My Support My Choice:

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

October 2021

Self Directed Support Scotland
the organisation of choice

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people at the centre

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Acknowledgements and Dedication

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

About this Report

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

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

COVID-19

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

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

Executive Summary

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

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

Between November 2018 and February 2020, MSMC heard from 75 people in Dumfries and Galloway who received SDS (or had been assessed in the previous 12 months) via a survey and interviews. Research took place prior to the appearance COVID-19 in Scotland. Overall, MSMC heard from 637 people across Scotland via a survey, interviews and focus groups. As the largest direct national consultation of its kind to date, the national report provides vital evidence, analysis and recommendations for improvement to SDS/ social care in the aftermath of the pandemic, based on people's experiences. This report provides analysis of the results from Dumfries and Galloway within that larger context.

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

Poverty and SDS

An estimated 24% of Scottish households with a disabled person live in relative poverty after housing costs. MSMC found that 71% of research respondents in Dumfries and Galloway who provided income data lived below the poverty threshold. National and local public bodies should take action to ensure that reductions in SDS budgets and tightened eligibility criteria do not negatively impact people on low incomes who access or are trying to access social care, given that they can lead to people having to manage without support, deteriorating physical and mental health, and demands on family and friends to assume roles as unpaid carers.

Data Gathering and Analysis

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

Overall Experiences of SDS

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

Information About SDS

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

Around half of participants indicated they required more high-quality information at an earlier stage (before needs assessments) to support their decision making about how support would be arranged. Many people had not been told about all four options when they started the process of accessing SDS. Some had not been provided with accessible information or documentation.

This pattern of variable information about the four options continued into people's needs assessments. A minority of people reported that they had "all four options" discussed with them during their assessments. It is welcome that most people felt that social work professionals explained things clearly, and that all their questions were answered.

Half of the respondents in Dumfries and Galloway indicated that they had received information about how much money they could spend on their care and support. However, the remaining half had either not received that information or were unsure.

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

Informed Choice and Control

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

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

Similarly, while it is positive that nearly half of the respondents in Dumfries and Galloway were offered the choice of who would manage their personal budget, it is concerning that a third of people reported being offered no choice; this also demonstrates that, amongst other things, they were not fully offered all four SDS options.

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

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

Several people in Dumfries and Galloway highlighted the positive impact of flexible support and SDS. This flexibility could be in how people are empowered and supported to use their SDS, but also related to people's ability to have ongoing conversations with social work professionals and adjust systems accordingly on a regular basis.

Participants – particularly those living in more rural areas of Dumfries and Galloway – indicated that they need more acknowledgement and accommodation of travel costs in their SDS budgets (particularly when it came to having choice of care providers). Some would also welcome assistance from social workers and third sector organisations in navigating the bureaucratic processes to obtain mobility vehicles and travel passes.

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

Communication and Relationships with Social Work

Participants in Dumfries and Galloway highlighted that good, consistent, trusting relationships with social workers and clear lines of communication are all essential for positive and effective experiences of SDS. A substantial majority of participants reported positive and favourable experiences of assessments and reviews with professionals, providing a range of good practice examples. However, some people outlined concerns about their interactions with social work professionals.

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

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

Care Staff Recruitment, Training and Quality

People reported mixed experiences of support worker recruitment, training and quality, as well as the positive impact that trusted care workers can have on people's lives. Several respondents indicated difficulties finding and retaining personal assistants (PAs) and care workers that were suitable for their requirements, and some people would welcome more assistance with staff recruitment and training. Dumfries and Galloway should work with people who access SDS and unpaid carers to improve systems and processes related to care staff recruitment, training and quality.

Independent Advocacy and Support

Respondents in Dumfries and Galloway value and benefit from the provision of independent advocacy, independent advice and support services, which need sustainable resourcing to continue their important role. Focused efforts are required to ensure all people are aware of – and can access – independent advocacy and support services. Local peer networks should also be encouraged and supported.

Recommendations

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

Poverty and SDS

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

Data Gathering and Analysis

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

Information About SDS

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Informed Choice and Control

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

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

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

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

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

when to spend personal budgets; with different amounts of spend and support at different times of the year.

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

23. People – particularly those living in more rural areas – require more acknowledgement and accommodation of travel costs in their SDS budgets.

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

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

Communication and Relationships with Social Work

26. Existing good work should continue to ensure positive conversations and meaningful, consistent relationships, with ongoing planning to guarantee high quality practice for all people using SDS.

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

28. 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.

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

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.

32. Professionals should ensure that all unpaid carers are offered carer's assessments/Adult Carer Support Plans and have their rights explained to them.

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

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

35. We encourage Dumfries and Galloway Council to indicate document

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

Care Staff, Recruitment, Training and Quality

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

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

Independent Advocacy and Support

38. Independent advocacy, independent advice and support services need sustainable resources to continue their important role in Dumfries and Galloway.

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

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

41. Local peer networks should be encouraged and supported.

National and Local Context for SDS/ Social Care

National Context

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

Local Context

Dumfries and Galloway is a council area with an approximate population of 148,000 people, across 69,000 households.[8] Dumfries and Galloway a largely rural area, covering a significant geographical area to the south of Scotland, and people live in both rural areas and towns. It is situated south of Ayrshire, with Scottish Borders to the east and Cumbria to the south.

Dumfries and Galloway Council publishes a range of information for people who access or wish to access SDS on their website (searchable via the search bar on the council website under the under the keywords "Self-directed Support" and "direct payments", but not searchable via "SDS").[9] The relevant page is titled "Personalisation and Self-directed Support". This provides people with a brief definition of SDS and the four options, introduces the assessment process, and gives some examples of SDS. There is no outline of the eligibility criteria used in Dumfries and Galloway on the SDS webpage, or of expected waiting times for assessments. However, the questionnaire used to assess eligibility is published by www.lriss.org.uk, and states that direct financial support is only available to people who have "critical or substantial needs".[10] This document also explain what level of support individuals are likely to receive for each category.

The eligibility criteria outlined on the Dumfries and Galloway Council assessment form reflect the National Eligibility Framework, which categorises risk as being critical, substantial, moderate, or low:

> *Critical risk: indicates that there are major risks to an individual's independent living or health and well-being and likely to call for the immediate or imminent provision of social care services.*
>
> *Substantial risk: indicates that there are significant risks to an individual's independence or health and wellbeing and likely to call for the immediate or imminent provision of social care services.*
>
> *Moderate risk: indicates that there are some risks to an individual's independence or health and wellbeing. These may call for the provision of some social care services managed and prioritised on an on-going basis or they may simply be manageable over the foreseeable future without service provision, with appropriate arrangements for review.*
>
> *Low risk: indicates that there may be some quality of life issues, but low risks to an individual's*

> *independence or health and wellbeing with very limited, if any, requirement for the provision of social care services. There may be some need for alternative support or advice and appropriate arrangements for review over the foreseeable future or longer term.*

There is additional information on Option 1 on the “Direct Payments” page, including an outline of employers’ responsibilities, and a downloadable “Personal Assistant’s Handbook”.[11] The main page also includes a link to a 2014 Scottish Government guide to SDS and a video from Carers Trust Scotland on SDS (although the latter link is defunct at time of writing). There are also additional webpages available on “Paying for care” and “Care at home”, including a list of care providers across Dumfries and Galloway and their contact details, and links to the Care Inspectorate for relevant reports. Dumfries and Galloway Health and Social Care Partnership also published a publicly accessible and relatively recent strategic social care plan (spanning 2018-2021).[12] These are all welcome examples of good practice in terms of transparency of process and clear information provision – although some web links could be clearer and information centralised more effectively.

At time of writing, to obtain more information on how to access SDS, the eligibility criteria, or to “apply for a support assessment”, people are invited to fill out an online form, email adultforms@dumgal.gov.uk, or call a phone number (an 030 number). There is no option to call a freephone number, which would enable people from low-income households to call without being charged. This consideration is particularly important given the number of people in Dumfries and Galloway – and respondents to MSMC specifically – who live below the poverty line. There are no direct links to independent support and advice or independent advocacy organisations on this webpage, or to other resources for people who are not deemed eligible for SDS.

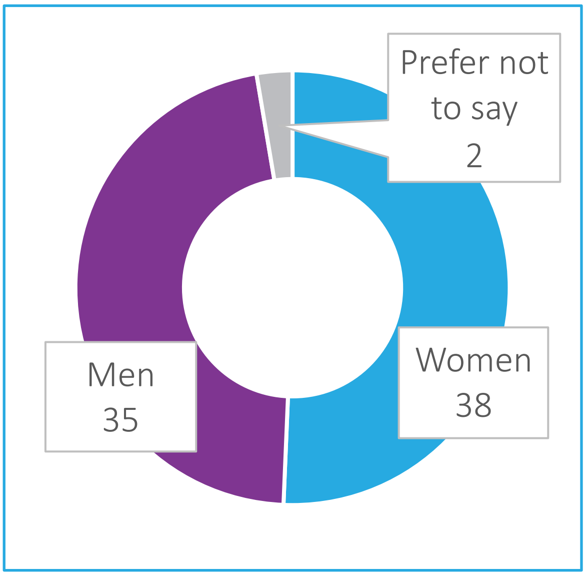
We encourage Dumfries and Galloway Council to indicate document publication dates and webpage timestamps. The Council’s website could also provide further information on their Equality Impact Assessments and the role these play in SDS/ social care decision making. Finally, to strengthen participatory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

Research Participants

MSMC heard about the experiences of 75 people who use or were being assessed for SDS in Dumfries and Galloway. We interviewed 10 people who spoke about their own experiences and the experiences of other members of their household who use SDS (spanning the experience of a total of 15 people who use SDS or who were being assessed for SDS). A further 60 people from Dumfries and Galloway completed the survey. Throughout this report some participant details (e.g. age) have been changed slightly to preserve anonymity, while maintaining the most important information. Where changes have been made to quotations those alterations are indicated via square brackets (e.g. "My advocate, [Name], was great").

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

Chart 1: Respondents' gender



Gender

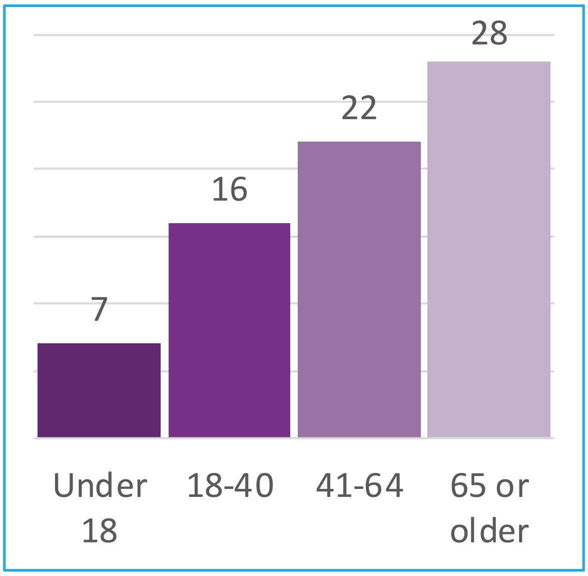
Overall, 38 women (51% of respondents) and 35 men (47% of respondents) participated in MSMC in Dumfries and Galloway. A further two people (3%) preferred not to disclose their gender.

While PHS figures are not available for the division of men and women accessing SDS (nationally or in Dumfries and Galloway), they do publish statistics on the number of men and women receiving social care support services more generally (of whom an estimated 99% access SDS – higher than in most local authorities). PHS reported that in 2017-2018 63% of people accessing social care support in Dumfries and Galloway were women and 37% were men.[13]

Age

We asked all participants to share their age. Of the 73 people who chose to answer the question, seven (10%) were under 18 years old, 16 (22%) were between 18 and 40 years old, 22 (30%) were between 41 and 64 years old, and 28 (38%) were 65 years or older.[14]

Chart 2: Respondents' age



In mid-2018, 56% of the population of Dumfries and Galloway was over

45 years old (higher than the Scottish average of 47%), with the average age expected to increase, especially in the 75 and over age group.[15]

PHS do not provide an overall breakdown of age groups accessing SDS, although age group data is provided by SDS Option Chosen and Client Group Profile. PHS provide age disaggregated data on people receiving social care support services more generally within Dumfries and Galloway (of whom an estimated 99% access SDS). PHS reported that in 2017-2018 in Dumfries and Galloway, 82% of people accessing social care support were over 65 years old, 17% were aged 18-64, and 1% were under 18 years old.[16]

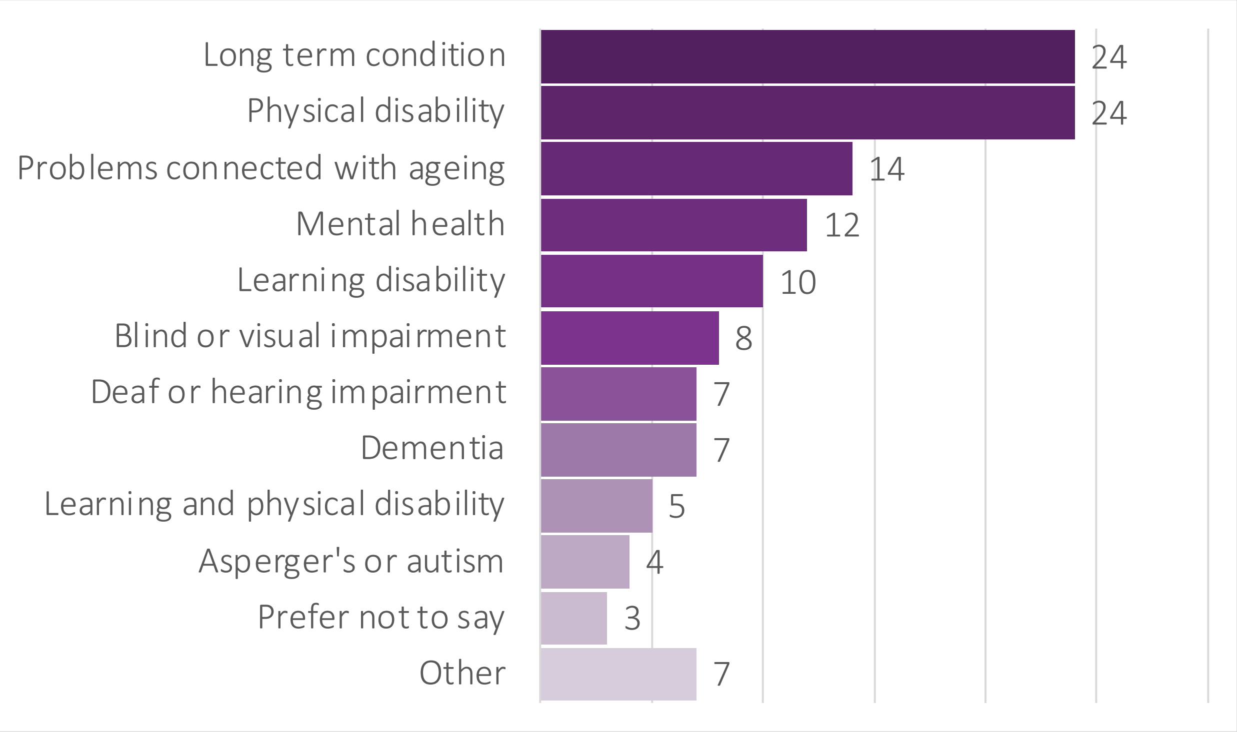
Ethnicity

58 MSMC survey respondents in Dumfries and Galloway identified as white. A further two people chose not to describe their ethnicity. Most interviewees did not disclose their ethnicity when self-describing themselves, and the majority of those that did described themselves as “white”.

