My Support My Choice:

People with Mental Health Problems’ Experiences of Self-directed Support and Social Care

Thematic Report, December 2020

Self Directed Support Scotland
the organisation of choice

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HEALTH AND SOCIAL CARE
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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. It is dedicated to members of the research team and those who shared their experiences as participants, who have since passed away.

About this Report

This report uses data[1] about people with lived experience of mental health issues who participated in “My Support, My Choice: User Experiences of Self-directed Support in Scotland” (MSMC), a research project run by the Health and Social Care Alliance Scotland (the ALLIANCE) and Self Directed Support Scotland (SDSS), funded by the Scottish Government.

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

COVID-19

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

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

Executive Summary

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

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

This document is part of a suite of MSMC reports and focuses on the experiences of people with lived experience of mental health issues who use SDS/ social care in Scotland. Between November 2018 and February 2020, MSMC heard about the experiences of 121 people who described themselves as having mental health problems via a survey, interviews and focus groups. Research took place prior to the appearance of COVID-19 in Scotland, and this report does not reflect people's experiences during the pandemic.

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

Poverty and SDS

An estimated 24% of Scottish households with a disabled person live in relative poverty after housing costs, and 72% of people with lived experience of mental health problems who provided income data for MSMC lived below the poverty threshold. National and local public bodies should take action to ensure that reductions in SDS budgets and tightened eligibility criteria do not negatively impact people with lived experience of mental health issues on low incomes who access or are trying to access social care, which can result in severe isolation and loneliness, deterioration in mental health, and suicidal ideation.

Data Gathering and Analysis

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

Overall Experiences of SDS

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

Information About SDS

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

Most people with lived experience of mental health problems indicated they required more information before deciding how their support would be arranged. Many people had not been told about all four options when they started the process of accessing SDS, and some had not been provided with information or documentation, even after requesting it from social work departments.

Around one third of respondents with lived experience of mental health problems reported outstanding concerns that were not addressed at their last assessment or review. The main issues highlighted included budgets, delays in implementing care and a lack of information about SDS.

Recommendations include ensuring that information is available at different points in a person's journey through the SDS system/process, e.g. finding out/first enquiry about SDS, pre-needs assessment, during needs assessment, after needs assessment, and once support is in place. Social work professionals should proactively check in with people after assessments to ensure outstanding concerns are addressed and resolved.

Informed Choice and Control

About half of respondents with lived experience of mental health problems felt they had enough time to choose their SDS option. It is encouraging that the majority indicated they were on their preferred SDS option and were offered the choice of who would manage their personal budget. However, the findings that a third had their SDS option chosen for them by a social worker (rather than choosing themselves) and one quarter were not offered a choice of who would manage their budget are concerning.

Recommendations include ensuring that people with lived experience of mental health problems are provided with the full range of SDS options and supported to advantages and disadvantages of each before making a meaningful choice. while professionals play an important roles in supporting access to appropriate services; this should not extend to making decisions on people's behalf.

People with lived experience of mental health problems who were on their preferred SDS option described how their support enabled them to do a diverse range of activities. However, others spoke in detail about the barriers faced in trying to access SDS for mental health reasons, as well as the negative impact on their mental health of substantial reductions to their support. Our findings suggest that some people experience inconsistent approaches on key issues like eligibility and budgets, and disjointed practice between mental health and social work teams. The impacts of not providing adequate, rights based, person centred SDS can be devasting, resulting in severe isolation and suicidal ideation.

Communication and Relationships with Social Work

People with lived experience of mental health issues highlighted that good conversations require effective communication, access to information, prompt decisions and good future planning.

Just under one half of respondents with lived experience of mental health problems reported being happy with the conversations they had about their support with professionals. These participants highlighted the importance of social workers having a breadth and depth of knowledge about SDS and local services, good listening skills and empathy, and taking time to listen to them and become familiar with their needs. Consistency of social workers is viewed as important because it gives people time to build trusting relationships.

Other people with lived experience of mental health problems reported less positive communications and relationships with social workers. Some reported a need for greater transparency about how care decisions were made and by whom, some people felt they weren't being listened to, and that their decisions and preferences weren't respected. Others felt that meetings were rushed and had difficulty obtaining information and answers to their questions. Some people with lived experience of mental health problems shared troubling stories of stigma and discrimination.

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, and access to appropriate training and ongoing support on equalities, human rights, intersectionality and conscious and unconscious bias at regular intervals.

Social work professionals should proactively inform services users 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).

Care Worker Recruitment, Training, and Quality

People with lived experience of mental health problems report mixed experiences of support worker recruitment, training and quality, and several indicated difficulties finding and retaining Personal Assistants (PAs) and support workers that are suitable for their requirements. Some people with lived experience of mental health issues would welcome more support to arrange staff training and recruitment from the local authority or relevant support organisations. Recommendations include ensuring that care staff training costs (e.g. specialist first aid or medical training required for them to carry out their job appropriately) are included in people's SDS budgets, to support a quality PA workforce.

Independent Advocacy and Support

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

Recommendations

People with lived experience of mental health problems generally reported that SDS had improved their social care experience. However, as the research highlights, there are some key improvements that could be made, which would respond to people's concerns, build on existing practice and increase the effectiveness and reach of positive SDS experiences.

Poverty and SDS

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

Data Gathering and Analysis

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

Information About SDS

3. People with lived experience of mental health problems and social work staff need access to good quality information in a range of accessible and tailored formats about the different SDS options.

4. Information is required at different points in a person's journey, e.g. finding out/first enquiry about SDS, pre-needs assessment, during needs assessment, after needs assessment, once support is in place, and further reviews.

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

6. More information should be available about what to expect from interactions with social work, and about people's rights.

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

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

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

10. People with lived experience of mental health problems should be informed about all four SDS options, rather than being given information about a more limited list of options.

11. If emergency support is put in place following hospital discharge, this should be followed by further discussions with the person regarding their options and preferences.

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

13. Professionals should proactively check in with people after assessments to address any outstanding concerns.

14. People should be promptly provided with all information pertaining to their SDS, including Personal Outcome Plans, budget agreements, and decisions about their support package. All information should be available in a variety of accessible formats.

15. People with lived experience of mental health problems should be offered a variety of options on how to contact social work, as best fits their access needs and preferences. Social work departments should consider different options, including online chat functions, a freephone support line, and/or direct email addresses so that people can communicate effectively with social work professionals.

Informed Choice and Control

16. People with lived experience of mental health problems should be given enough time to choose their preferred SDS option.

17. People with lived experience of mental health problems should be supported to consider the advantages and disadvantages of each SDS option before making an informed decisions.

18. Improvements could be made to safeguard supported – rather than substitute – decision making by people with lived experience of mental health problems about their care and support.

19. Any proposed changes (particularly reductions) in budgets or support should be communicated to – and discussed with – people with lived experience of mental health problems well in advance.

20. Social work professionals and decision makers should consider the significance of social engagement for people with lived experience of mental health problems (and their mental health) before reducing any support.

21. People have the right to expect a reasonable notice period for needs assessments or reviews, and their right to have another person present during the assessment should be respected by social work professionals.

22. Professionals should use equality impact assessments in their processes – both for service users and their families.

Communication and Relationships with Social Work

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

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

25. Social workers need to have good listening skills and empathy, and the time and skills to build relationships and trust with people

with lived experience of mental health problems and unpaid carers.

26. Social workers should be trained in supported decision making, to prioritise people's ability to choose and reduce the number of cases where social workers are making decisions about which SDS option people use, and who manages personal budgets.

27. 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.

28. No person with lived experience of mental health problems should encounter discriminatory language or attitudes from health or care professionals. Appropriate training and ongoing support on equalities, human rights, intersectionality and conscious and unconscious bias should be provided to staff at regular intervals.

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

30. 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).

31. 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.

Care Staff Recruitment, Training and Quality

32. Some people with lived experience of mental health problems need more help from local authorities and health and social care partnerships 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.

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

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

Independent Advocacy and Support

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

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

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

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

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

39. Local peer networks should be encouraged and supported.

Research Participants

The MSMC project heard about the SDS/ social care experiences of 121 people with lived experience of mental health problems. 91 people completed the survey, we interviewed ten people who spoke about their own experiences and those of other members of their household who use SDS, and 20 people participated in focus groups. Throughout this report some participant details (e.g. age) have been changed slightly to preserve anonymity, while maintaining the most important information. Where changes have been made to quotations those alterations are indicated via square brackets (e.g. “My advocate, [Name], has been great”).

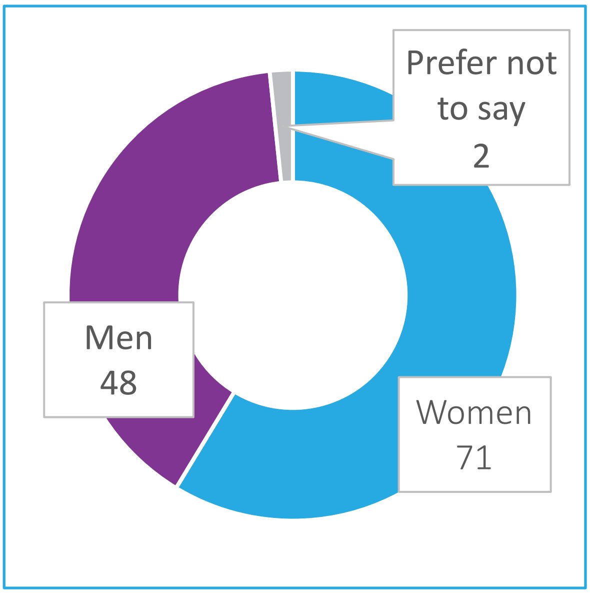
According to figures published by NHS Scotland, an estimated one in six adults in Scotland experiences a mental health problem at any one time. This figure is higher among disabled people and people living with long term conditions,[4] and is also higher among people living in Scottish Index of Multiple Deprivation (SIMD) communities.[5]

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

Gender

Overall, 71 women and 48 men with lived experience of mental health problems participated in MSMC. Two people preferred not to disclose their gender. ISD figures are not available for women and men accessing SDS in 2017-18, however they do publish statistics on the number of women and men accessing social care support services more generally – of whom an estimated 45% access SDS – although not every local authority submitted gender disaggregated data. ISD report that in 2017-2018 62% of people accessing social care support were women and 38% were men.[7] Gender disaggregated data of people with lived experience of mental health problems who access SDS is not available on the ISD dashboard.

