care for them. Furthermore, there are no suitable services in the local area that could provide additional support. They summarised their concerns as follows:

> *"Without [Name], I'm going to tip over into substantial very, very quickly. And that is a huge fear for both of us. And it puts a whole load of strain on her. But as long as she is not dead yet, there are no support services. […] The system provides for quality of life only if you're severe. But quality of life is not an issue under low and moderate needs. There is no provision for that."*

We also asked survey participants whether they were in the process of appealing the decision made in their last review or needs assessment. Of the 27 respondents, three people in Glasgow indicated that they are in the process of appealing the outcome of their last social care assessment or review. One survey respondent provided additional information about their appeal; they reported that they were being supported in their appeal by a friend or family member after being denied access to short breaks. One interviewee was also appealing decisions about substantive cuts to their care, with the support of independent advocacy.

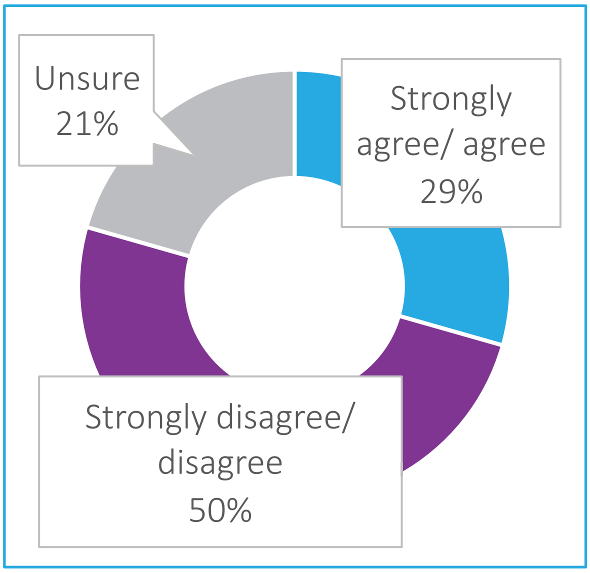
Outstanding Concerns and Appeals: The research invites further work in Glasgow to ensure that people are not left with unaddressed concerns following needs assessments – particularly when those concerns relate to how they will be able to live independently following cuts to their support. People should be provided with alternative, accessible communication routes – like online chat functions, a freephone support line, and direct email addresses for professionals – that allow them to follow up and have questions answered later, if it is not possible during meetings. Social work professionals should proactively check in with people after assessments to identify and address any outstanding concerns. They should also be equipped to signpost and refer people to other sources of information, including independent support and advice organisations and independent advocacy. Professionals should ensure that all unpaid carers are offered carers assessments and have their rights explained to them, and should not assume that family members and friends are able or suitable to provide unpaid care. 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.

Informed Choice and Control

Time to Consider Options

In the survey, we asked if people agreed with the statement "I had enough time to choose the option of SDS that suited my needs." Of the 34 respondents, ten (29%) agreed or strongly agreed, 17 (50%) disagreed or strongly disagreed, and seven (21%) stated that they did not know. The findings suggest that improvement work may be required to increase the number of people who feel they have enough time to decide on the best SDS option for them.

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

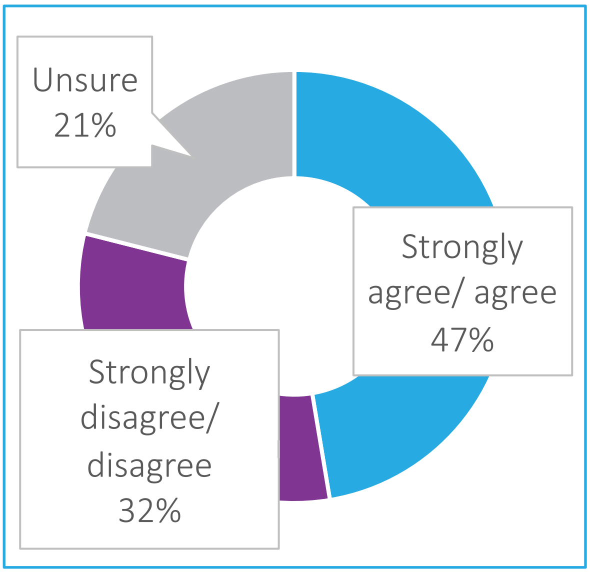


One interviewee felt that support services were being pushed upon them, faster than they were comfortable with – especially when, they acknowledged, they take time to trust new people coming into the house. The interviewee indicated that they would have appreciated more time to consider their options.

Waiting Times

In the survey, we asked people to agree or disagree with the statement, "Waiting times, or waiting for responses, makes Self-directed Support more difficult for me." Of the 19 respondents, nine (47%) strongly agreed or agreed, six (32%) disagreed or strongly disagreed, and four (21%) stated that they were unsure.

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



Interviewees reported variable wait times for assessments and support to be put in place; some waited three or four months, while others waited over a year before the start of support provision.

Interviewees uniformly appreciated short waiting times for a response or decision from social work. Those who waited the longest generally reported the highest levels of stress and difficulty in accessing SDS. One interviewee spoke about how they would have benefited from a clearer outline of the timescales involved, to enable people waiting to access SDS to plan accordingly when making decisions about support:

> *"You need to give consideration to the fact that the assessment process takes so long and by the time there is a package approved, the needs might have changed dramatically and then you are kind of back to pushing to have a reassessment."*

The interviewee recounted that while SDS is now in place, in the time it took to arrange an assessment and support (over a year) there was a significant deterioration in the physical and mental health of the person for whom they provided unpaid care, and they lived an increasingly restricted life.

Other respondents commented on additional waiting times that they did not expect, between initial phone contact with social work, assessments, decisions on packages and finances, and finally the eventual implementation of support. People indicated that more information about waiting times at each stage of the process would have been useful in helping them manage expectations and plan accordingly.