The 2011 Scottish Census indicated that 96.5% of the population of Dumfries and Galloway identified as “White: Scottish” (78.8%) or “White: Other British” (16.4%), with a further 2.3% selecting “White: Irish” (0.7%), “White: Polish” (0.6%), or “White: Other” (1%). The remaining people identified as being part of minority ethnic groups: 0.7% of the population identified as “Asian”, “Scottish Asian”, or “British Asian”, and 0.5% as belonging to “other ethnic groups”. The overall spread of MSMC respondents is less ethnically diverse than 2011 Scottish Census data for Dumfries and Galloway.[17]

PHS do not provide a disaggregated breakdown of the ethnicity of people accessing SDS. They have some disaggregated data on the ethnicity of people receiving social care support services more generally (of whom an estimated 99% access SDS), using the limited categories of “White”, “Other”, and “Not provided/ Not known”. PHS reported that in 2017/2018 in Dumfries and Galloway, 65% of people accessing social care support were “White”, 35% were listed as ethnicity “not provided/not known”, and 14 people (0.2%) were categorised as “Other” (including “Caribbean or Black, African, Asian and Other Ethnic Groups”).[18]

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

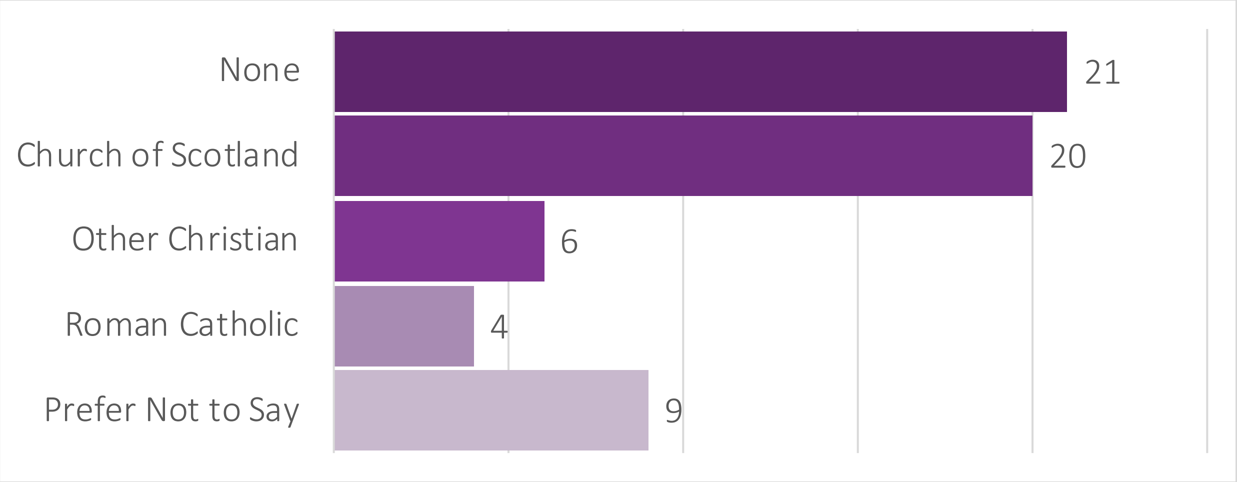


Client Group/Disability/ Long Term Condition

MSMC survey respondents in Dumfries and Galloway self-identified as living with a range of conditions, with the majority reporting that they were living with multiple conditions. 24 people (40%) said they live with a long term condition, 24 people (40%) selected physical disability, and 14 people (23%) stated that they experienced “problems connected with ageing”.[19]

Interviewees also discussed their conditions, and – if they were unpaid carers – those of the people for whom they care. Their reasons for accessing SDS were broadly in keeping with survey respondents’. Of the 15 people whose experiences of SDS we heard about during interviews, 14 accessed SDS because of their own conditions, and one accessed SDS as an unpaid carer.

Chart 4: Survey respondents’ religion



Religion

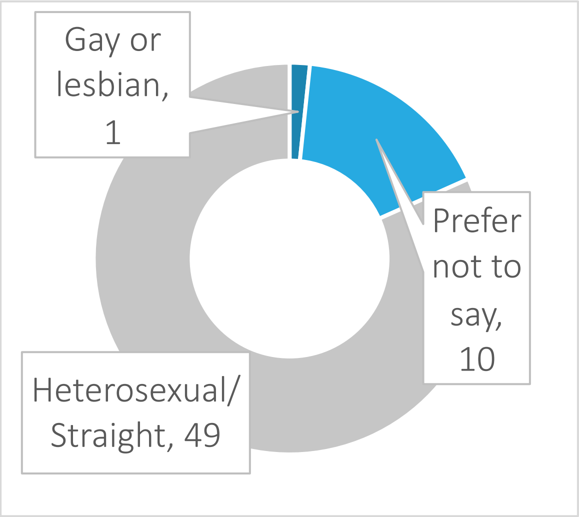
When asked about their religion (if any), 21 survey respondents (41%) stated “none”, 20 were part of the Church of Scotland (39%), six described themselves as “other Christian” (12%), and four were Roman Catholic (8%). Nine people (18%) preferred not to answer.

Most of the interviewees did not choose to explicitly disclose their religion when self-describing themselves. The overall spread of MSMC respondents is slightly less religiously diverse than 2011 Scottish Census data for Dumfries and Galloway.[20] Data about people’s religion is not available on the PHS dashboard.

Sexual Orientation

49 survey respondents described their sexual orientation as heterosexual or straight and one person was gay or lesbian. A further five people stated that they preferred not to disclose their sexual orientation, and five people did not answer the question. The 2011 Scottish Census did not record data on sexual orientation at local authority level (although the 2022 Scottish Census is expected to do so); as such, we do not have local statistics on sexual orientation available as a comparison. Data on people’s sexual orientation is not available on the PHS dashboard.

Chart 5: Survey respondents’ sexual orientation

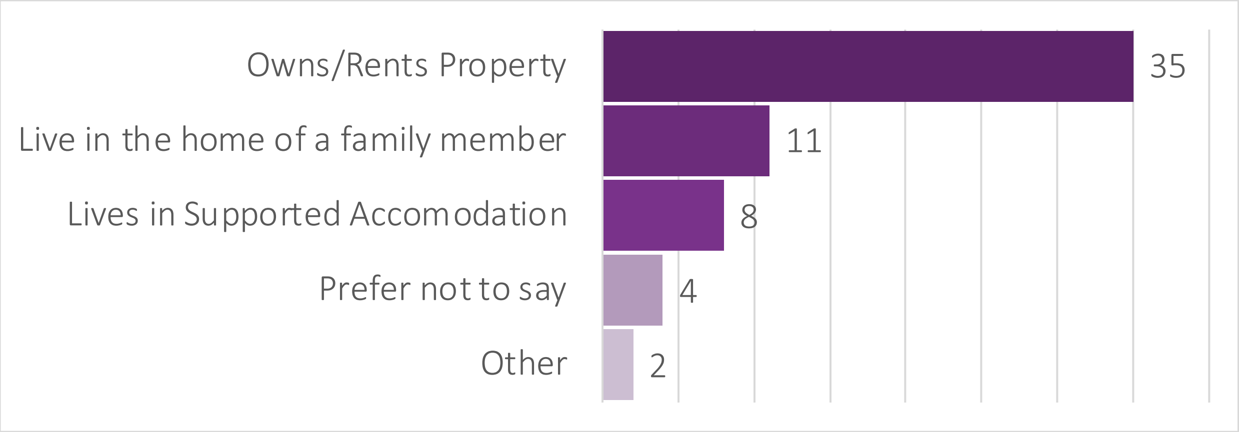


Housing

35 survey respondents (58%) either rented or owned their own home, eleven people (18%) reported that they lived in the home of a family member, and eight (13%) lived in supported accommodation, and two selected “other” without providing supplementary information. Four people selected “prefer not to say” (7%). Data on people’s housing situations (other than residential care) is not available on the PHS dashboard.

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

Chart 6: Survey respondents’ housing arrangements

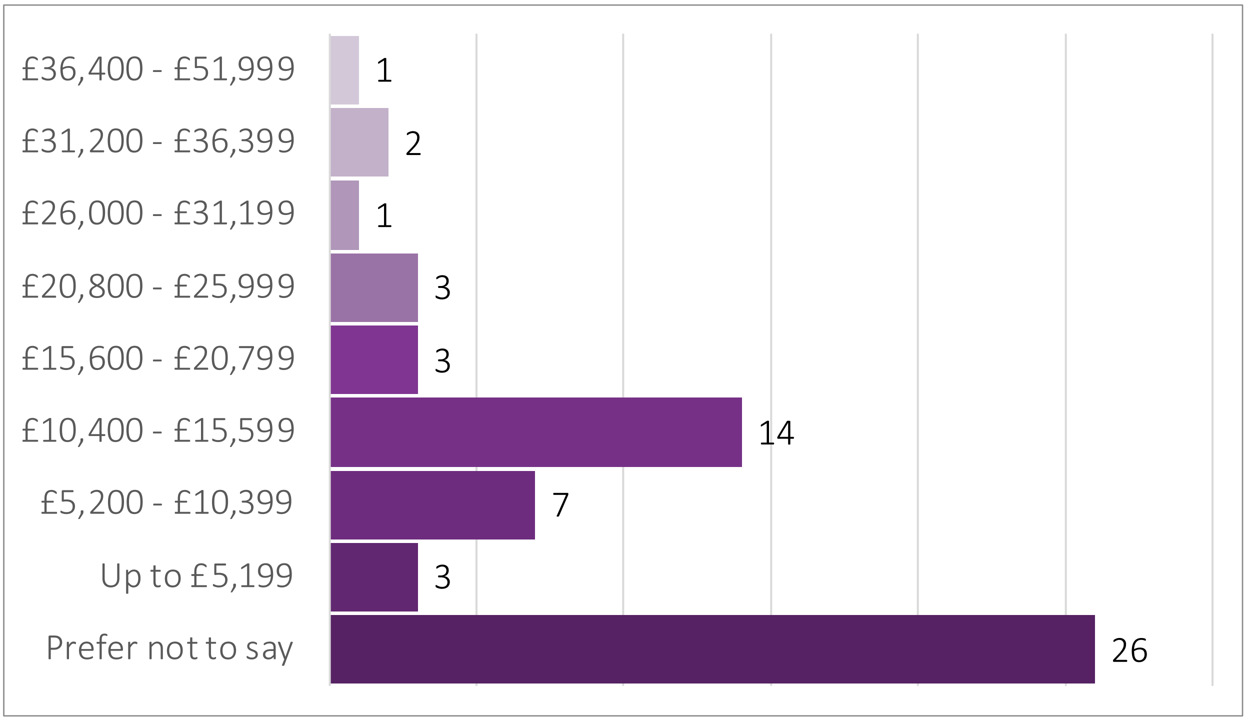


Household Income

We asked survey respondents about their household income. We were interested in this information because in Scotland an estimated 24% of households with a disabled person live in relative poverty after housing costs, compared to 17% of the population with nobody with a disability in the household.[21]

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

Chart 7: Survey respondents’ annual household income



According to Scottish Government data, the median housing income in Scotland in 2015-2018, before housing costs, was £499 per week (£25,948 per annum).[22] 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).[23] Based on this definition, 24 (71%) of the respondents in Dumfries and Galloway who chose to provide details of their household income are living below the poverty threshold. Data on the household incomes of people accessing SDS is not available on the PHS dashboard.

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

SDS Option

Of the 55 participants in Dumfries and Galloway who shared which SDS option they used, 23 people (42%) indicated they used Option 1, two people (4%) used Option 2, 21 people (38%) used Option 3, and four people (7%) used Option 4. Five people (9%) stated that they did not know what option they used.

Figures from PHS indicate that in 2017-18 there were 467 people in Dumfries and Galloway using SDS Option 1, no one using Option 2, 6,788 using Option 3, and 224 using Option 4.[24] In some instances, people are logged as being on two options simultaneously (e.g. Options 1 and 3) rather than Option 4, which distorts these figures.