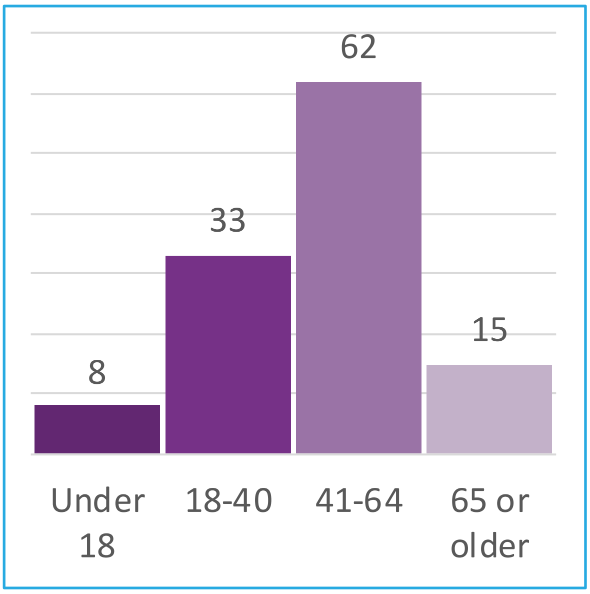
Chart 1: Respondents' gender



Age

We asked all participants to share their age. Of the participants who chose to answer the question, eight respondents were under 18 years old, 33 were aged 18 to 40 years, 62 were aged 41 to 64 years, and 15 were 65 or older. Three participants did not wish to share their age.

Chart 2: Respondents' age



ISD's SDS 'Client Group Profile Data' indicates that in 2017-18, 24 people aged 17 and under accessed SDS for support with mental health, 3,387 people aged 18-64 years, 1,036 aged 65-74 years, 942 aged 75-84 years, and 569 aged 85 and older.[8]

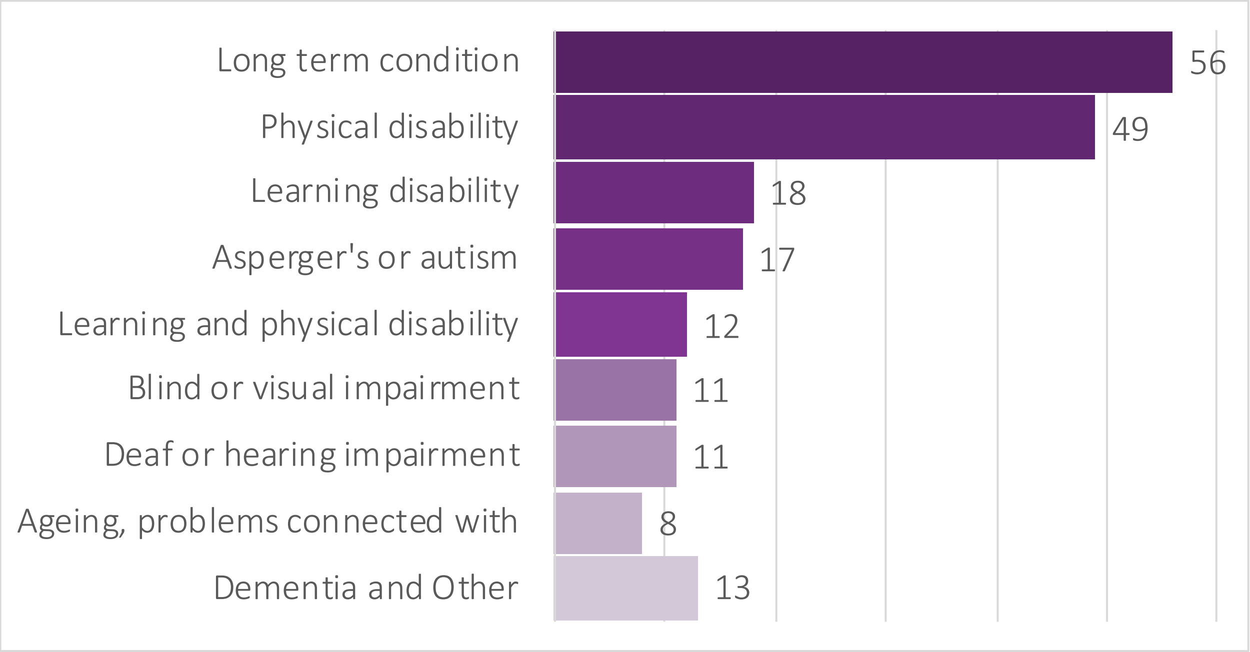
Ethnicity

88 MSMC survey respondents with lived experience of mental health problems identified as white and three people identified as belonging to other groups. None of the interview or focus group participants explicitly disclosed their ethnicity when self-describing themselves. The spread of respondents is slightly less ethnically diverse than is typical for Scotland.

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

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

Chart 3: Client group/disability/long term condition in addition to "mental health" (Survey)



Client Group/Disability/Long Term Condition

MSMC survey respondents who self-identified as having mental health problems also lived with a range of other conditions, and the majority reported that they lived with multiple conditions. In addition to self-identifying as having mental health problems, 56 people (62%) said they lived with a long term condition, 49 (54%) selected "physical disability", and 18 people (20%) selected "learning disability". Only eight people (9%) reported that they had mental health problems and no other condition.

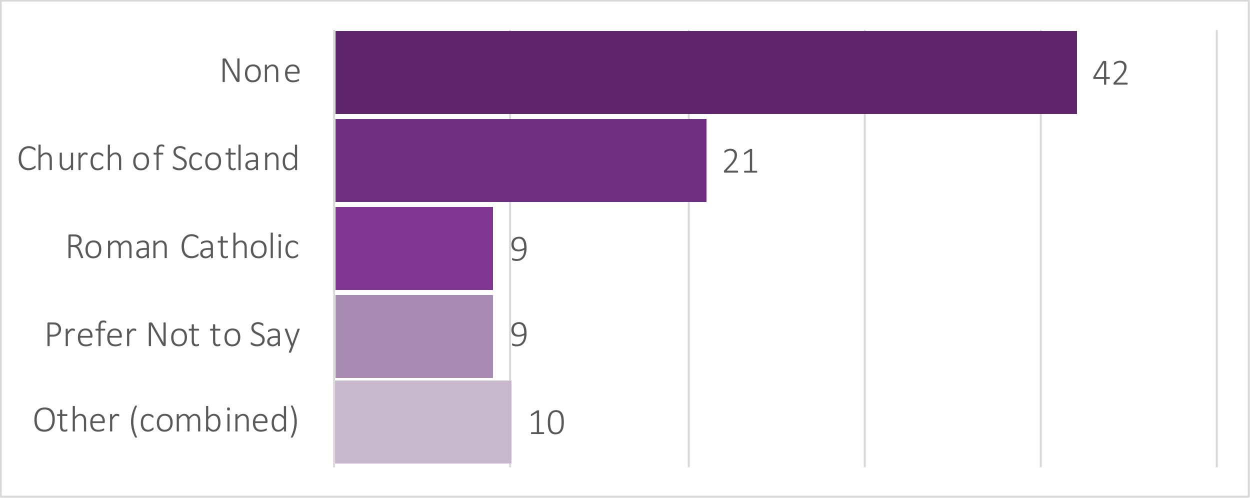
ISD data indicates that during 2017-2018, 12,936 people accessed social care services for support with mental health problems (6.4% of people receiving social care support), and 5,959 people are indicated as belonging to the SDS 'Mental Health' client group.[10]

Religion

When asked about their religion (if any), 42 survey respondents with lived experience of mental health problems stated "none", 21 belong to the Church of Scotland, nine identified as Roman Catholic, eight described themselves as "other Christian", two identified as belonging to other religions, and nine preferred not to answer. None of the interview or focus group participants explicitly disclosed their religion when self-describing themselves. These results are slightly less diverse than 2011 Scottish Census data for Scotland.

Data on people's religion is not available on the ISD dashboard.

Chart 4: Survey respondents' religion

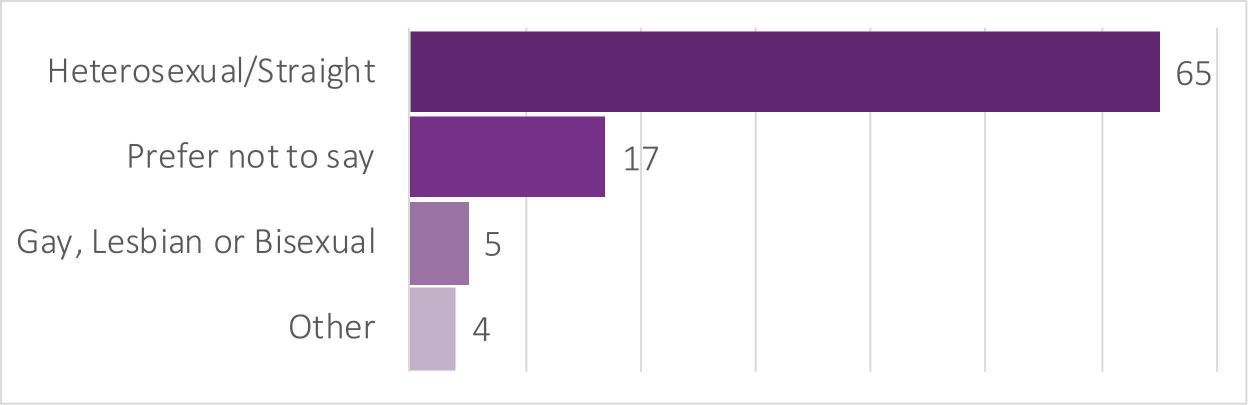


Sexual Orientation

65 survey respondents with lived experience of mental health problems described their sexual orientation as heterosexual or straight, five people identified as gay, lesbian or bisexual, and four people selected "other". 17 people preferred not to answer the question. A small minority of the interviewees and focus group participants self-described themselves as part of the LGBT+ community. The 2011 Scottish Census did not record data on sexual orientation at local authority level (although the 2021 Scottish Census will do so); as such, we do not have local statistics on sexual orientation available as a comparison.

