

My Support My Choice:

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

September 2021





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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 Moray. 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 Moray, 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 Moray. Key findings are highlighted throughout, with a separate chapter on recommendations. The report concludes with a response to the research from Moray 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 Moray, 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 54 people in Moray 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 Moray within that larger context.

Research participants in Moray 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 79% of research respondents in Moray 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 Moray 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 Moray 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. People also highlighted the value of healthcare staff being informed about SDS.

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

This pattern of variable information about the four options continued into people's needs assessments. Half of people reported that they had "all four options" discussed with them during their assessments, with around one quarter reporting that either "none" or "some but not all" options were discussed with them. It is welcome that most people felt that social work professionals explained things clearly, and that all their questions were answered.

Three quarters of the respondents in Moray indicated that they had received information about how much money they could spend on their care and support. However, the remaining quarter 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 Moray 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 Moray 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 a quarter 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

Moray were offered the choice of who would manage their personal budget, it is concerning that nearly a fifth 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.

Budgets, care charges, communication with social work, 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 Moray 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. Others highlighted the need for greater approval of flexible uses of SDS. Participants – particularly those living in more rural areas of Moray – 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).

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 Moray highlighted that good, consistent, trusting relationships with social workers and clear lines of communication are all essential for positive and effective experiences of SDS. The 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 respondents reported that social work professionals needed to be able to take more time with needs assessments and ensure that people's needs and concerns were understood. Respondents also highlighted the need for prompt and easy communication lines with social work. Some people raised the need for greater transparency about how care decisions are made and by whom, alongside inclusive communication and easy access to information.

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 Moray. 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. Moray 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 Moray 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 Moray 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 Moray.^[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 Moray 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 should be able to choose care workers even when their support is organised by others – and this should be reflected in local commissioning processes.

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

21. 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.

22. 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.

23. 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.

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

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 Moray 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, Moray 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 Moray.

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

Moray is a council area with an approximate population of 95,000 people, across 42,500 households.^[8] Moray is a rural area in the North-East of Scotland, and people live in both very rural areas and small towns. It is situated between Highland to the west and Aberdeenshire to the south and east.

Moray 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 "Selfdirected Support", "SDS" and "direct payments").^[9] The relevant page is titled "Self-directed Support". This provides people with a brief definition of SDS and more detailed information about the four options.

Moray Council provide a range of additional information on social care eligibility criteria, assessments, and independent advocacy via their website – albeit not direct links to the SDS webpages. The eligibility criteria and associated examples

states that direct financial support is only available to people who have "critical or substantial needs".^[10] This document also provides examples and explains what level of support individuals are likely to receive for each category, as well as a copy of the questionnaire used by social workers to assess eligibility. Similarly, the page "Community Care Assessment" provides an outline of how to arrange an assessment, what happens, and Moray's policy on care charges.^[11] There is a tab titled "Free Personal Care", but at time of writing there is no embedded link, or information provided.

There are no direct links to independent support and advice or independent advocacy organisations on the SDS webpages, or to other resources for people who are not deemed eligible for SDS – although the Care Inspectorate's thematic review of SDS in Moray indicated that the three tier system used by social work in Moray does provide inperson sign-posting to services, even if people are not considered eligible for SDS. Information on independent advocacy and links to Circles Advocacy is available elsewhere on the Moray Council website, searchable via the keyword "advocacy".[12]

The eligibility criteria outlined on the Moray Council policy document reflect the National Eligibility Framework, which categorises risk as being critical, substantial, moderate, or low:^[13]

• Critical risk: indicates that there are major risks to an individual's

independent living or health and wellbeing 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 ongoing 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 dedicated page for that option. There is a range of answers to FAQs, and links to relevant resources for people considering or using Option 1, including documents for employers, advice on recruitment, and information on pension enrolment and finances. 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 or

request an assessment, people are invited to email accesscareteam@ moray.gov.uk or call a phone number (an 01343 number). There is no option to call a freephone number, which would enable people from lowincome households to call without being charged. This consideration is particularly important given the number of people in Moray – 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.

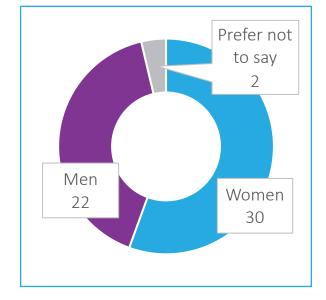
We encourage Moray Council to indicate document publication dates and webpage timestamps. The Council's website could also provide further information on their Equality Impact Assessments and the role these play in SDS/ social care decision making. Finally, to strengthen participatory decision making, Moray 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 54 people who use or were being assessed for SDS in Moray. We interviewed ten people who spoke about their own experiences and the experiences of other members of their household who use SDS. A further 44 people from Moray 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 guotations 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 Moray 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

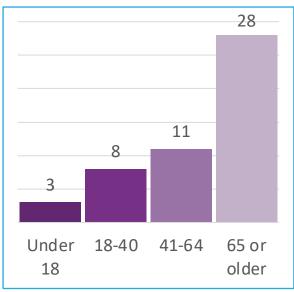
Overall, 30 women (56% of respondents) and 22 men (41% of respondents) participated in MSMC in Moray. A further two people (4%) preferred not to disclose their gender.