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

Choice over SDS Option and Support

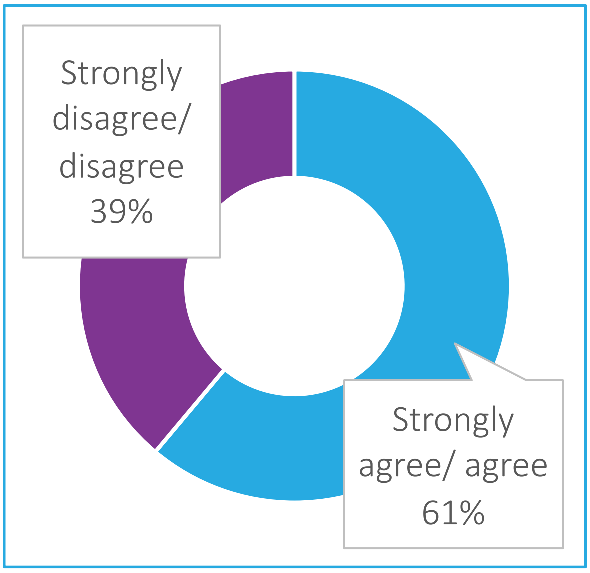
We asked survey respondents if they were on their preferred SDS option. Of the 23 participants who answered, 17 (74%) were on their preferred option, three were not on their preferred option (13%), and three were unsure (13%).

A similar pattern was found with interviewees. Eight out of the ten households interviewed said they were on their preferred SDS option. Of the two who were not on their preferred option, one was in the process of changing options (after some difficulty), and PA recruitment problems meant that another person was effectively unable to access Option 1.

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

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 18 respondents, 11 (61%) strongly agreed or agreed, and seven (39%) disagreed or strongly disagreed. The finding that the majority of people are fully involved in decisions about their care is encouraging, but the substantial minority (more than a third) of people who did not feel involved in decisions invites further work in this area.

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

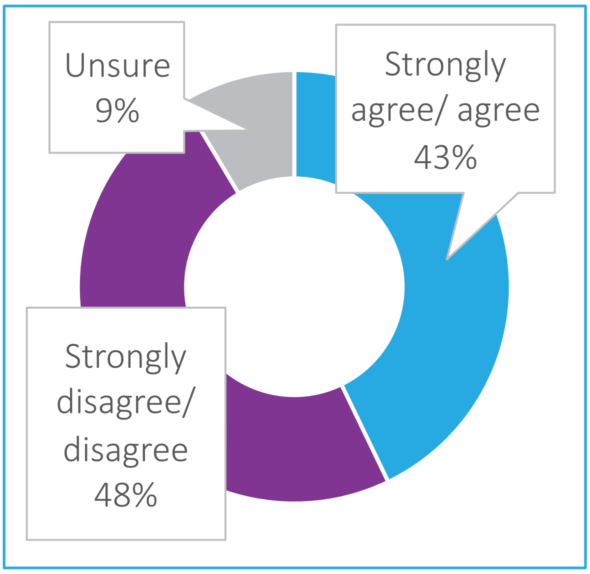


We also spoke to interviewees about which SDS option they had chosen. One person outlined they are now on their preferred SDS option, but that this had taken significant effort to arrange. They described that they were originally on Option 3, after being "knocked back three times for direct payments". After the interviewee was advised by an acquaintance that there were no grounds for refusing their request to use Option 1, they "pushed and pushed" and after a reassessment and several months they were able to access Option 1 and employ PAs. Until that point, they stated that "it wasn't really a choice".

Another interviewee explained that they are not on their preferred SDS option and were trying to use Option 1. However, constant recruitment and retainment of PAs was proving a challenge, which meant that in practice the participant uses Option 4 with the use of some agency services.

In the survey, we also asked people to respond to the statement "I had a say in how my help, care or support was arranged." Of the 35 respondents, 15 (43%) strongly agreed or agreed, 17 (49%) disagreed or strongly disagreed, and three (9%) stated that they did not know.

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

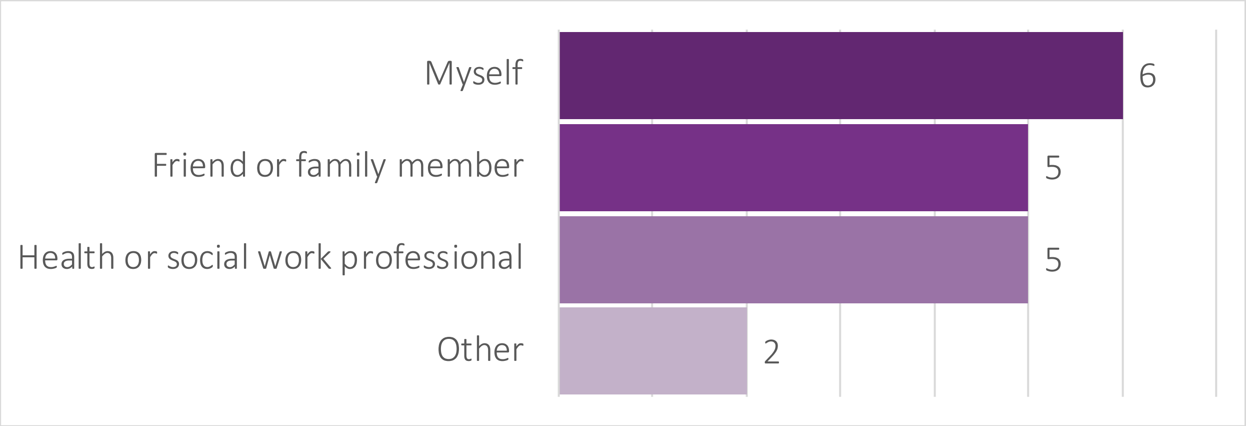


We also asked survey respondents who chose the way that their support is arranged now. Of the 20 respondents, six (30%) said that they chose the way their support was arranged. One person who said they chose how their support is arranged stated that they "chose but had to fight for it"; another stated that "it was what I wanted 'at the time'".