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

Chart 5: Survey respondents' sexual orientation

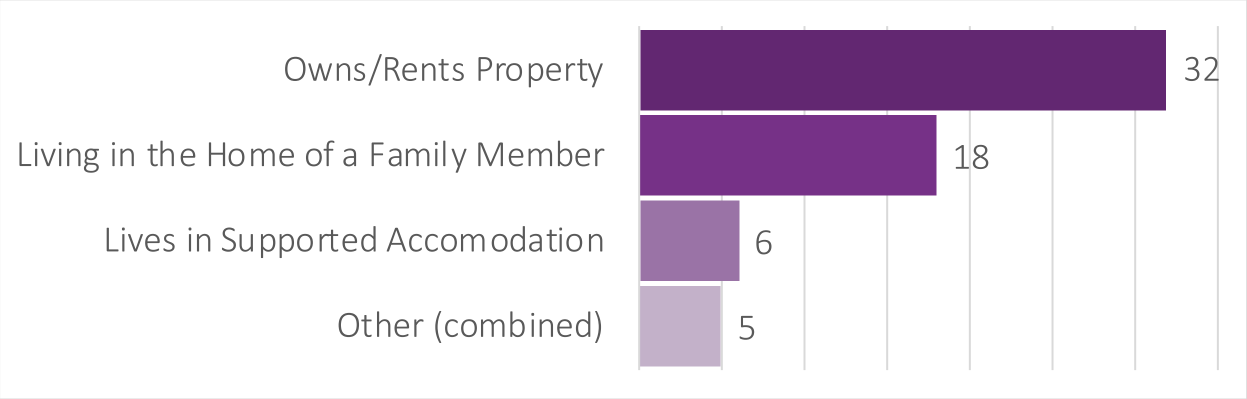


Housing

Of those respondents who answered this question, 32 people with lived experience of mental health problems either rented or owned their own home, 18 people stated that they lived in the home of a family member, and six people lived in supported accommodation.

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

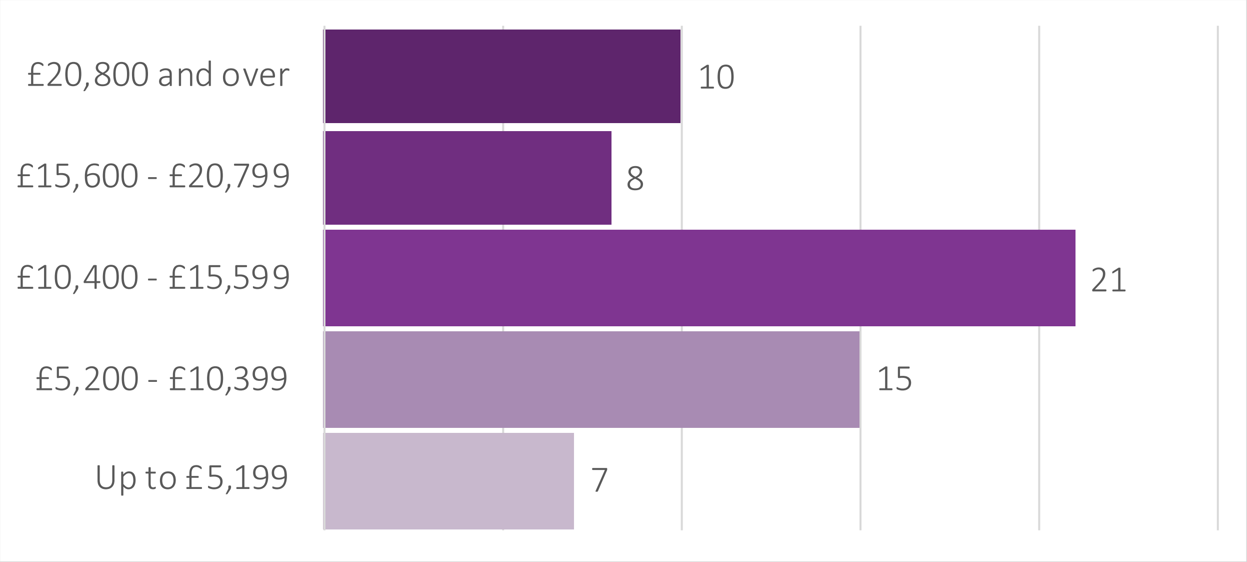
Chart 6: Survey respondents' housing arrangements



Household Income

We asked survey respondents about their household income. We are interested in this information because within Scotland an estimated 24% of households with a disabled person live in relative poverty after housing costs, compared to 17% of the population with nobody with a disability in the household.[11]

Chart 7: Survey respondents' annual household income



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

According to Scottish Government data, the median household income in Scotland in 2015-2018, before housing costs, was £499 per week (£25,948 per annum).[12] The relative poverty threshold was defined as household income below 60% of the median, which for the same period was defined as £302 per week

(£15,704 per annum).[13] Based on this definition, 43 (72%) of the people with lived experience of mental health problems who provided details of their household income are living below the poverty threshold.

Poverty and SDS: Reductions in SDS budgets and tightened eligibility criteria can pose serious risks to people with mental health problems on low incomes who access or are trying to access social care. It can result in severe isolation and loneliness, further deteriorations in physical and mental health (and potentially more intensive and expensive intervention later on), and suicidal ideation.

SDS Option

Of the MSMC participants with lived experience of mental health problems who shared which SDS option they used, 36 people (49%) indicated they use Option 1, ten people (14%) use Option 2, 13 people (18%) use Option 3, and four people (5%) use Option 4. A further ten people (14%) did not know what option they used.

ISD data indicates that in 2017-2018 there were 8,390 people in Scotland using SDS Option 1, 7,435 people using Option 2, 78,054 people using Option 3, and 4,257 people using Option 4.[14] In some instances, people were incorrectly logged as being on two options simultaneously (e.g. Options 1 and 3) rather than Option 4, which skewed these figures. ISD data does not indicate which SDS option people with lived experience of mental health options use across Scotland.

Data on the SDS options chosen by people with lived experience of mental health problems for 2017-18 is not available on the ISD dashboard.

Data Gathering and Analysis

As this chapter demonstrates, there are concerning gaps in SDS data gathering and analysis. Information Services Division (ISD) have reflected on difficulties gathering disaggregated data on people's use of and experiences of SDS/ social care in their experimental statistics publication Insights into Social Care in Scotland.[15] They highlight differences in reporting periods for social care data across local authorities, and that some local authorities and social care partnerships were either not tracking or not able to share disaggregated data about SDS and the people using it.[16] Data gaps are also in part due to existing patterns of data collation – leading, for example, to the ISD Social Care Information Dashboard tracking ethnicity via the limited and problematic categories of "White", "Other", and "Not provided/Not known".[17]

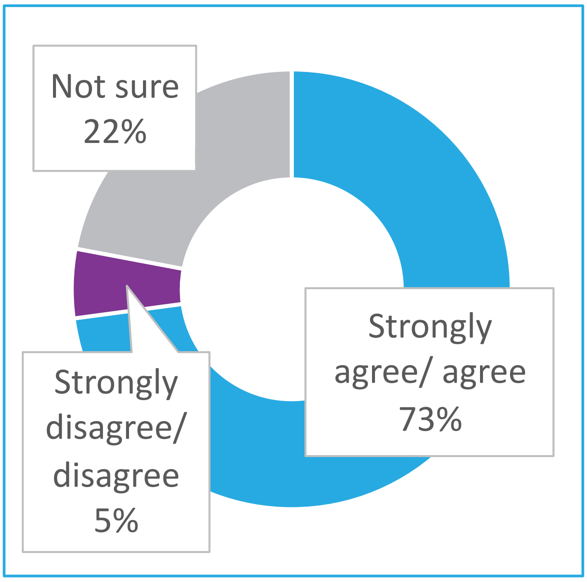
Data Gathering and Analysis: Disaggregated data gathering and intersectional analysis is essential to develop fully realised policies and practices that prioritise equal access to SDS/ social care for everyone, including people with lived experience of mental health problems, following human rights principles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

Overall Experiences of SDS/ Social Care

We asked survey respondents whether they felt that SDS had improved their social care experience.

43 people with lived experience of mental health problems (73%) stated that they "strongly agree" or "agree" with the statement "SDS would/has improve/d my social care experience". Only three people (5%) disagreed or strongly disagreed with that statement. 13 people (22%) responded that they were unsure.

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



One interviewee with lived experience of mental health problems summarised the positive impact of SDS on their life as follows:

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

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

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

Survey participants were also asked to share an overall summary of their experiences and any advice they might have to offer other people considering using SDS. Many statements by people with lived experience of mental health problems were positive, such as:

> *"Do it!" (x2)*
>
> *"Go for it." (x3)*
>
> *"It gives you greater options and choices."*
>
> *"It's been a really good experience for me."*

"If you have the right support it's worth doing."

"I think this is the best option to give people exactly what they need for support."

"It's worth doing if you really need very person centred care and support."

"The bureaucracy is a nightmare, but the flexibility and choice it gives is priceless."

"It's helped me a great deal. At the start I wasn't keen on it but knowing the help I get now I would say to someone who is considering to go ahead with it."

"In Scotland we are very privileged to have an excellent system of SDS in place and when done properly it is amazing and so it is definitely worth applying."

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

However, some respondents were more cautious or explicitly negative about their experiences of SDS, particularly relating to difficulties with paperwork and assessment processes, insufficient budgets, and stigma around mental health problems:

"Don't bother." (x3)

"Not worth the stress."

"It's like getting blood out of a stone."

"Be prepared for a nightmare of paperwork."

"A lot of extra stress when you're already at breaking point."

"It is invasive and stressful and then you don't get any help anyway."

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

"Be aware that your mental health issues if you have them will lead you to be treated as if you are intellectually challenged. The social work assessor in my case delayed matters then sent my needs form off without a second meeting, any input I had prepared, [and] expected to attend a psychiatric appointment without asking my permission."