Data Gathering and Analysis

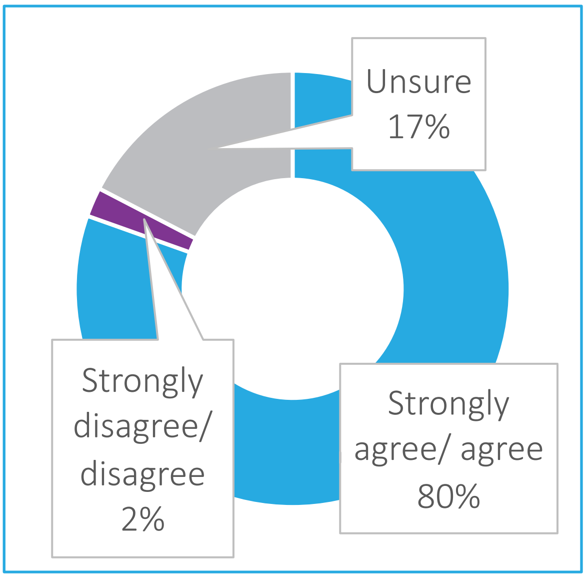
As the chapter on research participants demonstrates, there are concerning gaps in SDS data gathering, analysis and reporting across Scotland. PHS have reflected on difficulties gathering disaggregated data on people's use of and experiences of SDS/ social care in their experimental statistics publication ***Insights into Social Care in Scotland***.[25] 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.[26] Data gaps are also in part due to existing patterns of data collation – leading, for example, to the PHS Social Care Information Dashboard tracking ethnicity via the limited and problematic categories of "White", "Other", and "Not provided/ Not known".[27]

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

Overall Experiences of SDS/ Social Care

We asked survey respondents whether they felt that SDS had improved their social care experience. Of the 46 people who answered this question in Dumfries and Galloway, 37 (80%) stated that they “strongly agree” or “agree” with the statement “SDS would/has improve/d my social care experience”. One person (2%) disagreed and eight (17%) were unsure. This was a higher satisfaction rate than across Scotland more broadly (74%).

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



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

> *“Advise them to do it. Just do it.”*
>
> *“Do it, it’s a great thing.”*
>
> *“Don’t be afraid to trust the care package.”*
>
> *“Go for it. It makes much more sense.”*
>
> *“It’s been a really good experience for me.”*
>
> *“It definitely gives you more choice and control.”*

Interviewees identified a range of ways that SDS has impacted them, with one saying that it had “transformed our lives”. Another interviewee described the impact of SDS as “absolutely awesome”, stating that they “don’t know what we would have done in life [...] if it wasn’t for SDS.”

One interviewee also highlighted that having support in place for the person for whom they care enables them to pay attention to their own health needs:

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

However, some people were more cautious or explicitly negative about SDS. One survey respondent stated, “Do not have SDS”.

Information About SDS

Finding Out About SDS

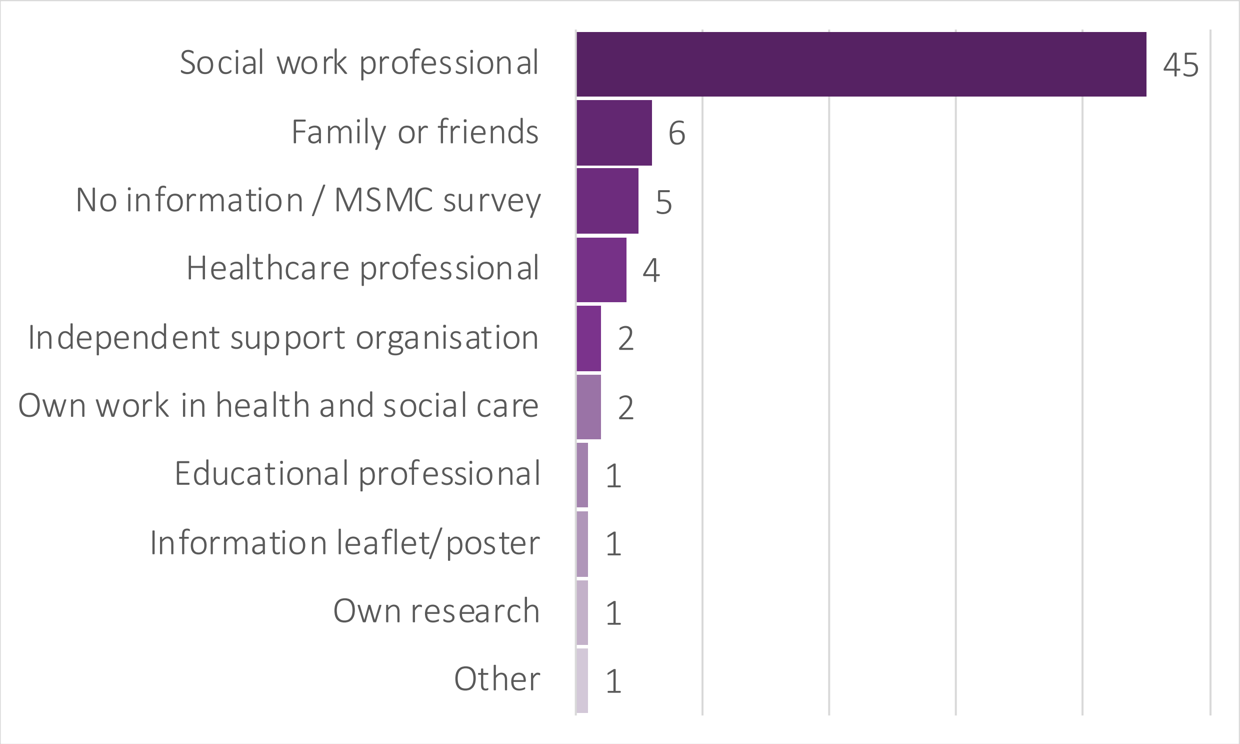
We asked participants in Dumfries and Galloway how they first found out about SDS.

45 survey respondents (66%) first heard from a social work professional (e.g. a social worker/social work assistant or an occupational therapist), six (9%) heard from friends or family members, and four (6%) from NHS health staff, including nurses working in the community. A further two people first heard about SDS from an independent support organisation, two from their work as a health or social care professional, one from an information leaflet/poster, one from an educational professional, one from their own research, and one from an unspecified "other" source.

Five survey respondents (7%) reported that they had never received information about SDS, of whom two stated that they first heard about SDS via this research project. Some interviewees also said that they did not understand or had not had SDS fully explained to them, even though they used SDS, and had done for some time. One interviewee expressed ongoing uncertainty about the definition and purpose of SDS, despite communication with social work and other professionals:

> *"I'm confused about what Self-directed Support actually means."*

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



Among the interviewees, social work was the most common method through which people first heard about SDS. This was followed by people hearing from friends or family members, people's professional work, and NHS staff.

Two interviewees discussed how their initial involvement with social work was a positive experience. One person stated that social work suggested that their children could benefit from SDS, and that they were supported through the process of presenting to a panel. Another interviewee's social worker stepped in to alleviate significant stress by helping them to access SDS on their child's behalf. The interviewee reflected that in hindsight social work should have become involved automatically when their child was born with complex needs. Instead, the interviewee found out about SDS through online forums used by parents of disabled children. However, they spoke positively about the assistance they had received from social workers in providing information and support throughout the initial assessment process, and thereafter.

Other interviewees highlighted that difficult circumstances are often the precursors to engagement with social work. One respondent, for example, outlined that their family's introduction to social work was through an application for guardianship for their child. This fraught process included assessments from medical professionals and mental health workers. Similarly, another interviewee was open about their initial reluctance to engage with social work. They stated that after their child was born:

> *"Everyone kept saying, 'You need a social worker, you need a social worker.' And we were like 'I don't want a social worker.' You know the taboo and everything that surrounds social work, I didn't want them anywhere near me. And that continued for a few months until we realised, right, well you can come in and we'll give you a try."*

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

Information and Preparedness Before Assessments

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

As the chart indicates, across the SDS options most respondents in Dumfries and Galloway received "all the information [they] wanted" on Option 1 and Option 3 (respectively, 54% (Option 1), and 51% (Option 3)). A substantial minority received all the information they wanted for Option 2 (45%) and Option 4 (46%). However, it is concerning that most people for Option 2 and Option 4 either had no information or were left wanting more in advance of their assessment. The detail of those who wanted more information is as follows:

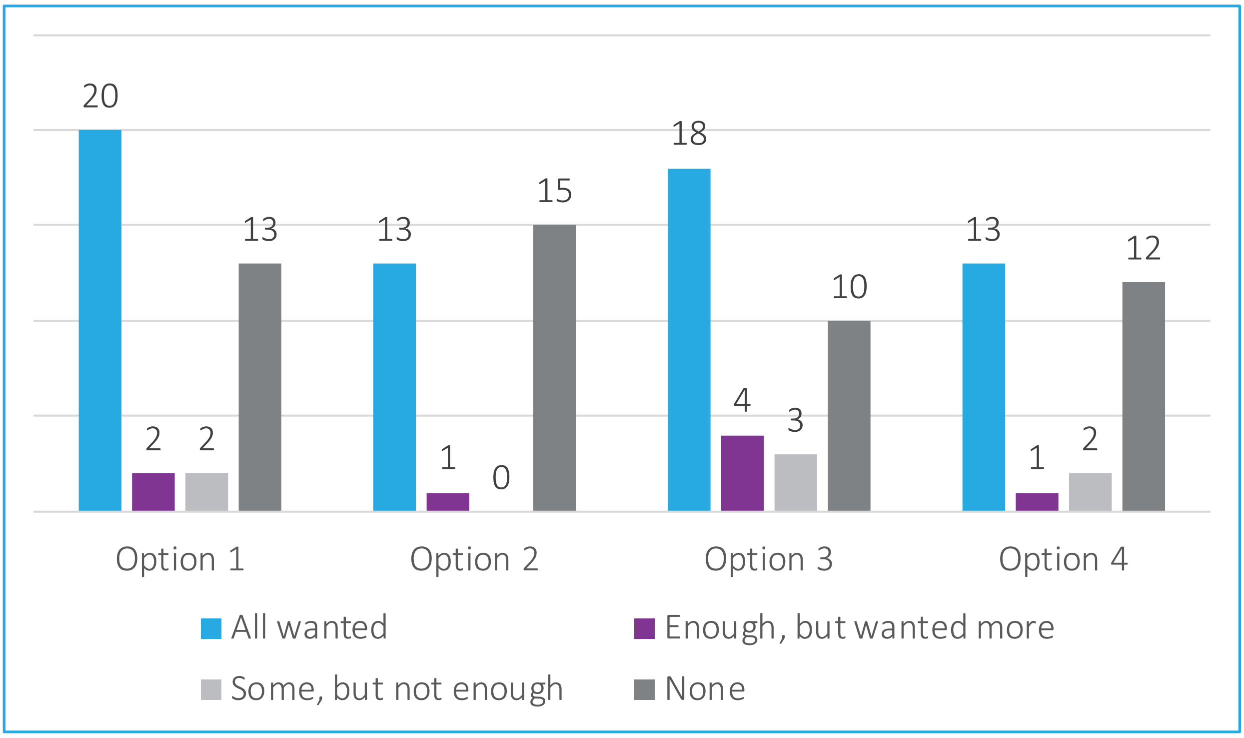
Option 1: 41% of respondents said that they received “some, but not enough” or no information, and 5% received “enough but wanted more”.

Option 2: 52% of respondents reported that they had “some, but not enough” or no information, and 3% received “enough but wanted more”.

Option 3: 37% of respondents said that they had “some, but not enough” or no information, and 11% received “enough but wanted more”.

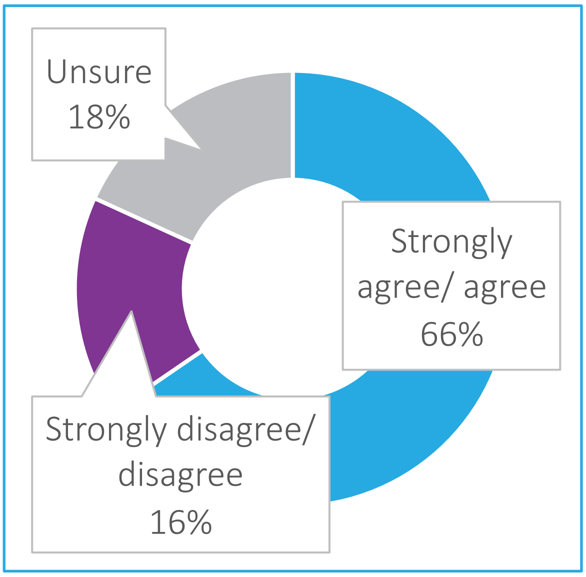
Option 4: 50% of respondents said they had received “some, but not enough” or no information, and 4% received “enough but wanted more”.

Chart 10: Information received before discussing support (Survey)



We also asked survey respondents whether they felt prepared for their needs assessment. Of the 55 participants who answered the question, 36 (66%) strongly agreed or agreed, nine (16%) disagreed or strongly disagreed, and ten (18%) were unsure. While it is encouraging that nearly two-thirds of respondents in Dumfries and Galloway felt prepared for their assessment, it is concerning that a third either felt unprepared or were unsure. This is a higher satisfaction rate than across Scotland more broadly, indicating good practice which could be usefully expanded.[28]

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



Some interviewees in Dumfries and Galloway had been fully informed about the options prior to their assessments, but others had not been told about all four options when they started the process of accessing SDS, which they said had made it harder to make informed decisions.

One interviewee highlighted an effort by Dumfries and Galloway Council to hold an SDS options information day with parents of disabled children in advance of their needs assessment. They commented that attendance at the event was low, and exercises on the day demonstrated people's confusion about "measurable outcomes". The interviewee stated that they and their partner are "both extremely well-educated people and we can't make our way through this minefield". They also pointed out that often parents need support themselves, particularly if they have learning disabilities, mental health problems, or dealing with personal challenges.