Seven people (35%) said that a social worker chose their support for them. One person provided additional detail and stated that they "discussed with social worker that [they] wanted [Option] 4. Ended up with [Option] 2." Just over a third of respondents reported that social work professionals chose how their support is arranged, with a similar proportion indicating that they did not have a say in how their care and support was arranged. These findings invite further work to embed supported decision making (instead of substitute decision making) in SDS/ social work practice in Glasgow.

A further five people (25%) stated that a friend or family member chose for them, one person selected "other" and stated that "as a family, we had input into [Name]'s support, along with what he wanted", and another person selected "other" without providing supplementary detail.

Chart 20: Who chose support arrangements? (Survey)



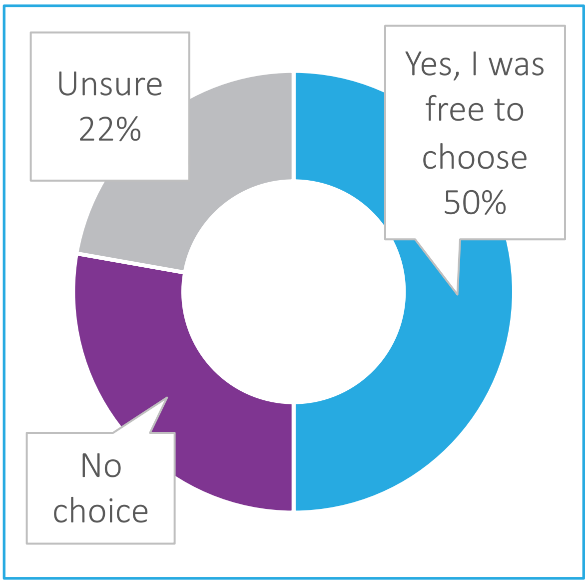
We also heard from interviewees about their SDS option choice. Some people felt that their social worker had decided what SDS option they would choose before completing the needs assessment (this finding corresponded with reports that they did not have all four options explained to them). Other interviewees highlighted the importance of access to information to make informed decisions, and of a suitable selection of local providers to enable meaningful choice.

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

Budget Management

We asked survey respondents whether they chose who manages their personal budget, and if so, who they chose to manage it. Of the 18 respondents, nine (50%) said that they were free to choose who they wanted to manage their personal budget, five (28%) said they were not given a choice, and four (22%) were unsure whether they had a choice.

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



Of the nine people who were given free choice of who would manage their personal budget, three (33%) selected the local authority, two chose a third sector provider organisation, and one selected a private care agency. A further three people (33% of those who were free to choose) selected an individual person (this response could include themselves).

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

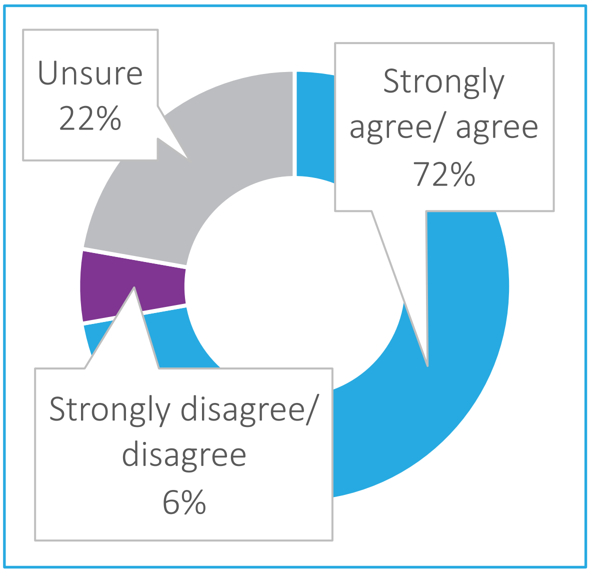
It is encouraging that half of respondents in Glasgow were offered the choice of who to manage their personal budget. However, it is concerning that around a quarter of respondents were unsure if they had a choice, and a similar number reported they had no choice. This indicates that, amongst other things, these respondents were not fully offered all four SDS options (as that would necessitate discussion of who would manage their personal budget).

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

Adequate Support

We asked survey participants to respond to the statement “Enough budget to meet my outcomes makes Self-directed Support easier for me”. Of the 18 respondents, 13 (72%) strongly agreed or agreed, one (6%) strongly disagreed, and four (22%) were unsure.

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



Some interviewees spoke in detail about the impact on their physical and mental health of substantial reductions to their SDS budgets and support. One interviewee had previously had a comprehensive SDS package that covered regular personal care throughout the day, which enabled them to be active in the community and live a good quality life. However, following a reassessment their package was cut substantially, to one third of the original provision – despite no change in their needs or stated outcomes. This means that they no longer have assistance to use the toilet during the day; as a result, they cannot participate in social activities or community life. They have also had health complications as a result of the reduced care available to them. The interviewee summarised one consequence of this reduction, and its impact on their mental health, as follows:

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

This interviewee's experience was not the only account reported during MSMC of a serious reduction in quality of life and an increase in mental health problems following substantial reductions to packages in Glasgow. Several other participants recounted similar experiences – and particularly highlighted the contrast between their current situation and previous levels of support and good quality of life.