"Be prepared for a VERY long process and feeling hopeless a lot of the time. Don't think that the money is going to change your life. My budget was a very appreciated sum of money but […] I can barely afford to put food on the table and clothe my children without help from baby bank and very soon a food bank."

"I would tell them it is a lot of work, and that if they don't have internet access it would be impossible."

"Read up on SDS. be prepared for a fight with social work. Be prepared to be fobbed off and told there is no money. Be prepared to be only given one option. Stand up for yourself and your family. Be really clear what it is you want from SDS."

"Don't be afraid to be pushy. Don't be afraid to go […] to your MP […] if you're fed up of years of waiting."

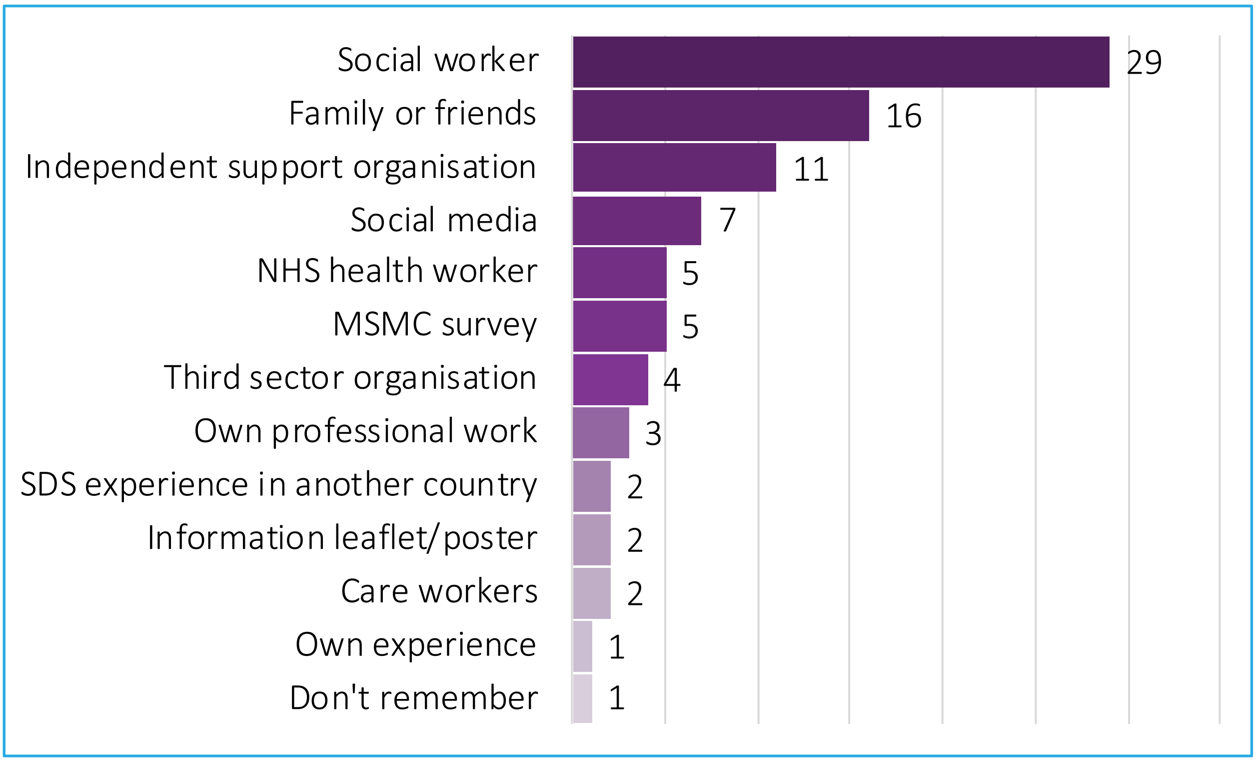
"I'd say find out what questions the assessment is based on first and have a think about

your answers. Have a look at the relevant legislation to ensure it is being followed.”

“I made a simple A4 sheet with bullet points of all the things needed to do to set up SDS for a friend. This included suggestions of insurance firms, suitable bank accounts, accountants, contracts, advert for carer, etc. This would have helped me immensely and it’s the poor documents and poor knowledge from the people who are supposed to be helping that I felt that I was having to research so much myself online and make it work on my own. It was hard and stressful. It didn’t need to be.”

Information about SDS

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



Finding Out About SDS

We asked people how they first found out about SDS. Of the survey respondents who answered the question, 29 (32%) had first heard about SDS from a social work professional, 16 people (18%) heard from friends or family members, 11 (12%) from an independent support organisation, seven from social media (8%), five from NHS health staff (6%), and four from third sector organisations (4%). Three people learned about SDS through their own professional work (respectively, in social work, academia, and the third sector), two from an information leaflet or poster, two from care workers, two from having received SDS in England before moving to Scotland, and one from their "own experience". One person did not remember how they first heard about SDS. A further five people first heard about SDS via the MSMC survey. Among the interviewees and focus group participants, the most common method through which people with lived experience of mental health problems first heard about SDS was from a social worker. This was followed by people hearing from an independent support organisation or a health professional.

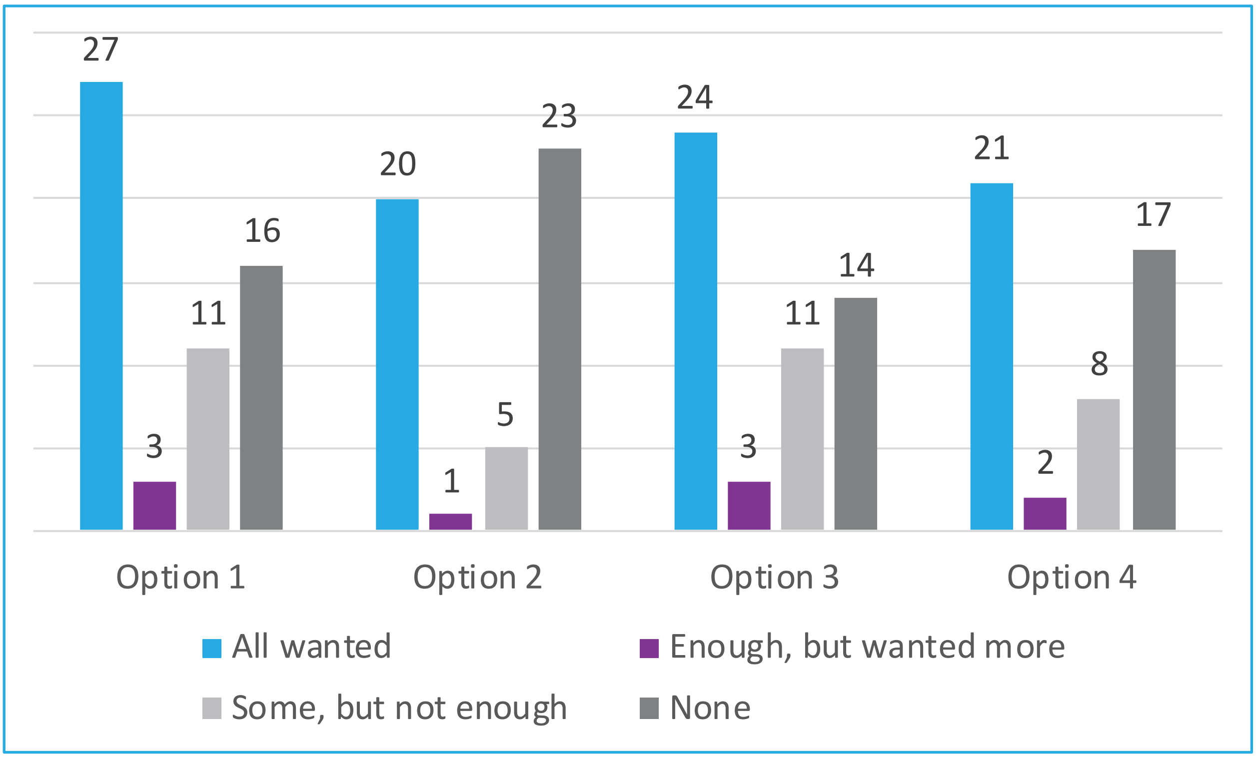
Finding Out About SDS: Overall, the results indicate that it would be helpful to widen the pool of professionals who are informed about SDS and can encourage people with lived experience of mental health problems to access it. Making more use of health and education professionals would be particularly valuable, as well as building on the existing expertise of social workers, independent advice and support organisations. Greater use of health professionals in the process would also help to strengthen the integration of health and social care.

Information and Preparedness Before Assessments

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

While some respondents with lived experience of mental health problems indicated that they received all the information they wanted in advance, most indicated that they wanted more information before deciding how their support would be arranged.

Chart 10: Information received before discussing support (Survey)



As the chart indicates, across all four SDS options, while some respondents received “all the information [they] wanted” (respectively, 47% (Option 1), 41% (Option 2), 46% (Option 3) and 44% (Option 4)), similar numbers of people were left wanting more information in advance of their needs assessment.

Of the respondents who felt they needed more information before meeting with a professional to discuss their support, 47% stated that they either received “some, but not enough” or no information at all about Option 1, while a further 5% said they had received “enough” information “but wanted more”. With Option 2 (which had the lowest satisfaction rate across the options), 57% of respondents reported that they had either “some, but not enough” or no information, with 2% receiving “enough, but wanted more”. For Option 3, 48% of respondents said that they had either “some, but not enough” or no information, and 6% had “enough, but wanted more”. Finally, 52% of respondents said they had received either “some, but not enough” or no information about Option 4, while 4% received “enough, but wanted more”.