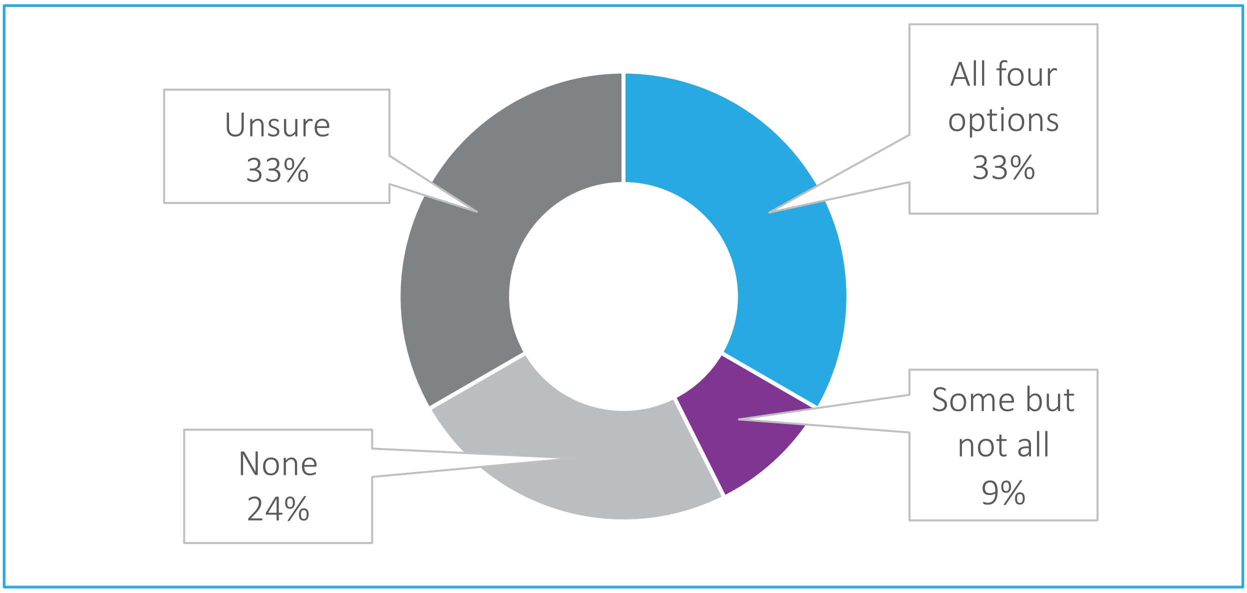
Information and Preparedness Before Assessments: The findings indicate that improvements could be made to ensure everyone in Dumfries and Galloway has adequate information in advance and feels prepared for a needs assessment. Comprehensive, high-quality information in a wide range of accessible formats should be proactively provided to people about the four SDS options – particularly Options 2 and 4 – carers' assessments and support plans, and what to expect of a needs assessment.

Information During Assessments

The 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.

Of the 54 survey respondents, 18 (33%) stated that the professional discussed "all four options" with them, five (9%) that "some but not all" options were discussed, and thirteen (24%) that "none" of the options were discussed. A further 18 respondents (33%) indicated that they were "unsure" which options were discussed with them. These findings indicate that more work is needed in Dumfries and Galloway to ensure that all four SDS options are outlined and discussed with people during needs assessments and reviews.

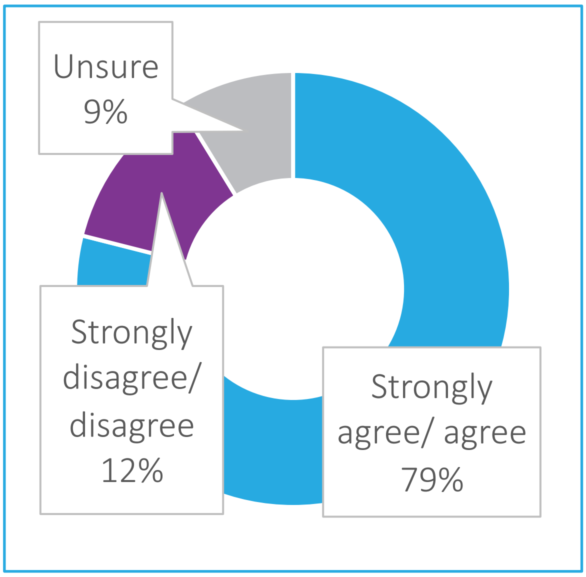
Chart 12: Discussing SDS options with professionals (Survey)



Two survey respondents stated that they felt they knew "very little about SDS" after their assessments – although one person added that they have "since remedied some of that" through their own research efforts.

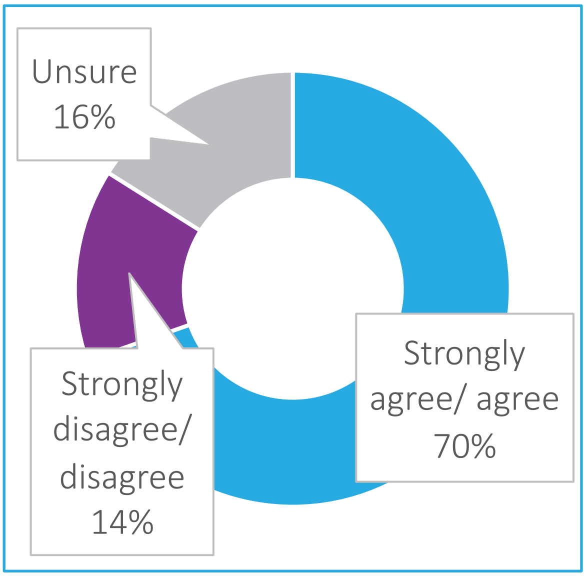
In the survey, we asked whether people agreed with the statement "The person I met with explained things clearly to me". Of the 57 respondents who answered this question, 45 (79%) strongly agreed or agreed, seven (12%) disagreed or strongly disagreed, and five (9%) were unsure. It is encouraging that such a high proportion of survey respondents report clear explanations. This is a higher satisfaction rate than across Scotland more broadly.[29]

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



In the survey, we also asked people to respond to the statement "All my questions were answered", regarding their meeting with a professional. Of the 56 respondents, 39 (70%) strongly agreed or agreed, eight (14%) strongly disagreed or disagreed and nine (16%) said that they did not know. Interviewees indicated similar experiences. That a high proportion of respondents in Dumfries and Galloway indicate that all their questions were answered is welcome; the finding that just under one third disagreed or did not know indicates further work is needed in this area to embed existing good practice. Overall, these results indicate that more people in Dumfries and Galloway felt their questions had been answered than was typical across Scotland.[30]

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



Several interviewees reflected on positive experiences during their needs assessments and reviews. However, other interviewees recounted more mixed experiences. Some people reported that the conversations they had with professionals felt rushed, or that social workers did not explain the process around SDS properly to them in a way they could understand.

Survey respondents also suggested asking social workers for "a list of alternative services in the area which may help your individual situation and how to access them." One respondent requested that local authorities arrange for more help for people accessing SDS for the first time – both in terms of developing support plans, and for help with the practicalities of registering for online banking as an Option 1 employer.

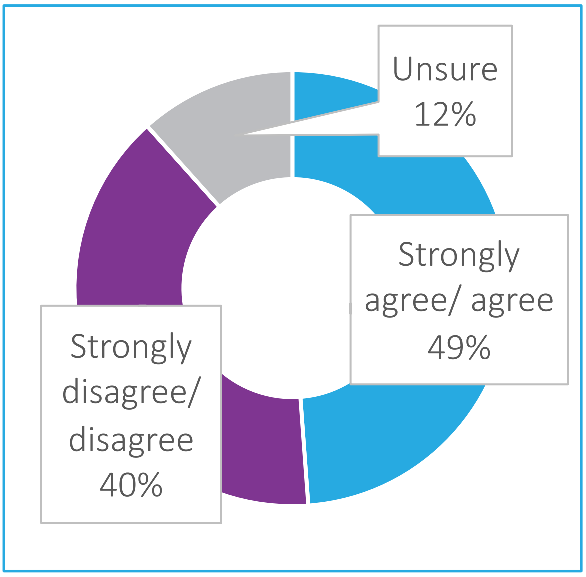
Overall, interviewees indicated that their questions to social work professionals covered a range of issues, including how support package decision making processes worked, expected wait times, and how to become an employer of PAs.

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

Information About Budgets

We asked survey respondents if they had been told the amount of money they can spend on their support (sometimes called an estimated or a personal budget). Of the 43 respondents, 21 (49%) said yes, 17 (40%) said no, and five (12%) said they did not know if they had been given a budget.

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



That nearly half of respondents in Dumfries and Galloway had received information about how much money was available to them is a positive finding. However, it is concerning that half of respondents either had not received that information (39%) or were unsure (12%). It is vital for informed decision making that people are given full information about their personal budgets.

In addition to these concerns, several participants reported that they did not receive enough information about their budget. Others found the level of scrutiny difficult, with one interviewee describing an "invasive process to justify the money".

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

Outstanding Concerns and Appeals

In the survey we asked if people had any outstanding concerns that were not addressed during their last assessment. Of the 57 respondents, 38 (67%) had no concerns, seven (12%) had outstanding issues, and 12 (21%) were unsure. While work remains to be done to respond to those who had unaddressed concerns, these findings are encouraging, and higher than the national average in MSMC – where 48% of people reported that they had no concerns, 29% had issues that they did not feel had been addressed, and 23% were unsure.

Of those respondents with outstanding concerns, the main issues were budgets, difficulty in accessing or financing short breaks, and a lack of information about SDS. One participant indicated that they had requested more information on independent living options from their social worker but they "did not come back with any information", leading them to conclude that they will "never be able to live independently." Another person stated that they were "told that Dumfries and Galloway local authority do not provide respite or short breaks through SDS", and that they "have not had any definitive answer why". Respondents highlighted that unresolved issues had direct and negative impacts upon their health and the health of the people for whom they care.

One interviewee stated that they found the bureaucratic burden of SDS challenging. They relayed their experience as follows:

> *"Yes, well a social worker went through the need assessment; we did paperwork, paperwork, paperwork. [PA] went off sick; paperwork, paperwork, paperwork. Got a new person; more paperwork, more paperwork. Person left the post and nobody in post; paperwork, paperwork. Paperwork for adult social care and now we've changed the system […] you ned to do more paperwork. I've just done paperwork for years which has resulted in absolutely nothing happening. […] I don't think it's unique to Dumfries and Galloway. It's very much, all the social work involvement that we've had has been paper driven."*

Two interviewees outlined issues they encountered in accessing information about SDS and wider social care and accessibility support. The interviewees were not told about any assistance that could be provided for the installation of adaptations to their home or improvements to their home's accessibility. After spending a significant amount of money on adaptations they were informed that they would need to reverse the changes. While some of these adaptations were the responsibility of other statutory services or parts of local government, rather than social work, the participants would have appreciated more information in order to understand who to contact and avoid confusion.

Two interviewees reflected on difficulties with transitions to adult social care, despite starting discussions 18 months in advance. One person, who had previously been content with their care arrangements, summarised their experience as follows:

> *"Everything fell apart. […] I know that they have this challenge but nevertheless they should be able to provide a base-line service. […] It's like a gatekeeper, that's how it feels."*

Some people highlighted that living in a rural area of Dumfries and Galloway effectively meant that they could not access all four options of SDS, due to limited care options. They also commented that rural living increased travel costs for themselves and (in some cases) their PAs.

We also asked survey participants whether they were in the process of appealing the decision made in their last review or needs assessment. Of the 48 respondents, three people in Dumfries and Galloway indicated that they were in the process of appealing the outcome of their last social care assessment or review. One person reported that they were being supported in their appeal by an organisation, one by a friend or family member, and one by their PA.

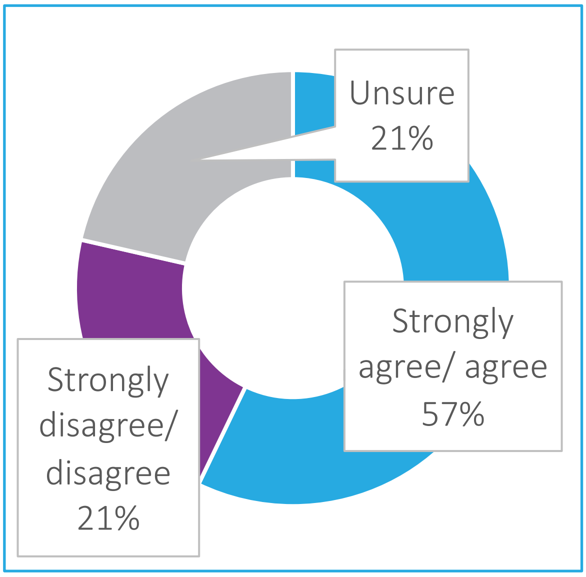
Outstanding Concerns and Appeals: The research invites further work in Dumfries and Galloway to strengthen and embed existing good practice to ensure that people are not left with unaddressed concerns following needs assessments. People should be provided with alternative, accessible communication routes – like online chat functions, a freephone support line, and direct email addresses for professionals – that allow them to follow up and have questions answered later, if it is not possible during meetings. Social work professionals should proactively check in with people after assessments to identify and address any outstanding concerns, and follow up on any questions or requests for additional information. They should also signpost and refer people to other sources of information, including independent advice organisations. Clear guidance and support should be given to enable people to access short breaks. People should not be left without support following a transition to adult social care.

Informed Choice and Control

Time to Consider Options

In the survey, we asked if people agreed with the statement "I had enough time to choose the option of SDS that suited my needs." Of the 56 respondents, 32 (57%) agreed or strongly agreed, 12 (21%) disagreed or strongly disagreed, and 12 (21%) stated that they did not know. While it is encouraging that most respondents in Dumfries and Galloway had enough time to choose an SDS option, the findings suggest that work may be required to improve the number of people who feel they have enough time to decide on the best SDS option for them.

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

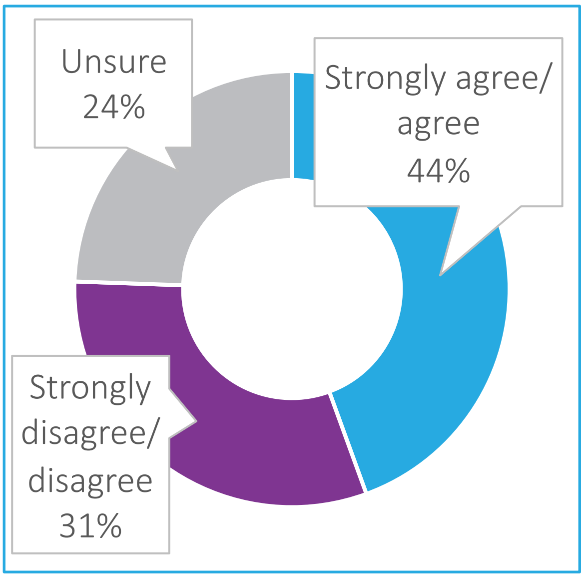


Overall, most participants felt they had enough time to choose an SDS option. However, a significant minority would have liked more time before deciding – a result that has strong overlaps with those people who wanted more information about their options. None of the respondents who wanted more time to decide said that they had received “all the information I wanted” about the four SDS options; one person said they received “some, but not enough”, and the remaining respondents said they had received no information about SDS options. These results indicate a correlation between the provision of clear information and people feeling able to make prompt decisions about their support.