Another interviewee reflected on struggling to access sufficient care and a lack of allowance for social engagement in their package, and the impact on their mental health. They summarised their experience as follows:

> *"I'm stressed out of my head, I'm not sleeping. It's just like – […] every day is a challenge, everywhere you go is a challenge, everything you do is a challenge. […] I want to get out and about, I'm a people person. I want to be socially active, […] to do all the things that non-disabled people take for granted every day, ordinary things that people do in their lives. I don't think that's unreasonable to want to do that. If you want to go to the cinema or go for a meal, why shouldn't you be able to do it? You should have an adequate budget to support you in doing that."*

Other people commented on the sense of precarity from regular reassessments, and the fear of losing key elements of their budget and their right to live independently. Some interviewees commented that they had had constructive conversations with their social worker, but that decisions about SDS budgets falls to a social worker team manager – who can reduce the agreed support package. One participant summarised this experience as follows:

> *"It doesn't matter how good they [social workers] are, because it's*

> *the team leaders that don’t want to put that budget to you. Two of the things I was told were if you come across too well, you still work and look good, that goes against you. So, you would rather I sit in the house with a big dinner stain down my top, no bra on, my hair all sticking up, watching Jeremy Kyle. If I do that, will I get better hours?”*

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

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

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

Adequate Support: The research reinforces the need in Glasgow for good quality, adequate support via SDS that acknowledges the importance of community engagement and social activities. This can be instrumental in ensuring good quality of life and plays an important role in helping people enjoy their right to independent living and equal participation in society. Unfortunately, we found that many people were not receiving adequate, person centred support in Glasgow. The impact of not providing rights based, person centred care can be devastating, resulting in isolation, loneliness and physical and mental ill-health. It can also place unacceptable demands on some people to act as unpaid carers without any choice by themselves or the people they care for. Any proposed reductions in SDS budgets/support should be communicated clearly and discussed with people well in advance of any changes being introduced. Health and social care staff should consider the possibility of isolation or mental health crisis when changing packages and eligibility criteria, and be able to arrange reassessments and signpost support services where needed. Additionally, if the support required by an individual is not available then any records should reflect that lack of availability and unmet need, rather than indicating that people refused services.

Access to Short Breaks

Access to short breaks was an important topic for many MSMC research participants in Glasgow – for SDS users and unpaid carers alike.[31] People who used SDS budgets to access short breaks described it as an essential way that individuals and families could benefit by having time and space to themselves, doing activities that they enjoyed. Using SDS to access short breaks was mentioned by several people as an important chance for people to recuperate and relax.

Several respondents stated that they had struggled to get approval to access short breaks, even when they were approved as part of their outcome or budget. Some participants reporting that their budget for short breaks (e.g. funding for a care worker to accompany the participant on a short weekend break once a year) was cut completely. One interviewee recounted that their social worker cut their short break budget at a recent assessment, stating that, “we are not paying for you to have a jolly”. Even in a restricted funding environment, such language is demeaning – as well as not considering the positive impact that occasional short breaks can have for people. Another person was advised by their social worker not to request a budget for short breaks, but to “let sleeping dogs lie” because “if you ask for it they might cut your hours”. While the individual in question appreciated their social worker’s honesty, people should still have the right to request access to short breaks without fearing their regular care will be reduced.

Access to Short Breaks: Flexible, regular access to short breaks should be strongly encouraged in Glasgow because it is an essential element of SDS that results in good personal outcomes for people who access social care, families and unpaid carers. People should be treated respectfully when requesting access to short breaks and should not have to fear cuts to other areas of their care if they request short breaks.

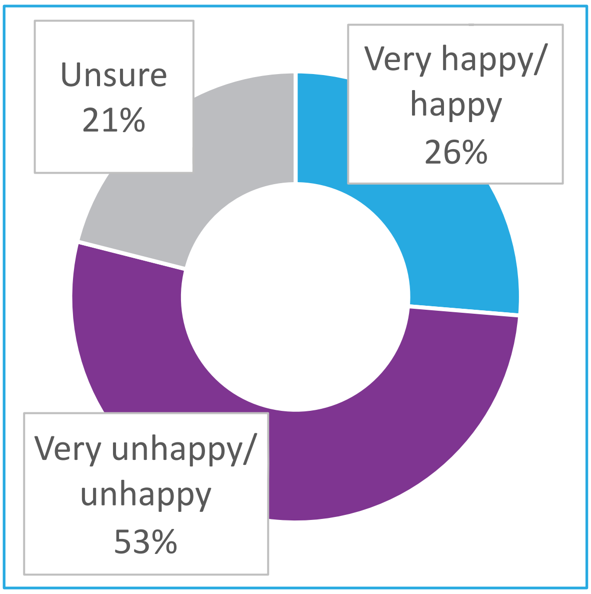
Communication and Relationships with Social Work

Good Conversations and Consistent Relationships

The importance of productive conversations in arranging appropriate social care support was highlighted in the 2019 Care Inspectorate thematic review of SDS.[32] As such, we asked survey respondents to rate how happy they were with the conversations they had about their support with professionals (e.g. social workers/ social work assistants, occupational therapists).

Of the 38 respondents in Glasgow, ten (26%) were happy or very happy, 20 (53%) were very unhappy or unhappy, and eight (21%) didn’t know.

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



Interviewees highlighted that good conversations require effective communication, access to information, and good future planning. One interviewee commented positively about how their social worker and care provider engaged with and responded to their concerns and preferences and supported their wish to have only care workers of the same gender as them providing personal care. They stated that they had a “good conversation” with their social worker, who was “knowledgeable” and “civil, […] business-like and informative”.

Another interviewee spoke positively of their experience of a recent review:

> *“I had a good conversation because […] I had a good social worker who was completely on my side, completely got what I was on about. Completely got that I was working, and I’m just trying to live a regular life. [The social worker] was fully on board, so when [they] went to the big table [they] fought for me.”*

Other interviewees highlighted that social workers who “listened” to them were helpful and supportive – particularly when there was sufficient time to discuss support plans in detail during assessments or reviews. One interviewee also spoke warmly of members of the sensory impairment team within Glasgow social work, whose expertise meant that the interviewee had received more tailored support and advice during their needs assessment.