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

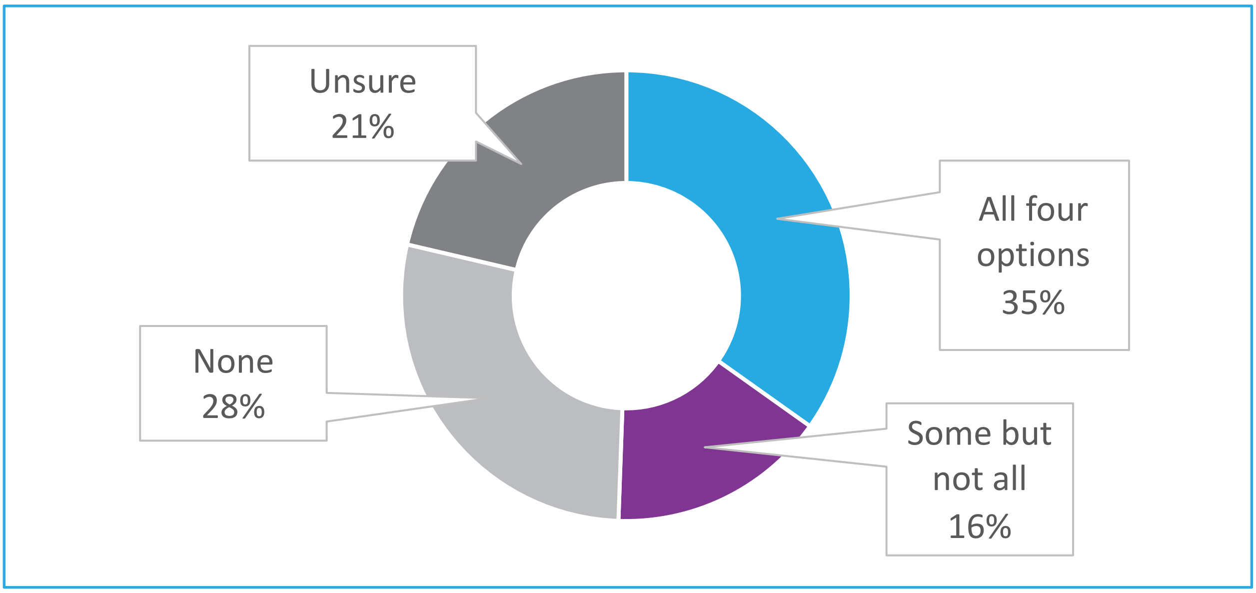
Information Before Assessments: These findings indicate that while some people with lived experience of mental health problems are receiving good quality information about the four SDS options in advance of needs assessments, most people require better information. More comprehensive high-quality information about the different options should be provided to people as well as advertising carers’ assessments and support plans. Overall satisfaction with advanced information about all SDS options could be improved, particularly with regards to Options 2 and 4. The benefits of earlier high-quality information include: early intervention, before people reach crisis point; reduced demands on staff time because people are better prepared for discussion and assessments; greater use of NHS staff in the process, strengthening integration of health and social care.

Information During Assessments

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

Of the 89 people who answered this question, 35% stated that the professional discussed “all four options” with them. However, 16% also reported that “some but not all” options were discussed with them, and 28% stated that “none” of the options were discussed. A further 21% stated that they were “unsure” which options were discussed with them during that meeting. This pattern indicates that more work needs to be done to fully outline and discuss the four options with people with lived experience of mental health problems during their needs assessments and reviews.

Chart 11: Discussing SDS options with professionals (Survey)

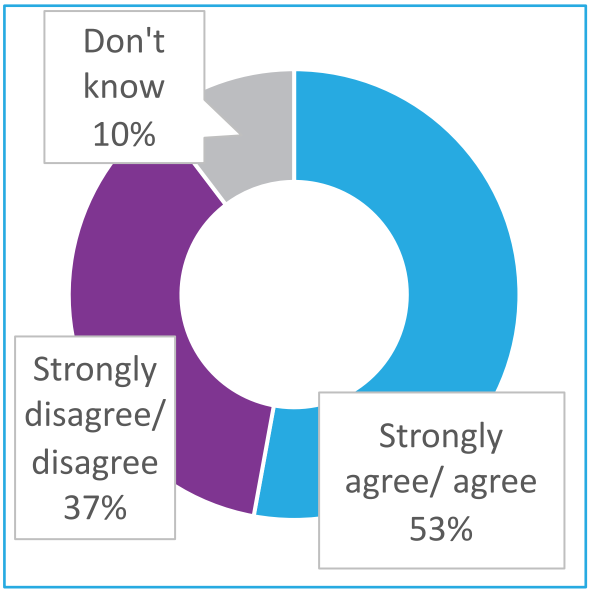


Some interviewees and focus group participants reflected on positive experiences during their needs assessments and reviews. However, many people stated that social workers did not explain the process around SDS properly to them in a way they could understand. Others stated that they did not understand SDS, even though they were receiving social care support.

In the survey, we asked people to respond to the statement "All my questions were answered", regarding their meeting with a social work professional. Of the 86 people with lived experience of mental health problems who answered this question, 37 (43%) strongly agreed or agreed, while 42 (49%) strongly disagreed or disagreed. A further seven people (8%) said that they did not know. Interviewees and focus group participants reported similar experiences.

In the survey, we also asked respondents if they agreed with the statement "The person I met with explained things clearly to me". 46 people (53%) with lived experience of mental health problems either "strongly agreed" or "agreed" with the statement, while 32 people (37%) disagreed or strongly disagreed, and nine people (10%) were unsure.

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



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

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

Outstanding Concerns and Appeals

We asked survey respondents whether they had any concerns that were not addressed during their last assessment or review. Of the 87 respondents with lived experience of mental health problems who answered this question, 32 (37%) had outstanding issues that were not addressed by social work, 18 (21%) were unsure, and 37 (43%) had no concerns.

Of those respondents with unaddressed concerns, the main issues included their budgets, delays in implementing care, and a lack of information about SDS and wider social security entitlements. People highlighted that these issues had direct and negative impacts upon their health and the health of the people for whom they care. Two people who had been the victims of crimes reported that they did not feel their safety concerns were addressed during their needs assessments. One person reported that their local authority was pressuring them to enter residential care rather than access SDS and remain in their own home.

Some respondents with unaddressed concerns at the end of their meeting with a social work professional provided further information, as follows:

> *"Budget brushed over too quickly. I had two [more] concerns: why no real review, [and] why no training for PAs?"*

> *"I was not given enough information about how much of a budget I would receive, which*

made it difficult to know if my needs were going to be met."

"How to use my budget when it was allocated. Significant delays in the budget being allocated due to the complexity of the […] process."

"[Specific local authority] are in breach of COSLA guidance and are hugely overcharging me for my care contributions – they have put me into thousands of pounds of debt. They are taking my whole DLA care allowance even though it is partially awarded for [specific medical condition]. I am suffering, [and] I face a brick wall with this problem."

"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."

"I suffer [from specific condition] and have psychological issues relating to being a victim of abuse. There was no attempt to find a way to put some form of care support in place or put me in the direction of places. I was not told what my budget would be, so neither my partner nor myself could look at options. There was no information on how […] this would affect household benefits and my PIP."

"My personal safety at home, risks to me following a crime committed against me, [and] how I felt."

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

We also asked all survey participants whether they were in the process of appealing the decision made in their last review or needs assessment. Overall, 25 people (7%) indicated that they are in the process of appealing the outcome of their last social care assessment or review, including six people with lived experience of mental health problems.

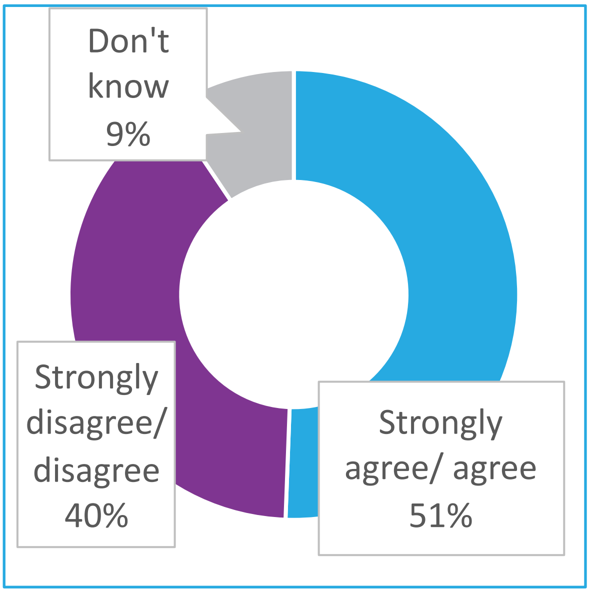
Outstanding Concerns and Appeals: The research invites further work to strengthen and embed existing good practice to ensure that people with lived experience of mental health problems are not left with unaddressed concerns following needs assessments. People should be provided with alternative, accessible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

Informed Choice and Control

Time to Consider Options

We asked survey respondents whether they agreed with the statement "I had enough time to choose the option of SDS that suited my needs." Of the 85 respondents with lived experience of mental health problems who answered this question, 43 (51%) either agreed or strongly agreed, 34 (40%) either disagreed or strongly disagreed, and eight people (9%) stated that they did not know.

Chart 13: Enough time to choose SDS option (Survey)



Overall, around half of all respondents with lived experience of mental health issues felt that they had enough time to choose their SDS option, and an important minority would have liked more time before deciding – a result that has strong overlaps with those people who wanted more information before deciding.

Time to Consider Options: The research indicates that more work could be done to ensure that people with lived experience of mental health problems have enough time to choose their preferred SDS option. There is also a correlation between the time people are given and the need for clear, prompt and accessible information so that people are able to make informed and appropriate decisions about their support.

Choice Over SDS Option and Support

We asked survey respondents if they were on their preferred SDS option. Of the 62 people with lived experience of mental health problems who answered, 50 people (81%) were on their preferred option, with the remaining respondents either unsure (nine people) or not on their preferred option (three people).

It is positive that most people with lived experience of mental health problems are on their preferred SDS option, however, the findings related to who chose the way that support is arranged render this finding more problematic.