Waiting Times

In the survey, we asked people to agree or disagree with the statement, “Waiting times, or waiting for responses, makes Self-directed Support more difficult for me.” Of the 45 respondents, 20 (44%) strongly agreed or agreed, 14 (31%) disagreed or strongly disagreed, and 11 (24%) stated that they were unsure.

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



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

One participant suggested that it would be useful for social work departments to give clear indications of timelines for each stage of the process; and, practically, that people should “apply as soon as possible as it did take about eight to ten weeks for funding to be released.”

Interviewees uniformly appreciated short waiting times for a response or decision from social work. Those who waited the longest generally reported the highest levels of stress and difficulty in accessing SDS. One interviewee drew attention to the need for quicker decision making processes surrounding SDS budgets, and clearer information about expected waiting times to access support. They highlighted that in the past the person for whom they care has been in crisis in relation to support needs at home and required specialist equipment to live at home safely. In the interviewee’s experience, approving these sorts of decisions can take up to six months, even working closely with a supportive social worker to try and speed up the process. During this period, the person for whom the interviewee cared did not have proper support at home for lifts, which adversely affected the whole family. The interviewee highlighted that even six weeks’ delay can force situations to breaking point for people in crisis – and that accurate information is key to planning workload when awaiting support.

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

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

Choice over SDS Option and Support

We asked survey respondents in Dumfries and Galloway if they were on their preferred SDS option. Of the 48 participants who answered, 41 (85%) were on their preferred option, two (4%) were not on their preferred option, and five were unsure (10%).

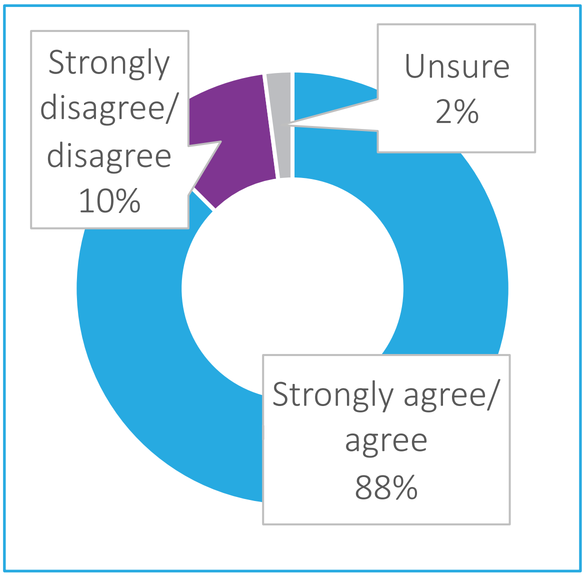
A similar pattern was found with interviewees. Most interviewees were on their preferred SDS option, however two interviewees indicated that they use Option 1, but not by choice. Not all respondents felt confident about being able to move from one form of SDS support to another – partially because they were unsure of their current arrangements. Some interviewees explained that they are unsure which option they or the people for whom they care used.

The interviewees who use Option 1 against their preferences have a small team of PAs to help them with personal care. They would prefer to use SDS Option 3, but they were informed that there were no council services available to meet their needs in their rural locality.

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

We also asked survey respondents to agree or disagree with the statement "I am fully involved in all decisions about my care and support". Of the 48 respondents, 42 (88%) strongly agreed or agreed, five (10%) disagreed or strongly disagreed, and one (2%) stated that they did not know. These findings are encouraging, and higher than the national average in MSMC – where 74% of people agreed that they are fully involved in decisions, 18% disagreed, and 8% were unsure.

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



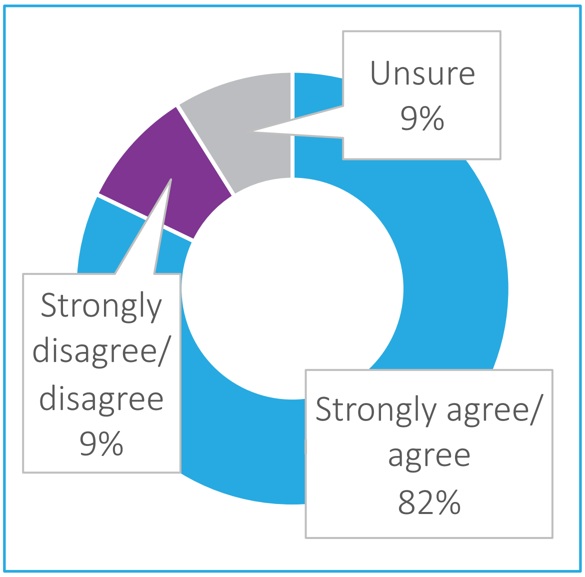
We also spoke to interviewees about their involvement in decisions about their care and support. Some relayed how they had a "really good package" following detailed discussions with social workers about their needs and personal outcomes, and stated that they were fully involved in decisions about their care and support.

However one interviewee, an unpaid carer, relayed that multi-agency meetings could be intimidating, and left them feeling as if they and the young person for whom they cared were not leading care decisions:

> *"A lot of the professionals speak in their own language, like those meetings I go to in the school, and they're sitting… and it's as if they've been talking on the phone beforehand, and they've agreed, and then they're just bringing it out in front of me. You know what I mean? You know, like a meeting's been set up, and you're sitting at the meeting, and maybe the head teacher will come up with something, and the social worker says, 'yes, I think that would be the way forward, I think we've all agreed that'. […] And you think oh, they must have been talking about this, you know, before bringing it to me."*

In the survey, we also asked people to respond to the statement "I had a say in how my help, care or support was arranged." Of the 56 respondents, 46 (82%) strongly agreed or agreed, five (9%) disagreed or strongly disagreed, and five (9%) stated that they did not know. These findings are also highly encouraging, and higher than the national average in MSMC – where 69% of people agreed that they had a say in their care arrangements, 22% disagreed, and 9% were unsure.

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

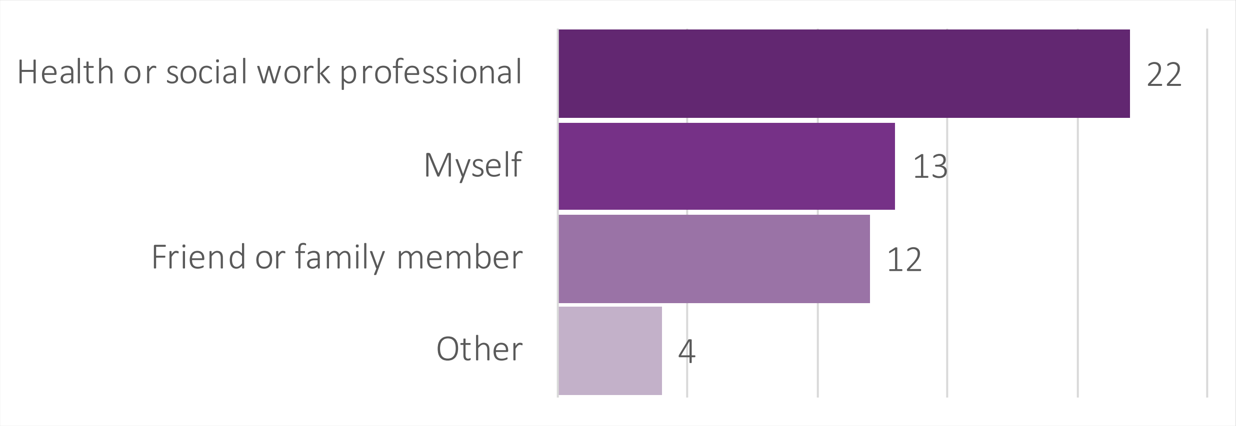


We also asked survey respondents who chose the way that their support is arranged now. Of the 51 respondents, 13 (25%) said that they chose the way their support was arranged, including one person who shared that decision with a family member. 21 (41%) said that a social worker chose their support for them, and one (2%) that their care manager chose for them.

Combined, that is a total of 22 respondents (43%) who reported that health and social care professionals chose how their support is arranged. These findings invite further work to embed supported decision making (instead of substitute decision making) in SDS/ social work practice.

A further 12 people (24%) stated that a friend or family member chose for them, including one person who reported that a social worker and a family member shared the decision. Four people (8%) selected "other", including one person who stated that they "didn't know" who chose the way that their support is arranged.

Chart 20: Who chose support arrangements? (Survey)



We also heard from interviewees about their SDS option choice. Some people felt that their social worker had decided what SDS option they would choose before completing the needs assessment, or were informed that Option 1 was the only possibility in their area. Other interviewees highlighted the importance of access to information to make informed decisions, since they felt that they were at the mercy of what knowledge their social worker had.

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

Budget Management

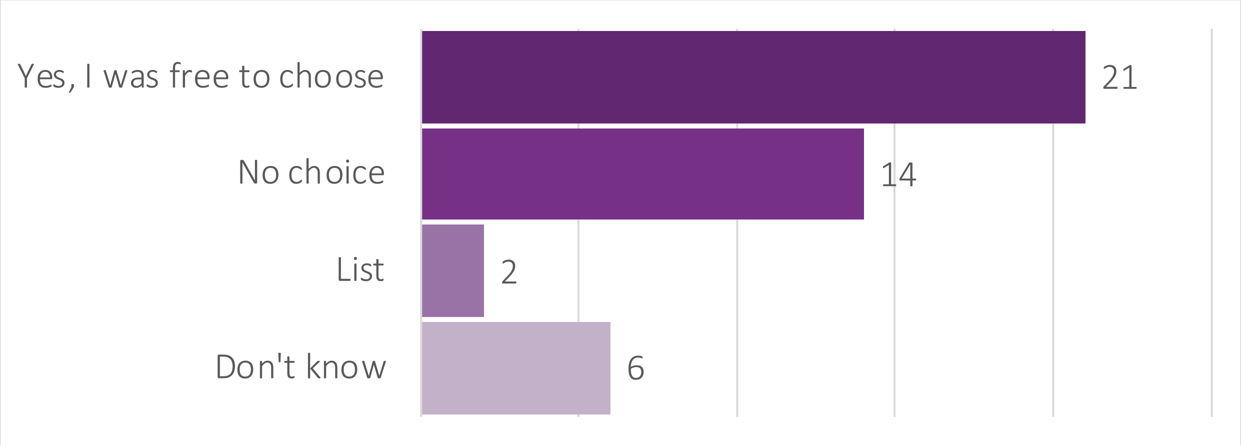
We asked survey respondents whether they chose who manages their personal budget, and if so, who they chose to manage it. Of the 43 respondents, 21 (49%) said that they were free to choose who they wanted to manage their personal budget, two (5%) chose from a set list of providers given to them by a social work professional, 14 (33%) said they were not given a choice, and six (14%) were unsure whether they had a choice.

Of the 21 people who were given free choice of who would manage their personal budget, two chose a third sector provider organisation, and one selected an individual broker. A further 17 people (81% of those who were free to choose) selected an individual person (this response could include themselves). One person did not state who they had chosen to manage their budget.

Of the two people who chose from a list, one person selected the council, and the other a private care agency.

Of the 14 people who said that they were not given a choice, and the seven who were unsure whether they had been offered a choice, none provided details of who manages their budget.

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



It is encouraging that nearly half of respondents in Dumfries and Galloway were offered the choice of who to manage their personal budget. However, it is concerning that a third of respondents reported that they had no choice, and a further 14% were unsure. This indicates that, amongst other things, these respondents were not fully offered all four SDS options (as that would necessitate discussion of who would manage their personal budget).

Pre-payment cards

Half of all interviewees in Dumfries and Galloway discussed the introduction of pre-payment cards (all of those using Option 1 or 4). This was not an intended focus of the semi-structured interview questions by the MSMC team; all references to them were introduced by the interviewees.

Some respondents felt that the change to pre-payment cards from transfer of funds to individuals' bank accounts indicated a lack of trust in their ability to manage their own money, and overall trustworthiness. One interviewee recounted that:

> *"Then they changed it to the pre-paid card. It got really bad then. Because I felt that changing it to the pre-paid card was a sign of them taking my authority off me. It was them like dangling the carrot. It was like 'we've given you a pre-paid card so that we can look at what you're doing'. Well there's no need for you to look at what I'm doing. As you can see if*

there's any extra money you get it back, we do reviews, I show you all my payslips. […] Trust is a big thing. I feel like the agenda is, it's not to say how my welfare is."

Another interviewee also commented negatively on the introduction of pre-payment cards, and saw them as an indication that the local authority felt they were not trustworthy:

> *"But just the whole thing about you cannot use cash because it is open to fraud. I'm like, you have checked my bank statement every few months for the last seven years, I have not been doing any fraud and it is unlikely that I am going to start doing any."*

Other respondents focused on the practicalities of changing from a bank account to a pre-payment card. Some respondents found this process uncomplicated, even across the introduction of two separate pre-payment card systems. One interviewee summarised their experience as follows:

> *"They send me the bill, and I just pay it off my card – you know the card that the council have? […] So that was quite easy. And the new card – it's transferred to a new system – it's been OK as well."*

Some respondents had more negative experiences of the change to pre-payment cards – in some cases, experiencing significant stress, with staff pay not being processed due to confusion with the transition. One interviewee summarised their experiences as "an absolute nightmare", following unclear instructions and roll-out of the cards:

> *"We all got used to that system and obviously, they couldn't just keep it the same, they changed it. […] The first time, they started paying money into my new card account. […] The card that they sent didn't correspond with the account that we had opened, they paid money into this account that I didn't have access to, [local authority staff member] couldn't sort it out because they didn't have access… I couldn't pay anything for months because I didn't have access, it was an absolute nightmare."*

Another recounted similar problems with practicalities:

> *"For years it worked, we had a bank account, [a support organisation] did all the things, and then they changed to these pre-payment cards. And I've had nothing but hassle since we moved onto them. […] It was just constantly – once everything shifted onto these cards it just got so much harder. And then everyone got used to the card, and then they changed to another card a couple of months ago, and it's just a nightmare to navigate."*

Another interviewee also highlighted the fact that some businesses do not accept card payments (e.g. the leisure facility they attend, covered by their SDS package). This led to respondents transferring money to individual employee's private bank accounts, and those people then paying cash to the business on behalf of the respondent. They also highlighted that the shift to a pre-payment card limited their options for providers of short breaks, as "you can only go to places that would take that card and invoice them".