Another interviewee commented that after difficulties with their first social worker a different one was appointed. The participant summarised the communication they had with their current social worker as follows:

> *“I felt more supported, and [the social worker] kept me fully up to date with everything that was going on. [Name] called me as soon as [they] came out of the meeting on [date] and told me how it went and [they] had went to the meeting and had asked for [care package] which was what I had agreed […] I felt a lot more supported by [Name] and I felt like [Name] was a lot more honest with me.”*

Interviewees also appreciated constructive advice or tips from their social worker while developing a support plan. One interviewee described how their social worker would prompt them to think about how much support they might require for doing specific household chores, and then point out that some tasks can be performed at the same time (e.g. washing clothes and cooking), so as to be more effective in how their hours of support were arranged and used.

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:

> *"Social worker […] was amazing and a font of knowledge in SDS"*

> *"Social worker […] had years of experience and understanding of SDS. Could recognise my needs. Understanding."*

> *"[Social worker] was really friendly, very proactive with a common-sense approach. [They] got where I was coming from and I really respected how honest [the social worker] was about me getting everything I wanted/needed. [They were] straight with me but very upbeat and determined."*

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

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

Poor Communication and Relationships

Most participants described more difficult experiences of communication and relationships with social work professionals in Glasgow. Of the 38 people who answered the survey questions about how happy they are with the conversations they have had about their support with professionals, 20 (53%) indicated they were either very unhappy or unhappy. Some stated that their social worker did not have enough time or knowledge to meet with them and discuss their needs and questions properly. Others indicated more fraught relationships.

The most common reasons for dissatisfaction were that people felt they were "not listened to", treated with disrespect, and/or felt they had received inadequate information about SDS. Key comments from people who were unhappy with their conversations and relationships with social work professionals are as follows:

> *"The social worker treated me like an idiot."*

"Felt like [they] wanted me to fit into boxes, not listen to my individual experiences and struggles."

"[The social worker had] a fixed view of how my needs could be met and refus[ed] to accept […] my rights as a disabled person to live in my own home and choose the level of risk that I am comfortable with."

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

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

Some respondents highlighted that while they were happy with their social worker, they found face-to-face communication difficult, and needed more information in advance of what to expect from assessments. One respondent reported that "the assessment was done orally but I work better seeing the questions in advance and writing down answers."

Finally, one interviewee recounted difficulties with the different language around SDS used by various stakeholders. They summarised this confusion as follows:

"It's SDS, but when I phoned up social work last week, they're like 'You get direct payments, not SDS'. And then they told me they couldn't help me with anything because GCIL has to do that. They […] said 'don't use carers, use PAs'. But when I phoned up to use a PA, the care agency had no idea what I was talking about."

Poor Communication and Relationships: Examples of poor communication raise clear concerns about decision making and autonomy; if information about SDS is not provided, or people do not have accessible documentation about their options, then they cannot be said to control or choose their support. The findings invite further work to develop practice in Glasgow to ensure that people's experiences of conversations and relationships with social work improve and are consistently good. No-one should have to deal with discriminatory or judgemental language, attitudes or behaviour from social work professionals and people must be treated with dignity and respect. All processes and paperwork should be transparent and shared in an accessible format with service users. Social work staff should proactively gather regular feedback – good and bad – from service users, families and unpaid carers as a way to support continuous improvement. People should be proactively informed on a regular basis about how they can challenge decisions, access independent advocacy and support, local authority complaints procedures and the independent oversight of the Scottish Public Services Ombudsman (SPSO).

Transparency

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

While some people spoke warmly about transparency in Glasgow, others expressed concerns about transparency of processes that were often synonymous with inaccessible information.

Participants reported that they would like access to copies of all documentation concerning their social care provision, including copies of their agreed budget and personal outcome plans, but struggled to obtain these documents from social work. Greater transparency and better communication may have reduced these points of conflict with the local authority.

Several respondents touched upon lack of transparency and accessible communication during their needs assessments and reported that they lacked access to the calculation of need carried out by social work or to the eligibility criteria for support. One interviewee summarised the difficulties they had experienced as follows:

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

Another interviewee highlighted a lack of information about why their package was reduced, and a need for more transparency about decision making and how to challenge it:

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

Transparency: The research indicates that while there are good examples of transparent process in Glasgow, this is not consistent across all areas and more work is needed to ensure systematic good practice and complete transparency across several elements of SDS/ social care. This includes publicly available information about eligibility criteria, needs assessments, budgets and support packages, changes to support, participation in decision making and how to challenge decisions. Further information on document publication dates, webpage timestamps, details of Equality Impact Assessments, and the role of people who use support, carers, and partner organisations in decision making, is encouraged.

Care Staff Recruitment, Training and Quality

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

Several interviewees outlined how SDS has provided them with person centred support that benefits their entire household. The benefits of having a trusted team of PAs or support workers was a key theme for several participants in Glasgow.

People in Glasgow commented that care staff travel and training costs (e.g. specialist first aid or medical training required for them to carry out their job appropriately) should be included in their SDS budgets. They felt that this would help ensure a quality care workforce (including PAs).

Important Characteristics of Care Workers

Many people commented on their priorities regarding care staff. One interviewee summarised the following important characteristics in a support worker:

> *"Open-mind […] fun to be with, able to be disability aware or be willing to learn. Prepared enough to recognise my needs and respect my choices. Always trustworthy and things like that because you need to be happy that you trust someone to have people in your home and when you go to bed, you have nobody else there and things aren't locked up. Trust is a really big thing."*

Interviewees also discussed the importance of care workers who meet their personal needs. Many respondents reported that being able to trust care workers was a key factor for successful use of SDS. One disabled parent shared that trust in care workers is crucial, especially when duties involve aspects of childcare. One participant described that:

> *"I've got a very reliable personal assistant. She turns up on time every day. […] I'm not reliant on phoning an office and saying please can I get somebody on Sunday, and then waiting on somebody to turn up."*

One interviewee described the positive impact of their PA and access to SDS on their mental health and lifestyle:

> *"This whole thing is reassuring, because while I've got a very high level of confidence in my personal assistant."*

Another interviewee summarised their experience as follows:

> *"I love that I can just do what I want and think for myself and plan stuff and […] it's a bit of nuisance with the PA side of it when I'm restricted getting PAs, and that's quite a strain and a worry. And I always think when things are going well it always goes pear-shaped with one person leaving or going off sick and it throws things up in the air. But when it works well it's great, and I love being in my own house, and doing*

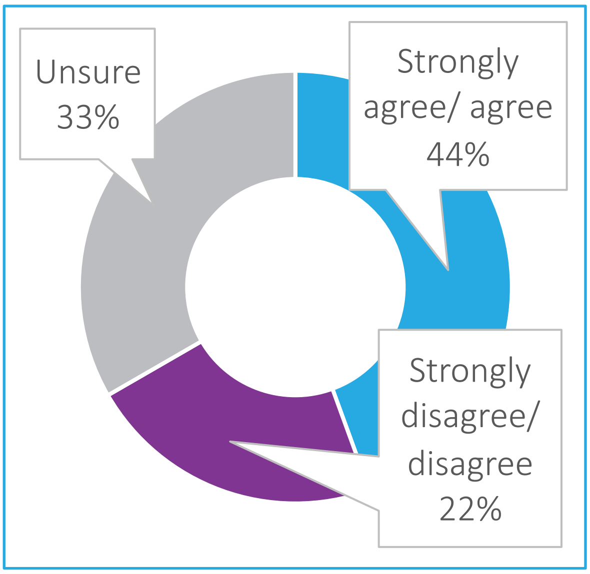
> *my own thing, and just pottering about. It's not anything elaborate half of the time, but I just like to have that control myself in choosing what I want to do."*

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

Staff Recruitment, Retention and Turnover

In the survey, we asked people to respond to the statement "Lack of a regular personal assistant makes SDS difficult for me". Of the 18 respondents in Glasgow, eight (44%) strongly agreed or agreed, four (22%) disagreed or strongly disagreed, and six (33%) were unsure.

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



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

Recruitment of suitable staff was a major issue for many respondents in Glasgow. One interviewee commented that they have found it increasingly difficult to recruit suitable PAs over the last few years:

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

Another participant discussed the impact that difficulties recruiting suitable PAs had on their mental health. They had previously had a very good relationship with their PA, who had since left post. Since then, they had struggled to find someone suitable, and been significantly more restricted in their ability to engage with the community and carry out their normal activities. The respondent summarised their experience as follows:

> *"I think […] if you have a physical disability, there seems to be this illusion there that you don't have any mental health problems or emotional health problems. But, obviously […] for anybody's mental health, we live in a world where […] there is a lot of loneliness. And I might be in a chair and I sit down a lot, but my mind is really active. […] I don't have a PA to go out. […] Basically, on my armchair just now is piles and piles of CVs, and there is two that actually turned up [to interviews]."*

Similar narratives with difficulties with care worker recruitment were reported by other interviewees. Problems with high turnover of staff, especially those employed through agencies, was a key theme when it came to factors that made SDS challenging for people. One interviewee shared that their disabled 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. Another participant outlined difficult experiences of SDS as a disabled parent. They require support with some household chores and help to access community life with their child. However, they reported significant prejudice about their capabilities, particularly from care workers who are unused to working with disabled people who have children. They reflected that the carers who provided help often attempted to override their decisions, including parental decisions. The interviewee summarised the power imbalance of this conflict as follows:

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

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

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

> *I was allowed to walk home if I wanted to. […] I'm not a child!"*

Several interviewees mentioned they had received support from third sector organisations (specifically GDA and GCIL) in arranging their care and interviewing candidates, which they appreciated. Some respondents suggested they would welcome more support from Glasgow City Council to arrange PA training and continued professional development.

Overall, almost every interviewee spoke of a sense of trepidation or fear about being left with inadequate or unsuitable care, due to problems with staff recruitment or retention. One interviewee highlighted that they felt the key problem around recruitment was respect for the care sector as a whole and commensurate pay. They summarised their perspective as follows:

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

Care Workers and Risk

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

One respondent discussed negative experiences due to poor quality care workers and inadequate training. They recounted how in one instance an employee, a new PA on a probationary period, repeatedly turned up late. When the interviewee confronted the individual about their unprofessional behaviour, the PA was verbally abusive while the interviewee lay in bed, feeling vulnerable. The PA then left without assisting the interviewee with any of their basic personal needs. Fortunately, a neighbour was able to help the interviewee in this emergency. The interviewee subsequently consulted her PA insurer about due process for giving employees notice, and dismissed the PA. After the PA's dismissal the interviewee received "a lot a lot of grief from [the PA], lot of cheeky texts".

A further interviewee reflected on the benefits and challenges of agency staff versus directly employed care workers. In their experience, agency workers were not able to be flexible, and had to follow rigid timescales around specific tasks (e.g. 15 minutes for showering). However, the interviewee worries about periods of sickness involving their directly employed care workers. As they point out, the agency approach provides a level of back-up which might reduce the amount of negative behaviour SDS users tolerate because they feel they have no alternatives or cannot face the stress of recruitment:

> *"And what are you meant to do for that full week if you don't have anybody there? You do think about it a lot. Whereas if you knew you had enough back up and could get someone else quite easily, you'd probably […] get rid of them a lot quicker. You're putting up with things that you shouldn't need to, you know, you definitely shouldn't."*

Care Staff Recruitment, Training and Quality: Some people would welcome more support with PA recruitment, training and continued professional development. More generally, Glasgow City Council and Health and Social Care Partnership should work with people who access SDS and unpaid carers to improve systems and processes related to care staff recruitment, training and quality. It is also evident that many people would welcome improved access to more suitably trained and high calibre care workers. While some people are comfortable with the role of employer and have experienced good, long term, working relationships with their support workers, this experience is not universal. This 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. 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.