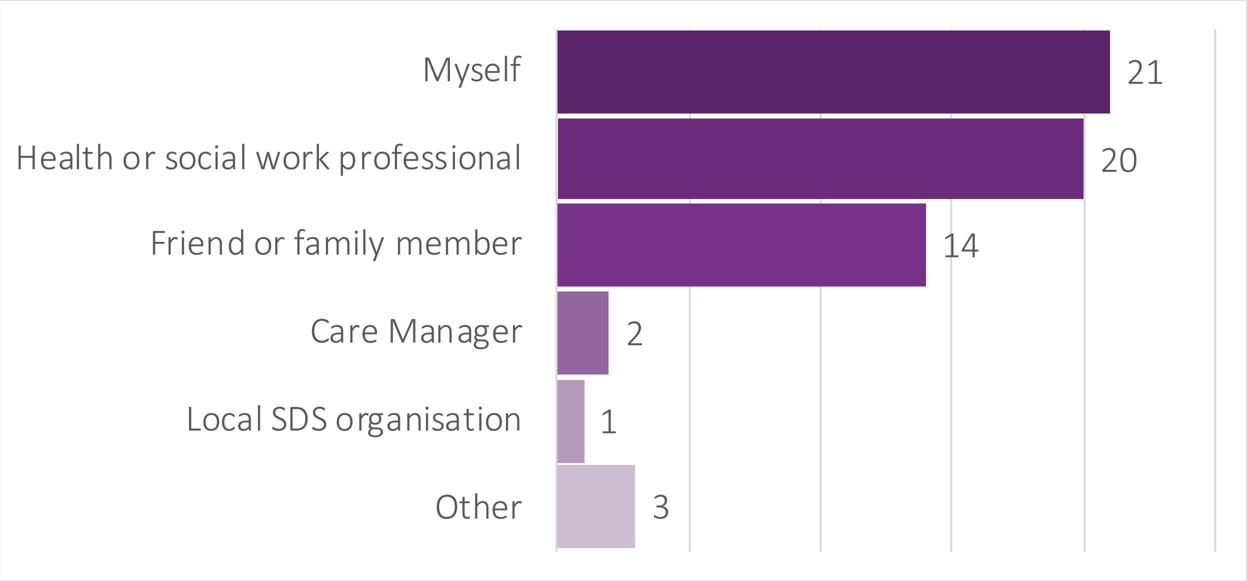
Of the 61 people with lived experience of mental health problems who answered this question, 21 people (34%) said that they chose the way their support was arranged – including one respondent who said "I chose, but I had to fight for it", and another who said "it was what I wanted at the time".

20 people (33%) with lived experience of mental health problems said that a social worker chose for them (including

one who stated that the decision was shared between their social worker and a community psychiatric nurse), with a further two people reporting that their care manager chose for them. 14 people (23%) with lived experience of mental health problems stated that a friend or family member chose for them, one person reported that a local SDS organisation chose how their support was arranged, and a further three people selected "other"; of these, one did not provide further details, one respondent stated that they didn't know, and one person said that the decision was shared between themself and a professional.

Overall, these findings indicate that while a third of people with lived experience of mental health problems chose their support, a similar proportion state that social work or health professionals chose for them. This proportion is higher than is typical compared to other groups that took part in the MSMC research project and invites further work to embed supported decision making (instead of substitute decision making) in SDS/ social work and healthcare practice.

Chart 14: Who chose support arrangements? (Survey)



Of the people with lived experience of mental health problems who spoke to the research team in interviews and focus groups, several felt that they had been offered limited or no choice over how their SDS was arranged, without all four SDS options being offered. One person reported that "we are not able to make choices and decisions; it's the ones above us." Another respondent summarised their experience as follows:

> *Respondent: It must have been my social worker, the doctors [who chose specific provider].*
>
> *Interviewer: You didn't have a say in the decision?*
>
> *Respondent: No.*

Another person was informed by their social worker that they would be placed "on Option 3, that the council is paying towards [their] support" and "all she said is that I will have to contribute", without any discussion of other options. Other people reported similar experiences – particularly when leaving hospital, and without any subsequent review or discussion of options later.

One participant, who has a learning disability and lived experience of mental health problems, reported that they had not received any support through SDS until they were admitted to hospital for their mental health. Upon being discharged, social work recommended SDS. The SDS user's carer reflected that:

> *"In terms of how it was arranged he, in terms of his mental health at the time, I think it [...] he really wasn't in a place to be kind of reaching out himself. [...] He'd had a really severe period of depression, which had resulted in a stay in hospital, and it was felt that, although he is able to do things independently in some ways, he was really struggling to, sort of, reintegrate with his group at [third sector organisation] when he returned and struggling sort of to keep up with the pace of activities. So after an assessment it was decided that having one-to-one support would hopefully enable him to take part in activities again, but also to withdraw as needed, with somebody there to kind of give him support if it was just getting too much for him."*

They reported that staff at a local third sector organisation also directed the family towards information on different SDS options, which were then supported by local social work professionals.

Choice Over SDS Option and Support: It is encouraging that most people with lived experience of mental health problems are on their preferred SDS option, although more work could be done to increase these numbers. The findings also indicate that improvements could be made to decision making. While health and social care professionals play an important role in helping people access appropriate services, that should not extend to making decisions on people's behalf – the principles of choice and control are clearly embedded in SDS legislation and policy, and extend to all population groups, including people with lived experience of mental health problems. Staff could be given more training about how to support decision making rather than lead it, and on co-production methods more broadly. People whose SDS starts following discharge from psychiatric hospital should receive follow-up information and discussions once support is in place, to ensure that the original arrangements of support suit their needs and preferences.

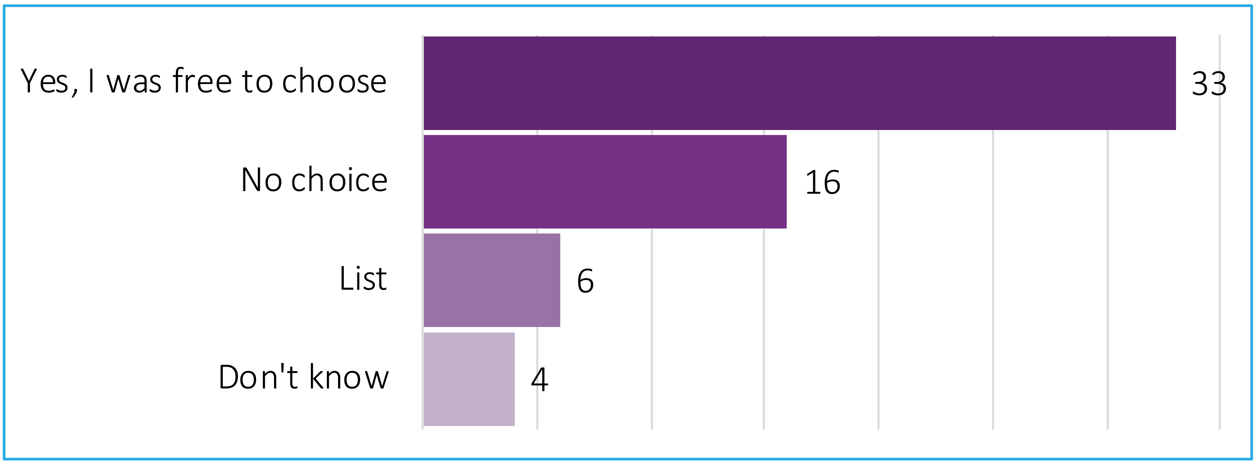
Budget Management

We asked survey respondents whether they chose who manages their personal budget, and if so, who they chose to manage it. Of the 59 people with lived experience of mental health problems who answered this question, 33 (56%) said that they were free to choose whom they wanted to manage their personal budget. Six people (10%) were able to choose from a list of providers. 16 people (27%) stated that they were not given a choice – a higher proportion than is typical for other groups participating in the MSMC research project. Finally, four people (7%) were unsure of whether they had a choice.

Of the 33 people who were given free choice of who would manage their personal budget, five selected the local authority, seven people chose a third sector provider organisation, one chose a private care agency, one selected an independent broker, and two selected an independent support organisation. A further 17 people (52% of those who were free to choose) selected an individual person (this response could include themselves).

Of the six people who chose from a list, two selected the local authority, two chose a third sector provider organisation, one chose a private care agency, and one was unsure who they chose. Of the 16 people who said that they were not given a choice and the four who were unsure, none provided details of who manages their budget.

Chart 15: Did you choose who manages your personal budget? (Survey)



Budget Management: That just over half of people with lived experience of mental health problems were offered the choice of who to manage their personal budget encourages work to ensure this pattern is continued and developed. However, the fact that around a quarter of respondents were offered "no choice" is concerning – and indicates that, amongst other things, they were not fully offered all four SDS options (as that would necessitate discussion of who would manage their personal budget). These findings suggest that further work is needed to ensure that people with lived experience of mental health problems who are applying and eligible for SDS are offered the choice of all four options.

Adequate Support

Those interviewees and focus group participants that indicated they were on their preferred SDS option described how support arrangements enable them to do a diverse range of activities. These included: personal care, assistance with household tasks and shopping, respite breaks, access to educational facilities, and support with social activities. One person reported that their "experience of SDS has been quite good really" and spoke warmly of what SDS enabled them to do on a regular basis – and stated that support with social engagement was particularly important. Another person stated that "the best thing was going to the college with SDS support", which enabled them to obtain a new Scottish Qualifications Authority (SQA) qualification.

However, participants also spoke in detail about the barriers faced in trying to access SDS for mental health reasons, as well as the impact on their mental health of substantial reductions to their SDS support. For example, 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 have a good quality of life. However, following a reassessment by a new social worker their package was cut substantially, to one third of the original provision – despite no changes to 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 serious health complications as a result of the reduced care available to them. The interviewee summarised the impact of their reduced provision as follows:

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

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

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

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

A different interviewee reported difficulties accessing SDS for support with their mental health problems. They found that it was only when they moved to a different local authority area that they were able to access support, due to differing eligibility criteria and attitudes towards supporting people with mental health problems. They described their experience in the first local authority as follows:

> *"I'd tried to apply for SDS previously, in my last flat, but kept hitting barriers of being told that it was a mental health [issue]. I have mental health problems, as well as physical problems. They would keep telling me it was a mental health issue, so I had to be under the mental health team – and then the mental health team would say, it's not a mental health problem, it's a physical problem,*

> *go back to social work. And I spent the entire time being batted back and forth between the two."*

Another respondent outlined how they "had quite a good set up", but after being admitted to hospital they required a new assessment on discharge. They described their experience as follows:

> *"When I came out of hospital I got a new social worker, and they changed the amount of hours and different times and all that. Otherwise I'd done so well. […] I said to them to them I want to [do specific activity previously covered by SDS], and they said, 'I don't think you will.' […] They threatened to section me."*

Another participant outlined how they had previously had carers (arranged through SDS) assisting them in taking medication daily. The individual stated that "the reason I wasn't admitted to hospital was because I was taking my medication", with this regular support enabling them to live independently in their own home. Against the participant's wishes, they were changed from daily support with lower levels of medication to a monthly injection, which was carried out by a community psychiatric nurse. This alteration meant considerable cuts to the individual's care package, including a reduction in their social engagement. They also experienced a range of unwanted side effects from the stronger dose of medication via the monthly injections. They stated that they are "not happy with the medication" and changes to their support arrangements.