Respondents also mentioned paperwork complications concerning pre-payment cards – some relating to tax returns, and others to the design practicalities of the online system:

> *"The first card we had was online, and you could just download the app, and you could just pay whatever. And this [second] one's online but you have to go onto a website, and it's a really irritating form you have to fill out every time you want to pay anything, there's no – there's a drop-down box for what you're paying for. So before I could just put down 'miscellaneous' or 'incontinence supplies' or whatever, but now there's certain categories, and if it doesn't fit in certain categories you can't pay the bill. So it's just a nightmare. I resisted moving on to the card, I kept phoning them and saying I don't want to, the bank account works well for us, and they said there's a couple of people in the region who can't get to a bank to do the banking, so we have to change onto something else."*

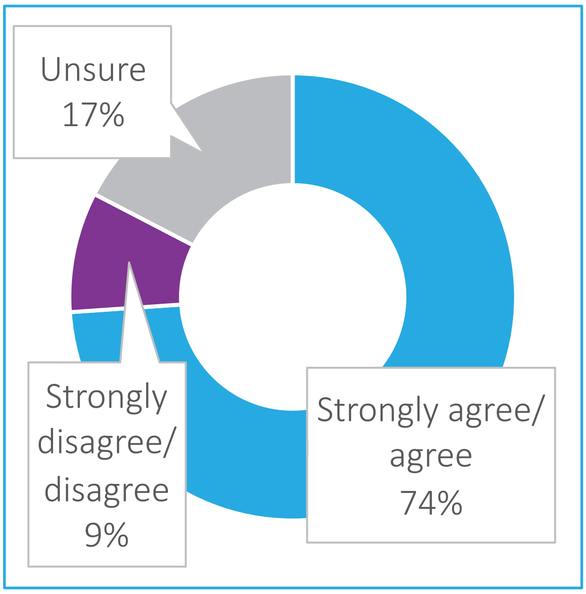
Of the respondents who mentioned pre-payment cards, only one did so without relaying any problems with the process. Of the remainder, all had suggestions for ways in which the process could have been smoother and less stressful. Examples include: editable fields for entering expenses (rather than set categories); a dedicated helpline for people encountering problems with the system, with staff trained in its use and familiar with SDS; multi-device functionality, accessible via web-browsers and Android/Apple apps; meaningful consultation with people who access social care prior to any decision being made and the implementation of new systems.

Budget Management: The findings indicate that further work is needed in Dumfries and Galloway to ensure everyone is offered a meaningful choice of all four SDS options and the opportunity to choose who will manage their personal budget. If any schemes like the pre-payment cards are introduced in the future, Dumfries and Galloway local authority/ HSCP should ensure that plans and systems are co-produced with the people who will be affected from the outset, to mitigate negative impact and experiences.

Adequate Support

We asked survey participants to respond to the statement "Enough budget to meet my outcomes makes Self-directed Support easier for me". Of the 46 respondents, 34 (74%) strongly agreed or agreed, four (9%) disagreed or strongly disagreed, and eight (17%) were unsure.

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



Some interviewees spoke in detail about the impact on their physical and mental health of substantial reductions to their SDS budgets and support. One interviewee was confused by an unexpected rise in care charge contributions after their last review. They explained to the social worker that they have limited income from social security entitlements and outlined what they could afford. The interviewee felt frustrated that conversations focus upon the potential reduction of hours using SDS, rather than support needs and outcomes. They stated that:

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

Another interviewee also raised the issue of personal contribution care charges, as well as the possibility of budget reductions. Personal contributions, they explained, can eat into an individual's weekly budget. They outlined that:

> *"A big challenge of SDS for me is wondering what if what to do if they decide to cut the budget. […] It's the unpredictability, you know? […] The contribution went up from £4.50 to £32 per week and [in] some of the cases it went up from £5 to £70 – so you can imagine how much that takes out of the weekly budget. […] I am always conscious that they could just turn up and say, 'it doesn't matter, cut the budget.'"*

A different interviewee echoed these concerns, stating:

> *"They keep cutting the money. […] When I first started SDS I was paying [personal contribution figure]. I got a letter saying that 'this is getting put up', and within the space of a year, a year and a half, they put it up to [double earlier figure]. I tried to explain to them that that doesn't go with inflation, like my benefits haven't changed, they're still the same benefits. They didn't have any consultation about the increase, they just said 'this is how much we want you to pay.' Which, I've told them from the start I won't pay it. […] I told my social worker about it and he's never really done anything about it."*

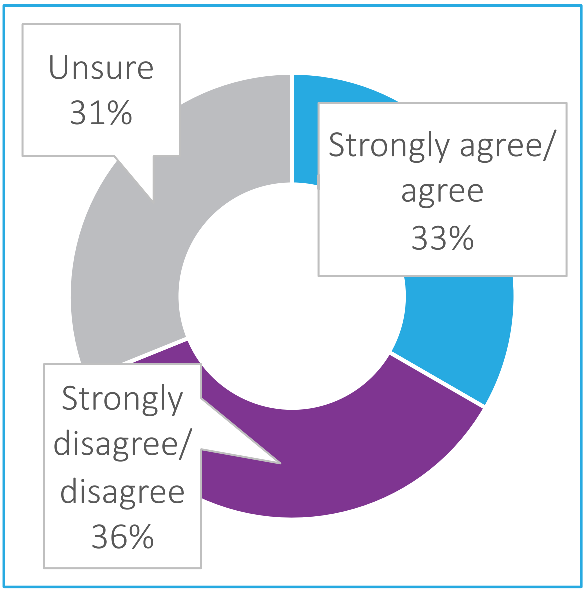
Interviewees discussed the need for greater empathy when it came to the local authority deciding which activities would be covered by SDS. One interviewee highlighted that only personal care tasks were accounted for in their budget. This, they said, ended up with blurred lines about their care, because personal assistants would be unlikely to leave dirty dishes lying around after the preparation of food. Additionally, they recounted how the social worker had suggested reducing the number of hours of support provided per week by relying on microwave meals instead of having freshly prepared meals.

As well as reporting on the negative impacts of cuts to social care support, some respondents described care arrangements that were not suitable. One survey respondent suggested independent research into available services was useful, both to "check out what services are available" and investigate "the criteria for engaging carers." Another survey respondent commented that it was important that people considering SDS realise that "having a budget to spend on care or support does not mean that there will be a provider who can do what you want when you want and to a good standard" and suggested that people "get help to consider the pros and cons" of each SDS option.

Given the concerns raised about effective communication of SDS options, it is reasonable to assume that some of these issues with individual care providers could be mitigated if – for example – individuals knew they had the freedom to move from Option 3 to Options 2 or 1 and receive support from different care providers or PAs.

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

Chart 23: "Lack of flexibility in how I can use my personal budget makes SDS more difficult" (Survey)



Flexibility

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

In the survey we asked people to respond to the statement "Lack of flexibility in how I can use my personal budget makes Self-directed Support more difficult for me". Of the 45 respondents, 15 (33%) strongly agreed or agreed, 16 (36%) disagreed or strongly disagreed, and 14 (31%) stated that they were unsure.

Interviewees talked about flexibility in a range of ways: from the flexibility to change SDS option, to being able to choose how and when to spend their personal budget, with different amounts of spend and support at different times of year. For example, one interviewee's budget was not fixed in terms of a set number of hours each week, to enable them to be flexible in how they arrange support.

Other interviewees recounted how they had changed from Option 2 to Option 1 as their needs altered, to help tailor their support. Interviewees imparted that flexibility is possible without fixing the hours too much weekly and shared that the flexible nature of the budget also enables banking of PA hours for occasional longer days out and short breaks.

Some interviewees used a "family budget". One explained that this has worked well in terms of flexibility. They described that:

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

One interviewee discussed how their main expenditure was for their children to take part in accessible sports. The children enjoy doing the same activities and the interviewee recounted that a local club provided a therapeutic environment. The club instils a safe, peer support atmosphere where everybody adopts a person centred approach and embraces difference. Without an SDS budget the children would be unable to participate in these activities.

A further interviewee pointed out that flexibility surrounding the activities or services that are funded is important. People's interests can change, and having variety helps with development, independence and choice (e.g. funding an outcome focused on physical activity and socialisation, rather than participating in a specific sport).

In other instances interviewees recounted how their budget evolved to meet their support needs. One interviewee outlined that originally SDS was put in place following hospital discharge, for support with intensive care at home. This approach has become an umbrella concept for the family, so that the interviewee's other children can be supported if they are attending hospital appointments. They discussed how the family support arrangements include a personal assistant who works part time, a relative who provides care, and a further budget for ad-hoc support.

Similarly, a different interviewee reported that using the budget flexibly was essential in meeting their family's needs. In periods where their child requires additional support (due to changes in health), or the family needs a short break, they remarked positively on the prompt response they receive from social work (and then their budget reduces again once the period of crisis and additional support needs has passed). While this experience was a welcome example of good practice, it was not universal; other interviewees stated that their SDS budgets were too inflexible to cope with periods of intense sickness. One interviewee recounted that they needed more support when they had caught a virus and become very ill. However, their SDS budget did not provide flexibility to add on additional hours of support so they were left in bed without proper care.

Flexibility: The research suggests that there is good practice with regards to flexible approaches to SDS in Dumfries and Galloway, which positively impact's people's lives and those of the people for whom they care. However, some people in Dumfries and Galloway are not able to use SDS as flexibly as they should, which can negatively impact on quality of life and enjoyment of rights to independent living and equal participation in society. Ensuring universal access to flexible SDS will help reinforce the positive impact of support. This flexibility could be in how people are empowered and supported to use their SDS, or provide additional support during health crises, but also relates to people's ability to have ongoing conversations with social work professionals and adjust systems accordingly on a regular basis.

Access to Short Breaks

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

Some interviewees reflected on difficulties accessing short breaks, and the negative impact this had on their health and wellbeing. One person stated that after they complained about a specific care provider, "for 18 months I got no respite, and that happens to a lot of families who challenge the support agencies – […] they will close ranks." Others recounted difficulties in getting short breaks approved as part of their budgets.

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

Travel Costs

Travel costs – for respondents, PAs and care staff – were repeatedly mentioned as a concern, especially for people living in more rural areas of Dumfries and Galloway. This was not always linked directly to people's SDS packages, but where people employed PAs, the time to travel by public transport to carry out activities was not always acknowledged in care plans. There was ambiguity amidst Dumfries and Galloway respondents concerning whether travel costs for SDS users and their PAs were covered by SDS budgets. Two interviewees had been told that they were not, one was awaiting confirmation, and another received funds to cover such expenses ("They do pay […] travel expenses, it's 20p a mile, that just about covers petrol").

Interviewees pointed out that travel costs, especially in rural locations, are often high, and adapted vehicles typically use more fuel than regular vehicles. This can cause significant financial strain for people who use social care and their families

– who, as covered elsewhere in this report, are more likely to have limited household income.

One participant highlighted that they were advised by social work to take a step back from providing unpaid care when the person for whom they cared transitioned to adult services. However, they were still expected to drive the person for whom they cared to a specialist college and various activities, without travel expenses being covered. This placed significant strain on their finances.

Another interviewee has also found that the lack of travel costs for a PA is impacting on their ability to pursue their interests. The interviewee is a keen sports enthusiast but at present they fund their PA's travel costs, as they are not included in their SDS budget. They summarised that PA costs outwith wages can add up, "because you're needing to contribute to travel […] and cover food."

Some respondents indicated that they would welcome more assistance from social work in accessing appropriate travel passes and in dealing with transport problems. Even in cases where decisions lie with the Department for Work and Pensions rather than local authorities, most people tended to reflect on transport issues and SDS without clearly delineating between the two parts of their experience of social support.

Interviewees discussed the problems caused by infrequent bus services, inaccessible pavements, and a lack of controlled crossings caused for disabled people trying to access public transport. People suggested that more should be done to ensure that services are both suitable and fully accessible for disabled people and people living with long term conditions. Some interviewees, particularly those who lived in more rural parts of Dumfries and Galloway, stated that they rely upon the use of their PAs' cars for travel, even for short journeys (e.g. to local shops). This requirement for PAs to drive can limit recruitment options.

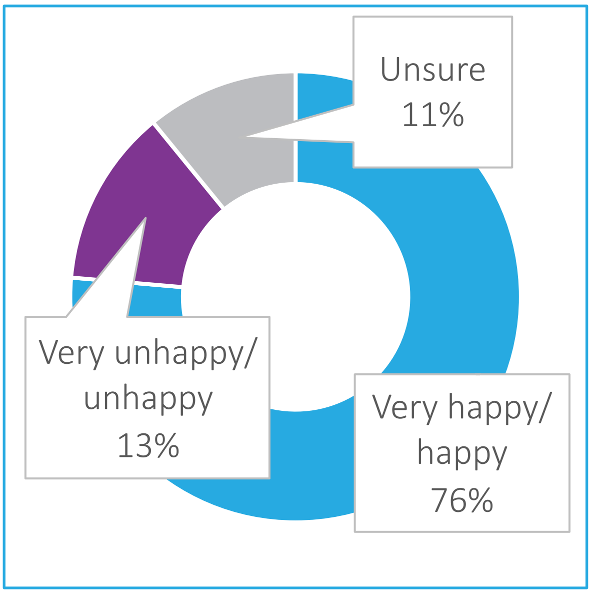
Travel Costs: People – particularly those living in more rural areas of Dumfries and Galloway – require more acknowledgement and accommodation of travel costs in their SDS budgets. Some would also welcome assistance from social workers and third sector organisations in navigating the bureaucratic processes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

Communication and Relationships with Social Work

Good Conversations and Consistent Relationships

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

Chart 24: "How happy are you with the conversations you have had about your support with professionals?" (Survey)



Of the 55 respondents, 42 (76%) were happy or very happy, seven (13%) were very unhappy or unhappy, and six (11%) didn't know. Respondents in Dumfries and Galloway were notably more satisfied with their conversations with professionals compared to people in other parts of Scotland.[33]

Interviewees highlighted that good conversations require effective communication, access to information, prompt decisions, and good future planning. People highlighted that they appreciated being able to both call and email their social worker and receive a prompt response – not just when they had questions about their support package, but about their wellbeing more generally.