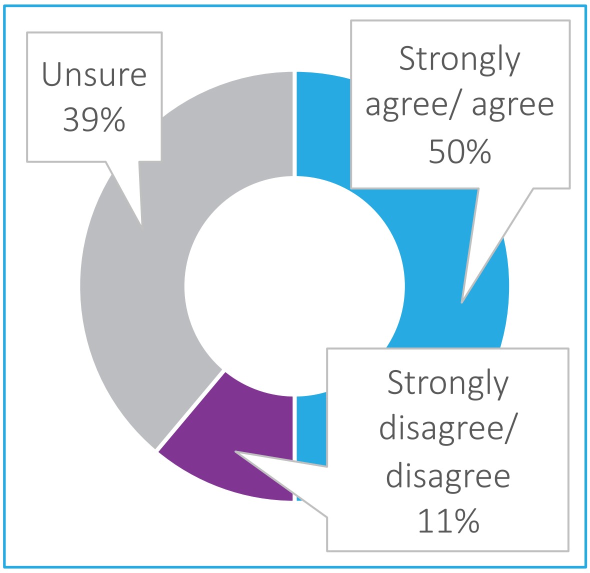
Independent Advocacy and Support

Respondents in Glasgow accessed independent advice and advocacy services for a range of different reasons. These included access to information, access to needs assessment criteria, assistance to develop a support plan, exploring flexibility with SDS budgets, mediation with social workers, support to appeal a decision, and advice on payroll and other PA employer related issues. Survey respondents and interviewees spoke positively of the benefits of independent advocacy and independent advice and support organisations in Glasgow.

Independent Advocacy

We asked survey participants to respond to the statement "access to independent advocacy makes SDS easier for me". Of the 18 respondents, 9 (50%) strongly agreed or agreed, two (11%) disagreed, and seven (39%) were unsure.

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

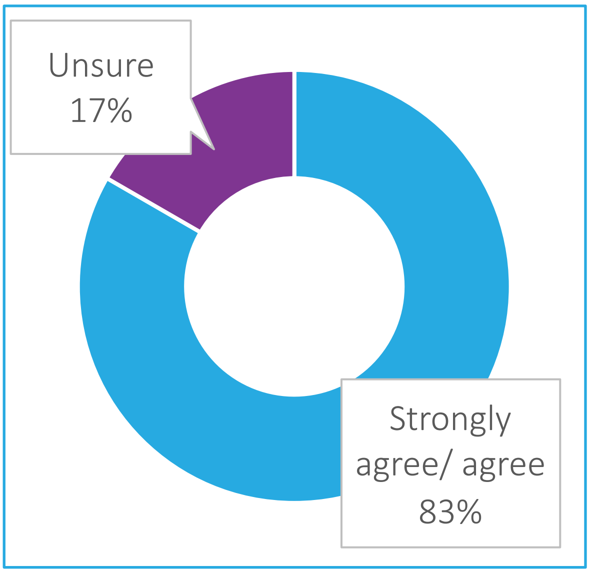


Survey respondents spoke of the value of independent advocacy and suggested that others should "get independent advocacy and help to ensure that you are listened to". More broadly, respondents recommended that people wishing to access SDS should "become more aware of legal literacy, [and] challenge whatever you feel is wrong or unjust."

Independent Advice and Support

When asked whether access to independent information and support made SDS easier for them, people responded in a positive fashion. Of the 18 respondents, 15 (83%) strongly agreed or agreed, none disagreed, and three (17%) were unsure.

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



Survey respondents and interviewees commented on the value of independent advice and support in accessing SDS. Several people highlighted that they had benefited from the involvement of independent advice and support services during their needs assessment and reviews, and others had first heard about SDS via GCIL, GDA or other organisations. One interviewee was explicit in stating that even when they did not require advice, "it's reassuring to know that this place is here, GCIL" to provide help if needed; another praised the support they received as "really good, really helpful".

Respondents drew upon independent advice and support organisations for support on a range of different issues. Respondents recommended that people contact advocacy and support services early in the process of accessing SDS – sometimes before an initial assessment had taken place. Respondents highlighted the benefits to becoming "informed about [SDS] first" and recommended that people who are awaiting an assessment should "get someone who knows the system to help you manage the application and decision-making process."

One person summarised their experience of receiving joint support from their social worker and GCIL as follows:

> *"GCIL were very supportive. I was out here with the social worker, when the thing [SDS] was being set up, and that was when I met [Name], the [GCIL] adviser. And [Name] was very business-like, and explained what needed to be done, very clear, and questions, [Name] was available – very supportive."*

Peer Support

Several people in Glasgow highlighted the value of peer support and encouraged the promotion or establishment of local peer networks. According to some participants, peer support helps to sound out ideas around how support could be arranged, facilitates access to information, combats isolation, and prompts some people to be SDS ambassadors. Often, peer support – digital or in person – can be an essential network for people – as outlined by one interviewee:

> *"I've got a friends network on Facebook. What you've got to remember is that in 30 years we've all got to know each other*

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

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

Response from Glasgow City HSCP

Glasgow City Health and Social Care Partnership (GCHSCP) welcomes the publication of this report into service users' experience of Self-directed Support (SDS) in Glasgow City. For practical reasons, we acknowledge that only a relatively small sample of our service users could participate in this research. Nonetheless, the findings provide a welcome and helpful insight into the experiences of those service users and the areas for improvement.

By way of additional context, GCHSCP has well established processes and systems that underpin and support SDS. This includes a range of information that is publicly available on GCHSCP's Your Support Your Way Glasgow website (including web content and a guide)[33] and Glasgow City Council's website,[34] as well as information that is available for professional and business support staff on the Council's intranet. We also have a very dedicated and experienced workforce who are well placed to have good conversations with our service users as part of care planning, assessment and review. We also acknowledge the pivotal role played by Independent Advocacy services and organisations such as the Glasgow Centre for Inclusive Living (GCIL) and Glasgow Disability Alliance to further support people's understanding and participation.