The interviewee previously mentioned, whose comprehensive SDS package was cut to one third of the original provision following a reassessment (despite no change in their needs or stated outcomes), added:

> *"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 that reported a serious reduction in quality of life and an increase in mental health problems following substantial reductions to packages. Several other participants recounted similar experiences – and particularly highlighted the contrast with previous levels of support and good quality of life with their current situation.

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

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

Finally, one of the survey respondents with lived experience of mental health problems shared that they were not happy with the treatment they received upon moving to a different local authority area, after using SDS in another local authority area. They stated that:

> *"Be aware that your mental health issues, if you have them, will lead you to be treated as if you are intellectually challenged. The SW assessor in my case delayed matters then sent my needs form off without a second meeting [or] any input I had prepared, expected to attend a psychiatric appointment without asking my permission. With four months' notice of my moving to the region my support package has stopped."*

Adequate Support: SDS is designed to be flexible to individual requirements, and good support via SDS can be instrumental to people's quality of life, independent living and equal participation in society. However, these findings demonstrate that some people with lived experience of mental health problems experience inconsistent approaches on key issues like eligibility and budgets, and disjointed practice between mental health and social work teams. This can leave local authorities and health and social care partnerships open to criticism about unfair decision making and inconsistent implementation. Reductions in SDS packages can have a clear and negative impact on people's health. The impact of not providing rights based, person centred care can be devastating, resulting in severe isolation and loneliness, mental ill-health and suicidal ideation. It is therefore vital that people are treated with dignity and respect in all interactions with health and social care professionals and that assessments and support are adequate and tailored to people's requirements. Health and social care staff should consider the possibility of mental health crisis when changing packages and eligibility criteria and be able to arrange reassessments and signpost support services where needed.

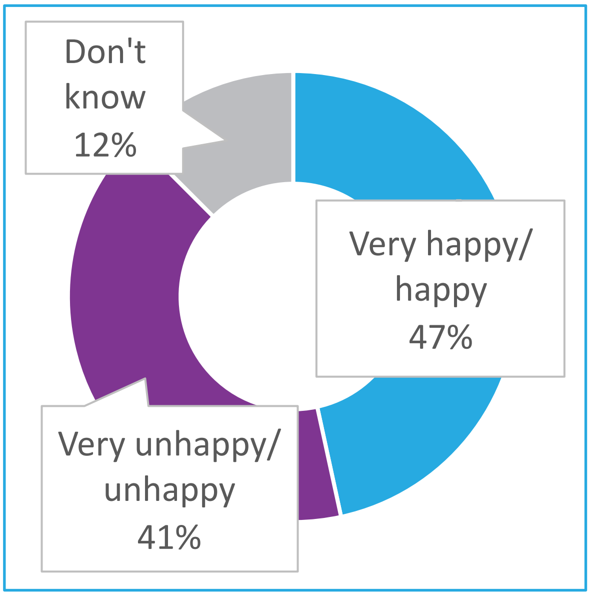
Communication and Relationships with Social Work

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

Of the 88 people with lived experience of mental health problems who answered this question, 41 people (47%) were either "happy" or "very happy" with their conversations with social work professionals, 11 respondents (13%) didn't know, and 36 people (41%) were either "very unhappy" or "unhappy".

Chart 16: "How happy are you with the conversations you have had about your support with professionals?" (Survey)



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

> *"They were very understanding of my needs."*
>
> *"They explained [...] in a way I could understand."*
>
> *"They listened to me and gave me time to say what I wanted."*
>
> *"He was empathetic and listened to my views and genuinely wanted to help."*

> *"Thorough explanation given and time for me to decide which [option] would be best."*

> *"The social worker listened carefully to what me and my mum said about my independent living. They asked good questions and had good ideas."*

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

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

> *"My care manager and the manager from the provider took time to explain my options and listened to my opinion. This reassures me."*

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

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

> *"I was initially worried about being responsible for budget and for paying PA wages, however after speaking with social worker she put my mind at ease when explaining that SPAEN [Scottish Personal Assistant Employers Network] can do all this for you including tax for PAs."*

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

Several participants who accessed SDS in part or primarily due to mental health problems spoke warmly in praise of the mental health team in their local authority areas. One interviewee summarised their experience as follows:

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

Another participant outlined that their positive relationship with their social worker was crucial for their well-being. They shared that:

> *"When it comes to the SDS, we have a really good relationship. When I have a dip in my mental health mood, I shut everybody out – but he perseveres, and he phones me or chaps on the door or things like that. He is there for me for everything really. I would say our relationship is really good […]. When I used to go downhill, I never ever got in touch with him and he is the person I should have gotten*

in touch with. I didn't get in touch with anybody, just shut the house down, didn't answer my phone, got into my jammies. […] I overdosed […] so many times. My liver hasn't fully recovered yet. If I refused the phone calls, he would knock on the door. And if I didn't answer the door, he would come the next day again. He certainly knows his job. He cares about the people he looks after. He is a good social worker."

Interviewees appreciated short waiting times for a response or decision. While talking about their local mental health social work team, one participant stated that:

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

After experiencing problems in one local authority area, one participant reflected on their more constructive experiences with a different social work department after relocating:

"[The social worker] just did, like, a quick assessment on my needs. Said that even waiting the four to six weeks […] is a long time not to have any carers in. So they've given us a few companies to try, to see if they'll do temporary care until they can get it sorted. And if not then Social Work will try and help us get sort of temporary measures in until that point. And it was quite nice that she said that, like, she took that into consideration that, you know, it is a long period of time to wait. […] I think that it's just they're taking it a bit more on board, and looking at the whole picture, and not just the physical and mental health problems. […] Because I was upfront and honest about my mental health, as well, and raised the fact that there's a lot of stigma surrounding [specific mental health condition] still – and that's where half the battle is coming from. And she […] had a lot more awareness than other people that I've met around it."

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

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

Poor Communication and Relationships

When asked how happy they were with the conversations they had about their support with professionals, 36 people (41%) with lived experience of mental health problems were either "very unhappy" or "unhappy". Some of these survey respondents stated that their social worker did not have enough time or knowledge to meet with them and discuss their needs and questions properly. Other comments indicated more fraught relationships with social work. Additional comments from people who were unhappy with their conversations with social work are as follows:

> *"I felt I was not listened to." (x4)*

> *"I was never told about my options."*

> *"Too upsetting, felt useless, social worker doesn't listen."*

> *"They are utterly clueless about how to communicate with me."*

> *"Very uninformative, no answers to questions, not very well explained so we still don't know what [SDS] really is or how it functions."*

> *"Lack of knowledge having just started the job. Unable to answer basic questions. Giving wrong information, e.g. you can start your carers now as your money will come through within two weeks (the money took six weeks and thankfully I got accurate advice via a friend)."*

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

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

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

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

Several people reported difficulties in obtaining further information from their social worker – and the importance of receiving answers to their questions:

> *"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."*

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

Cumulatively, these comments highlight the importance not only of good communication with social workers during needs assessments, but the need for sustained communication and depth of knowledge.

In interviews and focus groups, respondents who had good relationships with social workers emphasised this as instrumental to the effective implementation of SDS. However, several people reported that they felt that the conversations they had with social work professionals during their needs assessments were rushed. Participants also highlighted the problems that communication difficulties and misinformation from social work professionals could cause, and the negative impact on their lives.

Some participants were sharply critical of their experiences, particularly around having decisions and preferences respected. Several mentioned issues when their social worker appeared not to empathise or understand the extent of their support needs. They stated that they would welcome more empathy and information about what to expect from interactions with social work.

Several participants with lived experience of mental health problems reflected that they no longer have a consistent social worker – but when in the past they'd had a named person to contact, this had made accessing and adjusting social care easier. One participant reflected that staff turnover could cause difficulties and trauma for people with lived experience of mental health problems:

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

Poor Communication and Relationships: The findings invite further work to continue existing good practice and ensure that people's experiences of conversations and consistent relationships with social work continuously improve. 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 direct and varied lines of prompt communication.

Stigma and Discrimination

One theme that emerged in discussions with participants with lived experience of mental health problems was their experience of stigma around mental health – including from health and social work professionals. Several respondents repeatedly raised this concern; key comments include:

> *"People judge mental health. It's still happening, and it's been happening for a long time. They don't think about the person at all; if the person looks OK, they think they are OK. […] All through social workers, doctors and nurses."*

> *"I don't find [social work] helpful at all. Just condescending and judgemental. […] They don't realise the emotional distress, the psychological and physical [affects] of the decisions."*

Others recounted difficult attitudes towards people with lived experience of mental health problems from their social work department. One focus group participant summarised a wider discussion about stigma as follows:

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

Other participants commented on how a lack of choice over support arrangements had a negative impact on people's physical and mental health – particularly for people from Black or ethnic minority communities who were less likely to self-report mental health problems. Furthermore, when people did request other options, they were often labelled as "troublemakers":

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

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

Stigma and Discrimination: No-one should have to deal with stigmatising or discriminatory language, attitudes or behaviour from health and social work professionals, and people must be treated with dignity and respect. Appropriate training and ongoing support on equalities, human rights, intersectionality, conscious and unconscious bias should be provided to staff at regular intervals.

Transparency

People with lived experience of mental health problems reported concerns about transparency of the SDS process, which were often synonymous with the ability to make active choices about their care and sharing of documentation.

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

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

Some people also discussed the limitations of available feedback and complaint options when they were unhappy with their interactions with social work.

Transparency: The research indicates that work can be done to ensure systematic good practice and complete transparency across several elements of SDS/ social care, including eligibility criteria, needs assessments, budgets and support packages, changes to support, participation in decision making and how to challenge decisions. 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).