One interviewee recounted how their social workers had supported them through their first needs assessment and thereafter:

> *"I have two fantastic social workers. I've had the same social worker for […] years; anything we need with support [they] help. Also, [social worker] was the one to get the support for [supported person] up and running. The […] social worker has been there for us, [they're] helping us with different things at the moment, with the [supported person] having a few more problems. But I couldn't fault my social work department at all in that way."*

Two interviewees outlined that they appreciated being able to stay in email contact with the social work department and their regular attendance at meetings. They stated that:

> *"I can email them [social worker] any time I want. Probably the quickest response I'll get is by email, because obviously they're busy. If I phone they always phone me back, because they know I don't phone just for the fun of phoning for a chat, they know there's a reason. I don't do it that often, but I've never had any problems. They've attended meetings they're supposed to attend, they've never let me down. So, so far so good! All going well."*

One of the interviewees also reported that they had developed a good relationship with their social worker, communicating mainly by email. They asserted that:

> *"Honest to God, at that point [the start of assessment process] I would never have said we'd get to this kind of relationship we have with [social worker] now. [They] just seem to get it […] – like the adaptions and things."*

Another interviewee shared that regular reviews worked well for them because the young person for whom they care needs regular adjustments to their support plan. They, along with several other respondents, were particularly positive about the support they received from the children and young people's social work team.

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:

> *"They explained in a way I could understand"*

> *"We have an excellent social worker who knows our circumstances really well."*

> *"Very good social worker who I was able to engage easily with. [Social worker] was very knowledgeable and a really good communicator."*

> *"[Social worker] was very pleasant in [their] manner. [They] explained everything as [they] went along. […] Patient and didn't rush things."*

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

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

> *"Good home visit. No time pressure. Empathy and understanding."*

> *"Conversations with social work […] were very constructive. Provided with ideas of other services to assist situation."*

People repeatedly referenced prompt communication, time for full explanations and discussion, and easy access to information as key to smooth communication with social work and effective SDS provision. Respondents also appreciated short waiting times for a response or decision from social work.

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

Poor Communication and Relationships

A minority of participants described less positive experiences of communication and relationships with social work professionals in Dumfries and Galloway. Of the 52 people who answered the survey questions about how happy they are with the conversations they have had about their support with professionals, seven (13%) indicated they were either very unhappy or unhappy. Some stated that their social worker did not have enough time or knowledge to meet with them and discuss their needs and questions properly. Others indicated more fraught relationships.

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

> *"Very hard to get in touch with them."*
>
> *"They did not really listen to my priorities and did not offer all the options."*
>
> *"Social worker didn't listen to me. I wanted to make my support individual to me but this didn't happen."*
>
> *"The social worker has no experience of SDS. [They are] very good at listening to what we need etc. but doesn't know the first thing about SDS and how it works. [The] mangers, who we have never met, just dictate stuff to [the social worker], some of which seems barely legal."*

One interviewee described feeling unsupported by their social worker, and that they would have appreciated greater signposting to resources. They stated that the social worker, "never tried to get me into any clubs, never said, 'What about charities?' [...] they never really gave me much help." The interviewee later requested a change of social worker. Following this request, a more senior colleague then started to attend home visits along with the member of staff the interviewee had expressed dissatisfaction with, which they found "quite intimidating, because it was two against one". The interviewee was then informed that a multi-disciplinary meeting would take place, which they were not allowed to attend. They were also not allowed to read the minutes of the meeting. The interviewee summarised this experience as follows: "I felt like I was being bullied and intimidated in my own home".

Two interviewees shared that during the last review of the person for whom they care, they were given conflicting messages about the provision of unpaid care. On one hand they were expected to pick up some tasks, while on the other hand they were told to justify their involvement and to take a step back from providing unpaid care. They stated that their social worker "told us that we had to make the support plan and cost the support plan, but we weren't allowed to know what was available."

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

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

Some interviewees recounted a lack of communication concerning the nature of visits. Two interviewees shared how a social worker arrived unexpectedly for a home visit. They were not sure who the social worker was, or what the visit was about.

Interviewees also mentioned that they felt their social workers needed to spend more time reviewing case notes and getting to know the people they were supporting. One interviewee reported that their social worker tended to turn up to meetings in a rush, without having read about their specific needs. Meanwhile, another interviewee's review highlighted inaccuracies in reporting in areas where they required assistance or additional healthcare provision.

One interviewee, who had appealed a decision, outlined that no information was given about how to challenge processes or complain. They stated that:

> *"But they [social work] don't tell you about the practices, they keep a lot of things hidden. They never say you could make a complaint to SSSC [Scottish Social Services Council]. Never told me that, I had to look at it, then I had to use some of the legislation."*

Overall, several respondents stated that they would welcome information about what to expect from interactions with social work, with reminders of visits where appropriate. It would be helpful for social workers to phone the morning of any intended visit, as well as providing written notice of the visit, and accommodate people's communication needs.

Poor Communication and Relationships: Examples of poor communication raise clear concerns about decision making and autonomy; if information about SDS is not provided, then they cannot be said to control or choose their support. The findings invite further work to expand existing good practice in Dumfries and Galloway to ensure that people's experiences of conversations and relationships with social work are consistently good. Professionals should ensure that all unpaid carers are offered carers assessments and have their rights explained to them, and should not assume that family members and friends are able or suitable to provide unpaid care. Health and social work professionals should respect service users' preferences if they do not wish to be reliant on family members and friends for their care and support. All processes and paperwork should be transparent and shared in an accessible format with service users. Social work staff should proactively gather regular feedback – good and bad – from service users, families and unpaid carers as a way to support continuous improvement. People should be proactively informed on a regular basis about how they can challenge decisions, access independent advocacy and support, local authority complaints procedures and the independent oversight of the Scottish Public Services Ombudsman (SPSO).

Transparency

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

While some people spoke warmly about transparency in Dumfries and Galloway, others expressed concerns about transparency of processes that were often synonymous with inaccessible information. Several respondents touched upon the lack of transparency during the needs assessment and that they lacked access to the calculation of need carried out by social work or to the eligibility criteria for support. People also reported that they would like access to copies of all documentation concerning their social care provision, including copies of their agreed budget and personal outcome plans, but struggled to obtain these documents from social work.

One interviewee was unhappy with an unexpected review from a social worker, who had informed them that the visit was a training supervision exercise. The review ended with a suggested reduction to their SDS budget – which caused considerable confusion and stress for the interviewee.

In order to counter some of these issues with accessing paperwork, one interviewee advised that writing everything down for and during any meeting with social work helps with organisation so that people can access required information. They also recommended this tactic to ensure that all points are raised during meetings with social workers and decision makers, especially if social workers are short on time. They said:

> *"I found at the meetings that if you didn't write everything down your head was just scrambled and things didn't come out right, and probably they went away, and you'd forgotten to say or ask for something."*

They also highlighted that a practice of notetaking maintains an audit trail from which actions and accountability can be tracked – a broader trend within the MSMC interview findings.

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

Care Staff Recruitment, Training and Quality

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

Several interviewees outlined how SDS has provided them with person centred support that benefits their entire household. One interviewee commented that employing PAs via Option 1 has meant that they have increased control over the care they receive. They stated that:

> *"It has given me a lot of freedom to use the hours the way I see fit. So sometimes in the morning I might take longer for getting help. But it's given me that freedom that I'm in control, I can say 'I need you this morning' and quite short notice I can give."*

While many respondents were positive about their experiences of care workers, some raised concerns around employer duties. People suggested that it was important that people "understand the time and commitment necessary to organise and administrate personally (or their legal representative)", and the "significant workload entailed" in "becoming an employer of personal assistants/carers."

Important Characteristics of Care Workers

Many people commented on their priorities regarding care staff. One respondent reflected on the pressures of responsibility as a parent caring for a young person with complex needs. They shared that it took a lot of trust for them to feel confident that their child's needs would be met by a care worker. They outlined that sometimes instead of being person centred, service delivery can be too procedural in nature. They explained that:

> *"[Name] has to sit in a wheelchair, so […] comes home with friction burns. And they can't feed [Name] properly because they have a procedure for feeding. Everything that has a procedure or paperwork or health and safety for carers is a barrier to caring […]. [Name] needs flexibility, needs changed in position, needs continuity of care, so they know how to give [Name] a drink. […] It's challenging; I mean I'm not criticising them, but there's no flexibility in the system for people in the future who need a very personalised care system."*

Having care workers who have a high level of empathy and communication skills is important. One interviewee stated that:

> *"It was fine, I was a wee bit apprehensive of somebody else taking [Name] out, because [they] can't communicate very well, and doesn't really use sign language anyway. Because of [Name's] learning disabilities it was a wee bit tricky to […] use a lot of sign language, so [they] do use bits and bobs, […] but is still very vulnerable because they'd go with anybody. But I find that we've got a couple, two or three care workers that are really nice,*

> *and they know [Name] now, so I'm really happy with them now."*

Another interviewee highlighted the difference that a trusted care worker had made to their life. They stated that:

> *"We couldn't do without a PA now. It's very beneficial for all of us, keeps us all sane. […] We know, if there's something coming up […] but it's not really a [Name] activity, we can kind of plan in advance, and get the PA to come and either come with us, and take [Name] off somewhere else, […] and we can go and do something with the kids. It's just trying to balance, so nobody is missing out on things."*

Several participants said that having access to suitable PAs made the use of SDS easy. One interviewee has had one PA for over ten years and another for seven years on attractive rates of pay. Another recounted that continuity and finding the right person to provide care is key, as this ensures that:

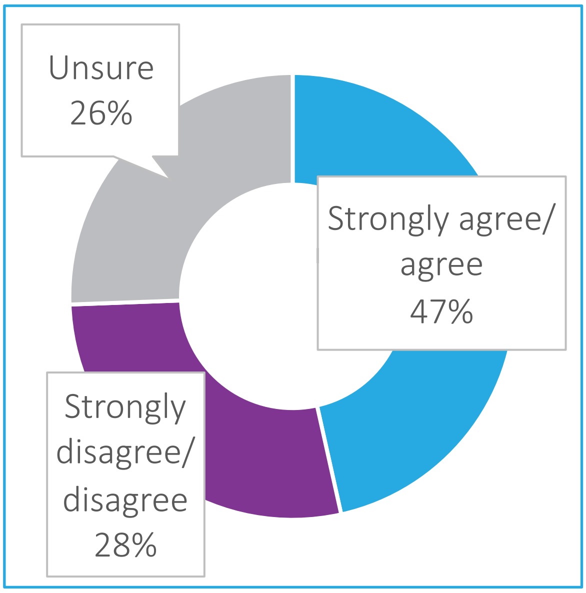
> *"They don't phone in sick because they know that if they don't turn up then [Name] can't get out of bed […], can't go to the toilet [without assistance]. When people have known you and they have known you since you were five, they are not going to not turn up just because they were out last night. Because they know you cannot go to the toilet or you cannot get out of your bed or prepare something to eat."*

A trait that interviewees tended to look for was that PAs were passionate about their support roles and that they did not treat it like a means to an end. An interviewee described that a care worker seemed to fit the family because:

> *"[Name] just seemed confident and [they] seemed to get when we said we needed somebody that would be like a friend for [Name], not somebody who would come in at nine o'clock and leave at three o'clock, regardless of what's happening type thing."*

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

Chart 25: "Lack of a regular personal assistant (PA) makes SDS difficult for me" (Survey)



Staff Recruitment, Retention and Turnover

In the survey, we asked people to respond to the statement "Lack of a regular personal assistant makes SDS difficult for me". Of the 43 respondents in Dumfries and Galloway, 20 (47%)

strongly agreed or agreed, 12 (28%) disagreed or strongly disagreed, and 11 (26%) were unsure.

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

One interviewee recounted how cuts to the level of wages within SDS budgets can impact upon the retainment of PAs, especially in rural areas. Two PAs had left their employment due to uncertainty about potential reductions in pay, and the interviewee shared that they had supplemented wages for a long time out of their own money. One interviewee summarised their difficulties with recruiting PAs as "like a merry-go-round – it's awful trying to get PAs in this area".

Another interviewee reported similar challenges. They outlined that there are responsibilities as a PA employer, such as sick pay or covering holidays, and that from their point of view, little support was provided by social work to recognise these challenges. They shared that their family struggled with the recruitment process. Even after approaching the council and local organisations for help, they asserted that:

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

Some respondents suggested they would welcome more support from Dumfries and Galloway Council to arrange PA training and continued professional development.

One interviewee highlighted the impact of Universal Credit on PA work. The interviewee had a new PA who was encouraged by the Jobs Centre to take up the part-time post. However, the way that Universal Credit worked out meant that most the money paid to the PA was effectively taken off them because the system required them to work 16 hours per week. The Job Centre began to encourage the PA to find alternative full-time work, and the interviewee had to find a new employee.

Care Workers and Training

Several people commented on the need for care workers to receive appropriate training. One interviewee reflected that they need care workers who are qualified to carry out the specific specialised personal care, with appropriate medical training. They stated that they also viewed this as part of their PA's continuing professional development:

> *"The first aid training, […] and also if there's anything else they feel that they want, or they see any courses that they think might help, we're quite willing to pay for any other training that's necessary."*

However, the interviewee also reported that it was not clear whether PA training costs should come out of their SDS budget. They recall having stated in the past to a social worker that high quality PA training is essential, and that social work seemed to understand that necessity.

Care Staff Recruitment, Training and Quality: Some people would welcome more support with PA recruitment, training and continued professional development. Dumfries and Galloway should work with people who access SDS and unpaid carers to improve systems and processes related to care staff recruitment, training and quality. It is also evident that some people would welcome improved access to suitably trained and high calibre care workers. While some people are comfortable with the role of employer and have experienced good, long term, working relationships with their support workers, this experience is not universal. This suggests that staff in Dumfries and Galloway should continue to work with people accessing SDS/ social care to find ways to improve systems and processes – particularly around difficulties with recruitment, training, and staff retention within the wider social care sector.