We remain committed to supporting the uptake of SDS in Glasgow City and continue to work in partnership with GCIL and other Disabled Persons Organisations to enable people to get information and advice on all four SDS options. We also work closely with third and independent sector providers and have put in place extensive frameworks for purchased social care supports. These provide service users with a large range of quality assured providers who can offer a wide range of supports including supported living, day opportunities, employability services and respite / short breaks. At this point in time, we have approximately 3500 people in receipt of SDS, and we would like to continue to see this number grow.

Notwithstanding the progress made to date and the examples of good practice highlighted in the report, we recognise that there is still more that can be done to improve people's experiences of SDS. This is evident from the report's findings, particularly around the timing, quality and accessibility of information received by some service users to inform choices and care planning decisions.

We also wish to highlight that the report includes some comments expressed by service users regarding professional practice which we consider merit further investigation,

but are advised that we are unable to do so without compromising the anonymity of respondents. We therefore encourage any individual who is concerned about the service they or a family member has received to raise this with us and information on how to do so can be found at the link below: **https://www.glasgow.gov.uk/index.aspx?articleid=17304**

GCHSCP will give careful consideration to the recommendations within this report and where necessary, identify opportunities to improve practice. We intend to progress this as part of a wider piece of work to review and refresh our SDS processes and supporting information in the context of the national SDS standards published earlier this year. We are very keen to involve service users, families, carers and partner organisations in this work and will be setting out a proposed approach in coming months.

Finally, I would like to acknowledge this valuable piece of work undertaken by the Health and Social Care Alliance Scotland and Self Directed Support Scotland, as well as the opportunity to comment on the report's findings.

Susanne Millar

Chief Officer

Glasgow City Health and
Social Care Partnership

Glasgow City
HSCP
Health and Social Care Partnership

Endnotes

1 To support readability, the 'N' number is not reported for all survey question responses. Due to the relatively small number of interviewees being discussed in this report (11 interviews, spanning 12 people's experiences of SDS), we use "some" or "several" to refer to three or four interviewees, "many" to refer to five or six interviewees, and "the majority" to refer to seven or more interviewees.

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

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

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

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

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

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

8 NRS Scotland, ‘Glasgow City Council Profile’. Available at: https://www.nrscotland.gov.uk/files/statistics/council-area-data-sheets/glasgow-city-council-profile.html.

9 BBC, ‘Scotland’s most deprived and least deprived areas named’ (28 Jan 2020). Available at: https://www.bbc.co.uk/news/uk-scotland-51279966. See also Scottish Government, *Scottish Index of Multiple Deprivation 2020: introduction (2020)*, p. 5. Available at: https://www.gov.scot/publications/scottish-index-multiple-deprivation-2020/pages/5/.

10 Glasgow City Council, ‘Personalisation’. Available at: https://www.glasgow.gov.uk/personalisation.

11 Glasgow City Council, ‘Carers’. Available at: https://www.glasgow.gov.uk/carers.

12 Glasgow City Council, ‘Direct Payments’. Available at: https://www.glasgow.gov.uk/directpayment.

13 Information Services Division (now Public Health Scotland), *Insights into Social Care in Scotland: Support provided or funded by health and social care partnerships in Scotland 2017/2018 (11 June 2019)*. Available at: https://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/Publications/index.asp?#2399. More recent data is also available from PHS, published after MSMC analysis was complete. Further information is 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/.

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

15 Ibid.

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

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

18 NRS Scotland, ‘Glasgow City Council Area Profile’. Available at: https://www.nrscotland.gov.uk/files/statistics/council-area-data-sheets/glasgow-city-council-profile.html.

19 Scotland’s Census (2011), ‘Ethnicity, Identity, Language and Religion’. Available at: https://www.scotlandscensus.gov.uk/.

20 Ibid.

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

22 Ibid.

23 Scotland’s Census (2011), ‘Ethnicity, identity, Language and Religion’. Available at: https://www.scotlandscensus.gov.uk/.

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

25 Scottish Government, ***Poverty and income inequality in Scotland: 2015-2018 (2018)***, p. 1. Available at: https://www.gov.scot/publications/poverty-income-inequalityscotland-2015-18/pages/1/.

26 Ibid., p. 12.

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

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

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

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

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

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

33 Your Support Glasgow, "Personalisation (Self Directed Support)", available at: https://www.yoursupportglasgow.org/glasgow-homepage/pages/personalisation-self-directed-support/content/personalisation-self-directed-support/. See also "Personalisation Guide", available at: https://www.yoursupportglasgow.org/Guide/Show/8863.

34 Glasgow City Council, "Personalisation". Available at: https://www.glasgow.gov.uk/index.aspx?articleid=17329.

Glossary

Budget / Hours / Package

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

Charging Policy

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

COSLA

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

Direct Payment

See "Option 1".

Disability

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

Eligibility Criteria

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

Guardian

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

Health and Social Care Partnership / HSCP

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

Independent Advocacy Service/ Independent Advocate

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

Independent Living

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

Independent Living Fund / ILF

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

Independent Support Organisation

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

Integration Joint Board / IJB

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

Impairment

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

Local Authority / LA

Local council (32 across Scotland).

Needs Assessment

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

Option 1 (also called “direct payment”)

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

Option 2

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

Option 3

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

Option 4

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

Occupational Therapist / OT

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

Personal Assistant / PA / Support Worker

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

Personalisation

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

Physical Impairment / Physical Disability

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

Reablement

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

Self-directed Support / SDS

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

Short Breaks

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

Sleepovers

The provision of care and support services overnight.

Social Care

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

Support Plan

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

Support Worker

See Personal Assistant / PA.

Unpaid Carer

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

About the Project Partners

ALLIANCE
HEALTH AND SOCIAL CARE
ALLIANCE SCOTLAND
people at the centre

About the ALLIANCE

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

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

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

The ALLIANCE has three core aims; we seek to:

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

Self Directed
Support Scotland
the organisation of choice

About Self Directed Support Scotland

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

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

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the organisation of choice

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