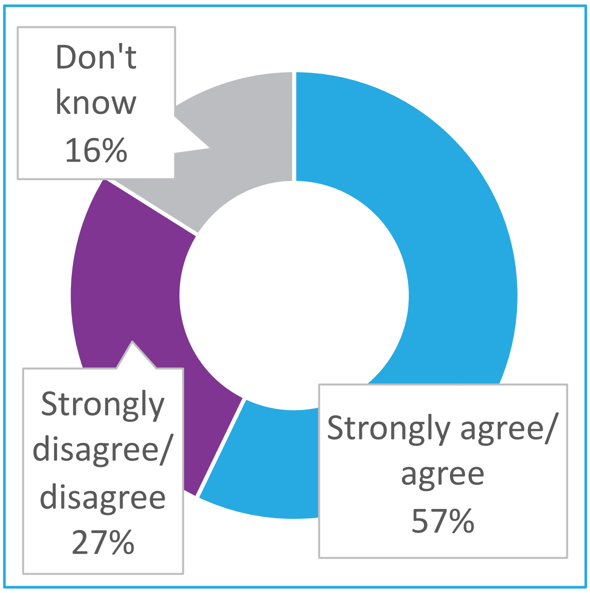
Care Worker Recruitment, Training and Quality

In the survey we asked people to respond to the statement "Lack of a regular personal assistant makes SDS difficult for me". Of the 56 people with lived experience of mental health problems who answered this question, 32 (57%) either "strongly agreed" or "agreed", while 15 (27%) disagreed or strongly disagreed. A further nine (16%) were unsure.

These findings support data from interviewees and focus group participants about the difficulties of finding and retaining personal assistants (PAs) who are appropriate to their requirements. Some people said that they would welcome more support from the local authority to arrange PA recruitment, training and continued professional development.

Several respondents commented on their priorities and concerns regarding care staff recruitment. One interviewee summarised their priorities in a support worker as follows:

Chart 17: "Lack of a regular PA makes SDS difficult for me" (Survey)



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

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

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

Others highlighted that it takes time to build up relationships with support workers, and that knowledge of working with people with lived experience of mental health problems is beneficial. One respondent highlighted that an established support worker can also assist during assessments and discussions with health and social care professionals:

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

In contrast to the above comment, the respondent then went on to reflect on their experience with a new support worker, who "might be quite new to you and not know you fully". They stated that in that situation "it's quite difficult to […] express yourself", whereas an established support worker knows the person and their history and is better placed to provide support. Several participants spoke of the benefits of being supported consistently by one or two trusted people, and problems with high staff turnover.

Care Worker Recruitment, Training and Quality: Some people with lived experience of mental health problems would welcome improved access to suitably trained and high calibre care workers. While some are comfortable with the role of employer – and have experienced good, long term, working relationships with their support workers – this experience is not universal, suggesting that the local authority should continue to work with people accessing social care/SDS to find ways to improve systems and processes – particularly around difficulties with recruitment, training, and staff retention within the wider social care sector. This support and acknowledgement of variable practice is particularly important when social care and social work professionals are discussing care arrangements with people who have had poor experiences in the past – whether that be difficulties with individual care workers, or as the victims of crime.

Independent Advocacy and Support

Survey respondents, focus group participants and interviewees all commented on the value of independent advocacy and having a range of independent support in accessing SDS. They recommended that people considering SDS get in touch with independent support as early as possible. Some key comments are as follows:

> *“Make sure they are clear as to what your budget will be. Get help to do the paperwork they make it very difficult indeed.”*

> *“Get very informed about it first and get someone who knows the system to help you manage the application and decision-making process.”*

> *“Speak to other people who are considering SDS. Consider self-help groups to discuss SDS. Consult [the] Care Inspectorate.”*

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

> *“Seek help from an independent organisation so that they get the information to make an informed choice that is right for them.”*

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

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

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

> *“Seek help from an independent support organisation who provides information and support to people looking to get SDS as they are knowledgeable*

> *about the processes in your area and can help you prepare for your assessment and get support in place.”*

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

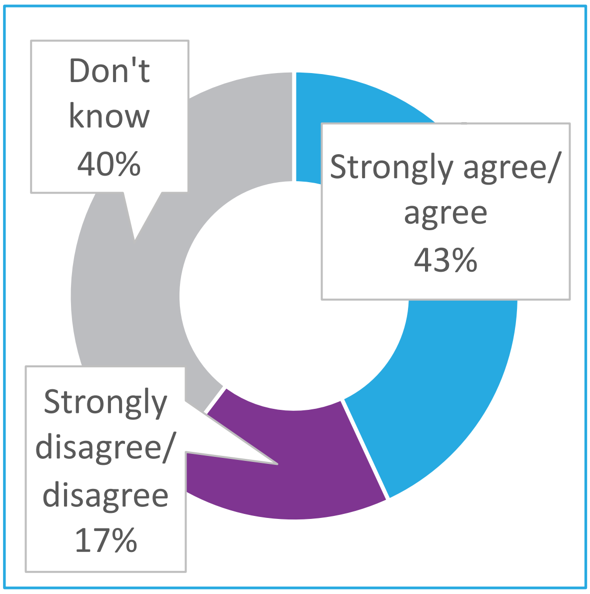
One interviewee stated that based on their experience they would recommend other people who want to access SDS should get in touch with independent advocacy or support and advice services. They reflected on their experience of SDS prior to the involvement of independent advocacy and support professionals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

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

Independent Advocacy

We asked survey participants to respond to the statement “access to independent advocacy makes SDS easier for me”. 25 people (43%) “strongly agreed” or “agreed” with that statement, and ten people (17%) disagreed or strongly disagreed with that description of independent advocacy. A further 23 people (40%) said that they were unsure.

Chart 18: “Access to independent advocacy makes SDS easier for me” (Survey)

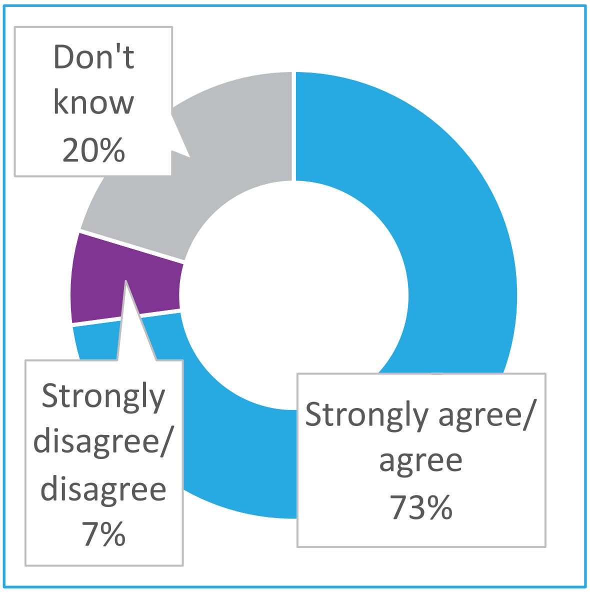


Several people highlighted that they had benefited from the involvement of independent advocacy services during their needs assessment and reviews. Interviewees and focus group participants also discussed independent advocacy and support services in greater detail. Various forms of advocacy were mentioned, ranging from local user-led service organisations to solicitors, and from national legal aid organisations to carers’ centres.

Independent Advice and Support

When asked whether access to independent information and support made SDS easier for them, people with lived experience of mental health problems who completed the survey responded in a positive fashion. 43 people "strongly agreed" or "agreed" with that statement (73%), and four people (7%) "disagreed" or "strongly disagreed" with that description of independent support organisations. A further 12 people (20%) said that they were unsure.

Chart 19: "Access to independent information and support makes SDS easier for me" (Survey)



Peer Support

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

Independent Advocacy and Support: These findings indicate that people with lived experience of mental health problems value and benefit from provision of independent advocacy, independent advice and support and peer support. As well as ensuring that these services continue to be sufficiently resourced to carry out their vital work, we recommend that local authorities and health and social care partnership staff be given more training about – and information from – local independent advocacy and support organisations, so they can more routinely refer people to these resources as part of assessment processes.

Endnotes

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

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

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

4 NHS Health Scotland, Mental Health: Inequality Briefing (2017). Available at: http://www.healthscotland.scot/media/1626/inequalities-briefing-10_mental-health_english_nov_2017.pdf.

5 A. D. Millard and G. McCartney, Scottish Mental Health Profiles for Adults: Summary Report (NHS Health Scotland: 2015). Available at: https://www.scotpho.org.uk/media/1034/mental-health-profiles-for-adults_5663.pdf.

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

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

8 Ibid.

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

10 ISD dashboard.

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

12 Ibid., p. 1.

13 Ibid., p. 12.

14 ISD dashboard.

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

16 Ibid, pp. 6, 48-60.

17 ISD dashboard.

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

Glossary

Budget / Hours / Package

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

Charging Policy

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

COSLA

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

Direct Payment

See “Option 1”.

Disability

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

Eligibility Criteria

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

Guardian

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

Health and Social Care Partnership / HSCP

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

Independent Advocacy Service / Independent Advocate

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

Independent Living

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

Independent Living Fund / ILF

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

Independent Support Organisation

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

Integration Joint Board / IJB

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

Impairment

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

Local Authority / LA

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

Needs Assessment

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

Option 1 (also called “direct payment”)

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

Option 2

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

Option 3

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

Option 4

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

Occupational Therapist / OT

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

Personal Assistant / PA / Support Worker

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

Personalisation

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

Physical Impairment / Physical Disability

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

Reablement

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

Respite

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

Self-directed Support / SDS

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

Sleepovers

The provision of care and support services overnight.

Social Care

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

Support Plan

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

Support Worker

See Personal Assistant / PA.

Unpaid Carer

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

About the Project Partners

ALLIANCE
HEALTH AND SOCIAL CARE
ALLIANCE SCOTLAND
people at the centre

About the ALLIANCE

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

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

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

The ALLIANCE has three core aims; we seek to:

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

Self Directed Support Scotland
the organisation of choice

About Self Directed Support Scotland

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

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

The ALLIANCE

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