Independent Advocacy and Support

Respondents in Dumfries and Galloway accessed independent advice and advocacy services for a range of different reasons. These included access to information, access to needs assessment criteria, assistance to develop a support plan, exploring flexibility with SDS budgets, mediation with social workers, support to appeal a decision, and advice on payroll and other PA employer related issues. Participants spoke positively of the benefits of independent advocacy and independent advice and support organisations in Dumfries and Galloway, including specific mention of Direct Inclusive Collective Enterprise (DICE):

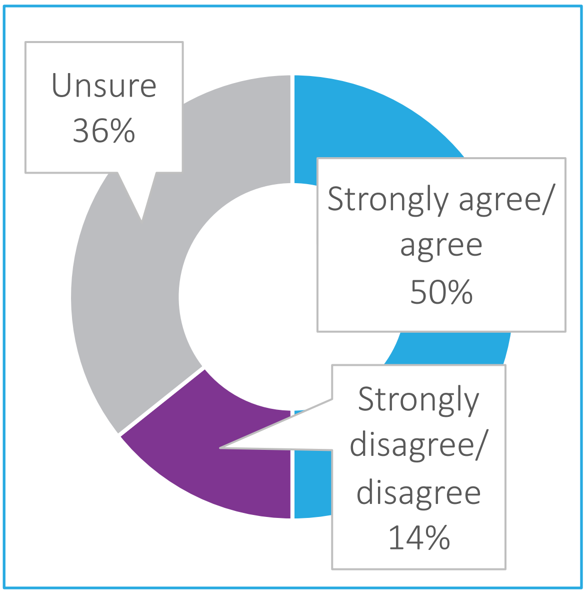
> *"I had really great support with DICE."*

> *"I had somebody from DICE with me [during a needs assessment] and [Name] was fantastic. A witness to kind of back me up."*

Independent Advocacy

We asked survey participants to respond to the statement "access to independent advocacy makes SDS easier for me". Of the 42 respondents, 21 (50%) strongly agreed or agreed, six (14%) disagreed or strongly disagreed, and 15 (36%) were unsure.

Chart 26: "Access to independent advocacy makes SDS easier for me" (Survey)



Some survey provided additional comments on the value of independent advocacy when accessing SDS. One participant suggested that people should "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!" Another respondent stated that people should "have an advocate or a professional who is trained in the distribution of SDS to help bargain the best care plan and how SDS can be used."

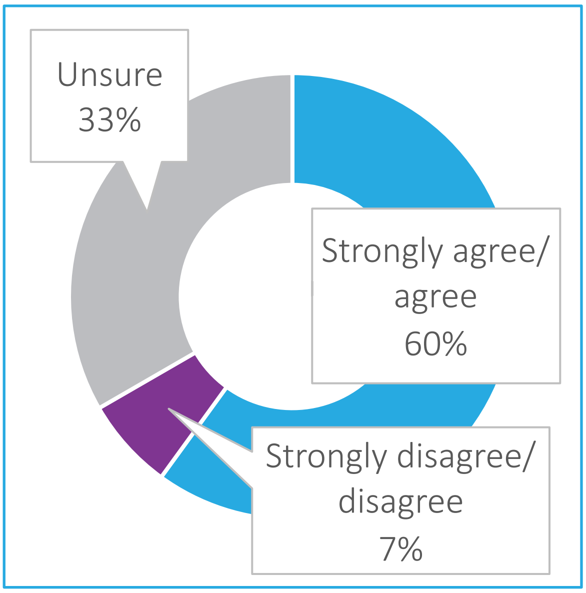
Some interviewees indicated that they were satisfied without the involvement of advocacy. One interviewee reflected that "in terms of advocacy, we're not backwards in coming forwards in meetings, myself and my partner", so they felt that additional support was not needed. A different interviewee thought that having an advocate involved would have increased the intrusive nature of SDS review meetings. They voiced the option that "if I wanted it, I would have asked for it. But it wasn't offered it was you know? [...] We don't want something invasive."

Several interviewees highlighted their access to independent advocacy had been helpful in accessing and managing SDS. One person also mentioned the lack of local independent advocacy organisations in their geographical area as a problem. This, they argued, affects people's ability to challenge decisions about SDS. Both interviewees and survey respondents was that anybody considering SDS should seek out support from an independent advocate. One interviewee said this can increase peoples' access to information, while another pointed out that social workers often change, are overworked, or are unknown to people before important meetings. They stated that independent advocates ensure that the person accessing for social care's voice is heard, and that they have a familiar person present to support them in meetings. Another interviewee pointed out that families often enter crisis before engaging with social work and that independent advocacy can be helpful for families in stressful circumstances.

Independent Advice and Support

When asked whether access to independent information and support made SDS easier for them, people responded in a positive fashion. Of the 45 respondents, 27 (60%) strongly agreed or agreed, three (7%) disagreed or strongly disagreed, and 15 (33%) were unsure.

Chart 27: "Access to independent information and support makes SDS easier for me" (Survey)



Survey respondents and interviewees commented on the value of independent advice and support in accessing SDS. Several people highlighted that they had benefited from the involvement of independent advice and support services during their needs assessment and reviews, and others had first heard about SDS via independent advice and support organisations.

Respondents drew upon independent advice and support organisations for support on a range of different issues. Specific examples include discussing the potential introduction of pre-payment cards for people using Option 1, increasing accessibility to public transport links, and gaining health condition specific information.

Peer Support

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

One interviewee wanted to see peer support developed across local authorities. Peer support, they felt, was an important way for people to learn about what rights, responsibilities and approaches they can use for SDS. When the interview took place, they had not managed to find any means through which SDS users could receive reassurance or advice concerning issues of care management, such as maintaining boundaries with care workers. Survey respondents echoed this advice, suggesting that it is worth "speak[ing] to existing users to draw on their experience."

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

Response from Dumfries and Galloway Council and Health and Social Care Partnership

Response to research

Dumfries and Galloway Council and Health and Care Partnership welcome the My Support My Choice research and findings as valuable and informative. It is encouraging that most people said in their responses that Self-directed Support had improved their lives and we would want to identify and continue good practice to this end. We have considered the recommendations and the range of feedback on people's experiences in our response.

Positives

It is positive that a large majority were on their preferred SDS option, and that carers are benefiting from short breaks to relax. It is also positive that there was comment on the benefits of the flexibility of support that SDS brings. We are pleased that a substantial majority reported positively on their experience of assessments and reviews with professionals, and that people in Dumfries and Galloway value and benefit from independent advocacy and independent advice and support services.

Areas for improvement

We would also wish to acknowledge that the experience of some respondents was not so good. We accept that we need to make improvements in the information we make available more generally and ensure the 4 options are fully explored with people, supporting them to make their own informed decisions. This requires adequate time to be allocated for meetings and we need to make sure that our staff have sufficient time to do this.

Recommendations

As the report acknowledges, there are a number of areas for improvement nationally as identified in the Self-directed Support Framework of Standards published in March 2021. We are developing a local action plan and participate in national networks to consider improvements required to fully meet these.

We have responded to some of the specific points with respect to practice in Dumfries and Galloway below:

Poverty and SDS

D & G Council and HSCP recognise the impact of poverty on many of its citizens and supports a number of initiatives to address this. Financial assessment towards people's contribution to their care is completed independently by a financial assessments team. Our Benefits Maximisation team and Citizen's Advice provide support in terms of income maximisation. There is also flexibility in the system to look again at budgets where these prove insufficient for the identified outcomes for them to be reconsidered.

Data gathering and analysis

We acknowledge there is a need for better use of information gathered locally and nationally. We are currently mapping our performance data and information against the SDS standards within the National Framework, and this will inform improvements in practice. We would welcome a national discussion on the key data required to better inform strategy and practice at both local and national level.

Information on SDS

Dumfries and Galloway provides and regularly updates documentation for practitioners to use and share with people in discussing their options under SDS. Easy read information is available and can be provided in other formats according to individual needs.

We also make best use of partnership networks to make information available to the public as widely as possible.

We endeavour to complete SDS assessments as soon after referral and prioritise urgent need.

We have recently developed a document to support discussion on the challenges and benefits of all options, but we must acknowledge that these choices are affected by variable availability of resource across the region. We try to tailor the means of communication to the needs and preferences of the individual and the Covid pandemic has increased the range of media we are now able to offer.

Advocacy services are available in Dumfries and Galloway and frontline practitioners make this information available for people to access these. We also provide support to do this where appropriate.

People are provided with documentation about their plan and budget in their preferred format. Careful conversations are had to ensure understanding, needs and preferences in budget provision including where signposting is needed about welfare benefits, financial and legal advice. We agree that more than one conversation can be required to achieve a clear understanding about options.

Informed choice and control

Current development of the Single Access Point and a Home Teams model in Dumfries & Galloway is aimed at improving efficiency in providing the right service to the right person at the right time.

Recent targeted recruitment to D & G Care & Support Services has focussed on areas where there has been a shortage of providers.

People being treated with dignity and respect is fundamental to health and social care practice: if anyone feels they have not been treated with dignity or respect we would encourage them to raise this with practitioners and their managers and to utilise our complaints process if the matter is not resolved. We have a clear comments and complaints procedure and strive to involve individuals, families and carers fully in processes and decisions. We advise people on how they can challenge decisions including to the Scottish Public Services Ombudsman.

Care is taken in addressing any changes in budget or service at an individual or community level, and their potential impact on the individual is an important part of this.

In Dumfries and Galloway carer's assessments are undertaken by the Carer's Centre if requested as part of the SDS process and carers may approach the carer's centre resource independently for support. Specific resources for carer support in different forms is available through carers assessments. Consideration of carer support such as short breaks from caring can be part of the agreed budget.

There are particular challenges in rural areas in addressing the need for travel to enable some people to access the right services to meet their outcomes. We acknowledge the need for further discussion in this respect. Our customer services department provides help in accessing travel passes and signposting to community information about local services.

Fundamental to our work is the consideration of equality and acting within the principles of human rights. All of our relevant policy is subject to Impact Assessment on the basis of the Equality Act 2010.

Communication and relationships with Social Work

We acknowledge the need to develop more routine feedback mechanisms for people to inform continuous improvement in the services we provide and commission.

Dumfries and Galloway Health and Care Partnership welcomes the learning from this research. We look forward to further opportunities to engage with individuals and communities to inform the ongoing improvement in the consistent delivery of Self-directed Support across our region.

My Support My Choice comments should be made by email to:
D&G.SDS@dumgal.gov.uk
General enquiries can be made by email to:
contact@dumgal.gov.uk or
calling 030 33 33 3000

Endnotes

1 To support readability, the 'N' number is not reported for all survey question responses. Due to the relatively small number of interviewees being discussed in this report (10 interviews, spanning 15 people's experiences of SDS), we use "some" or "several" to refer to three or four interviewees, "many" to refer to five or six interviewees, and "the majority" to refer to eight or more interviewees.

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

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

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

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

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

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

8 NRS Scotland, “Dumfries and Galloway Council Area Profile”. Available at: https://www.nrscotland.gov.uk/files/statistics/council-area-data-sheets/dumfries-and-galloway-council-profile.html.

9 Dumfries and Galloway Council, “Personalisation and Self-directed Support”. Available at: https://www.dumgal.gov.uk/article/15772/Personalisation-and-self-directed-support.

10 Dumfries and Galloway Council, “Eligibility criteria and priority framework”. Available at: https://lx.iriss.org.uk/sites/default/files/resources/sds_eligibility_220140204_v2.pdf.

11 Dumfries and Galloway Council, “Direct Payments”. Available at: https://www.dumgal.gov.uk/article/15771/Direct-Payments.

12 Dumfries and Galloway Integration Joint Board, “Health and Social Care Strategic Plan@: Part 1 (2018-2021). Available at: https://dghscp.co.uk/wp-content/uploads/2020/12/Strategic-Plan-2018-2021.pdf.

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

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

15 National Records of Scotland “Dumfries and Galloway Council Area Profile”. Available at: https://www.nrscotland.gov.uk/files/statistics/council-area-data-sheets/dumfries-and-galloway-council-profile.html.

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

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

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

19 This was a multiple choice question and some respondents chose more than one option.

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

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

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

23 *Ibid., p. 12.*

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

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

26 ***Ibid., pp. 6, 48-60.***

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

28 In the national MSMC report, 53% of survey respondents agreed that they felt prepared for their needs assessment, while 15% were unsure and 32% disagreed.

29 In the national MSMC report, 65% of survey respondents reported that the person they met explained things clearly to them, while 8% were unsure and 27% disagreed.

30 In the national MSMC report, 52% of survey respondents reported that all their questions were answered, while 12% were unsure and 36% disagreed.

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

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

33 As demonstrated in the MSMC national report, of the 434 respondents overall, 242 (56%) were happy or very happy, 135 (31%) were very unhappy or unhappy, and 57 (13%) didn’t know.

Glossary

Budget / Hours / Package

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

Charging Policy

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

COSLA

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

Direct Payment

See “Option 1”.

Disability

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

Eligibility Criteria

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

Guardian

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

Health and Social Care Partnership / HSCP

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

Independent Advocacy Service/ Independent Advocate

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

Independent Living

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

Independent Living Fund / ILF

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

Independent Support Organisation

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

Integration Joint Board / IJB

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

Impairment

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

Local Authority / LA

Local council (32 across Scotland).

Needs Assessment

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

Option 1 (also called “direct payment”)

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

Option 2

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

Option 3

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

Option 4

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

Occupational Therapist / OT

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

Personal Assistant / PA / Support Worker

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

Personalisation

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

Physical Impairment / Physical Disability

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

Reablement

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

Self-directed Support / SDS

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

Short Breaks

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

Sleepovers

The provision of care and support services overnight.

Social Care

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

Support Plan

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

Support Worker

See Personal Assistant / PA.

Unpaid Carer

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

About the Project Partners

ALLIANCE
HEALTH AND SOCIAL CARE
ALLIANCE SCOTLAND
people at the centre

About the ALLIANCE

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

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

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

The ALLIANCE has three core aims; we seek to:

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

Self Directed
Support Scotland
the organisation of choice

About Self Directed Support Scotland

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

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

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