While PHS figures are not available for the division of men and women accessing SDS (nationally or in Moray), they do publish statistics on the number of men and women receiving social care support services more generally (of whom an estimated 36% access SDS). PHS reported that in 2017-2018 66% of people accessing social care support in Moray were women and 34% were men.^[14]

Age

We asked all participants to share their age. Of the 50 people who chose to answer the question, three (6%) were under 18 years old, eight (16%) were between 18 and 40 years old, 11 (22%) were between 41 and 64 years old, and 28 (56%) were 65 years or older.^[15]





In mid-2018, 79% of the population of Moray was 64 years old or younger (lower than the Scottish average of 82%), and 19% of people are 65 years old or above, with the average age expected to increase, especially in the 75 and over age group.^[16]

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 Moray (of whom an estimated 36% access SDS). PHS reported that in 2017-2018 in Moray, 80% of people accessing social care support were over 65 years old, 19% were aged 18-64, and 1% were under 18 years old.^[17]

Ethnicity

40 MSMC survey respondents in Moray identified as white. One respondent selected "Asian, Asian Scottish, or Asian British", and one selected "African, Caribbean, Black, Black Scottish or Black British". 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".

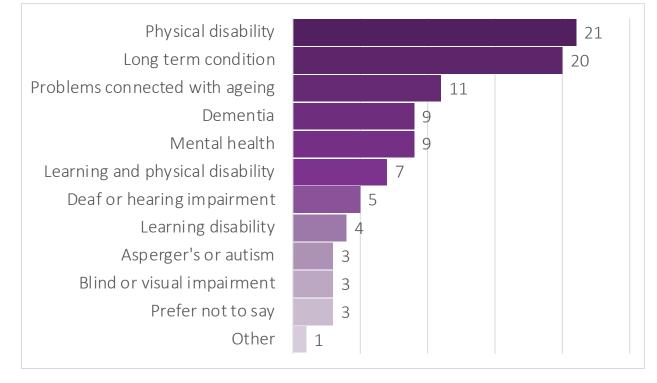
The 2011 Scottish Census indicated that 95.7% of the population of Moray identified as "White: Scottish" (77.7%) or "White: Other British" (18%), with a further 3.3% selecting "White: Irish" (0.5%), "White: Polish" (1.1%), or "White: Other" (1.7%). The remaining people identified as being part of minority ethnic groups: 0.6% of the population identified as "Asian", "Scottish Asian", or "British Asian", and 0.5% as belonging to "other ethnic groups".^[18]

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 36% access SDS), using the limited categories of "White", "Other", and "Not provided/Not known". PHS reported that in 2017/2018 in Moray, 81% of people accessing social care support were "White", 18% were listed as ethnicity "not provided/not known", and 15 people (0.5%) were categorised as "Other" (including "Caribbean or Black, African, Asian and Other Ethnic Groups").[19]

Client Group/Disability/ Long Term Condition

MSMC survey respondents in Moray self-identified as living with a range of conditions, with the majority reporting that they were living with multiple conditions. 21 people (48%) selected physical disability, 20 people (45%) said they live with a long term condition, and 11 people (25%) stated that they experienced "problems connected with ageing".^[20]

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



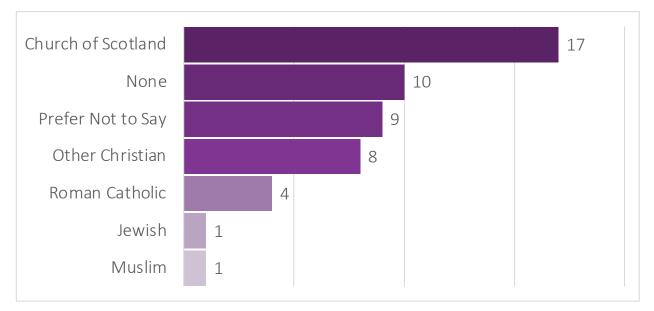
Interviewees also discussed their conditions, and – if they were unpaid carers – those of the people for whom they care. Their reasons for accessing SDS were broadly in keeping with survey respondents'. Of the ten people whose experiences of SDS we heard about during interviews, all accessed SDS because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

Religion

When asked about their religion (if any), 17 survey respondents (39%) were part of the Church of Scotland, ten stated "none" (23%), eight described themselves as "other Christian" (18%), four were Roman Catholic (9%), one was Muslim (2%) and one was Jewish (2%). Nine people (20%) preferred not to answer.

None of the interviewees chose to explicitly disclose their religion when self-describing themselves. The overall spread of MSMC respondents is broadly in keeping with the 2011 Scottish Census data for Moray.^[21] Data about people's religion is not available on the PHS dashboard.

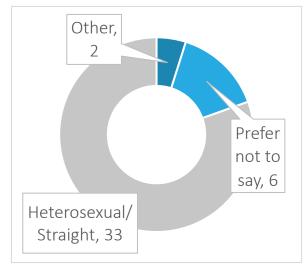
Chart 4: Survey respondents' religion



Sexual Orientation

33 survey respondents described their sexual orientation as heterosexual or straight and one person selected "other". A further six people stated that they preferred not to disclose their sexual orientation, and four 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

30 survey respondents (68%) either rented or owned their own home, nine people (20%) reported that they lived in the home of a family member, and one person (2%) stated that they were "moving to supported accommodation". Four people selected "prefer not to say" (9%). 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.

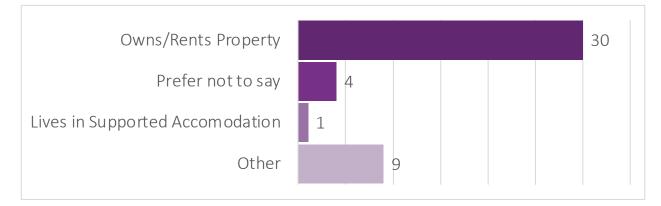


Chart 6: Survey respondents' housing arrangements

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.^[22]

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.

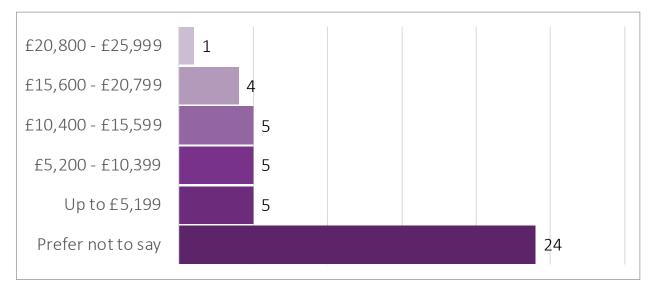


Chart 7: Survey respondents' annual household income

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).^[23] 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).^[24] Based on this definition, 15 (79%) of the respondents in Moray 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 43 participants in Moray who shared which SDS option they used, 19 people (44%) indicated they used Option 1, four people (9%) used Option 2, ten people (23%) used Option 3, and eight people (19%) used Option 4. Two people (5%) stated that they did not know what option they used.

Figures from PHS indicate that in 2017-18 there were 233 people in Moray using SDS Option 1, 226 using Option 2, 908 using Option 3, and 153 using Option 4.^[25] 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.^[26] 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.^[27] 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".[28]

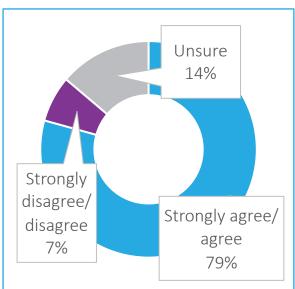
Data Gathering and Analysis:

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 29 people who answered this question in Moray, 23 (79%) stated that they "strongly agree" or "agree" with the statement "SDS would/has improve/d my social care experience". Two people (7%) disagreed and four (14%) were unsure.

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



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

"Go for it – don't worry, you receive great service."

"SDS is the best service, easy to use, they are very helpful."

"Say yes to this support because of the help and support given."

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

"I just think it is a really good system – I think they really have made a good system there."

"Self-directed Support is a fantastic idea; it has improved my life no end. I would recommend it to anyone that it is suitable for. Once you get through the initial paperwork, setup, etc. it gets easier."

Interviewees identified a range of ways that SDS has positively impacted their lives, with one interviewee summarising their experience as follows:

"If I didn't have [SDS-funded activities], I don't know if I would still be here [...] they didn't expect me to recover. [...] [My social worker] pushed really hard at me to get into the groups because I was just shutting down myself in the house. If it wasn't for SDS, I don't think I would be here."

Another two interviewees reflected that before they accessed SDS, they were members of Dignitas^[29] – but that now "that's gone completely", and the interviewee has "a far more fulfilled life, control over what happens" and better physical and mental health. A different interviewee reflected that the person for whom they care accesses SDS, and that that person was "increasingly getting worse" and "couldn't cope any more" prior to support being put in place. After their SDS package was approved and appropriate care support was put in place, the SDS user "was much more able to speak to people" and their quality of life improved. This change also resulted in a reduction in stress for family members who provided unpaid care, and improvements in their health.

Several participants, who accessed SDS in part or primarily due to mental health problems, spoke warmly in praise of the mental health team in Moray, and of the Moray Wellbeing Hub. One interviewee summarised their experience as follows:

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

However, some people were more cautious or explicitly negative about SDS, particularly relating to waiting times and difficulties with paperwork: "Go for it – but be prepared for loopholes and fences to jump. In my experience that's what I've had to do. SDS has been good – not all bad – but the surrounding issues are hard to deal with."

"I would say really fight for what you want [...] because you won't get given anything unless you really kick up a fuss. [...] Just keep going and get what you [...] need – not what you want, what you need."

"There is currently no allocated social worker and we now have to contact the emergency team and we have had difficult experiences with them in the past."

"Don't hold your breath. Process takes ages, too many long forms. [...] Wait[ed] ages for social work, then pushed into PA option as it's cheaper for local authority. That's if you meet the criteria."

Information About SDS

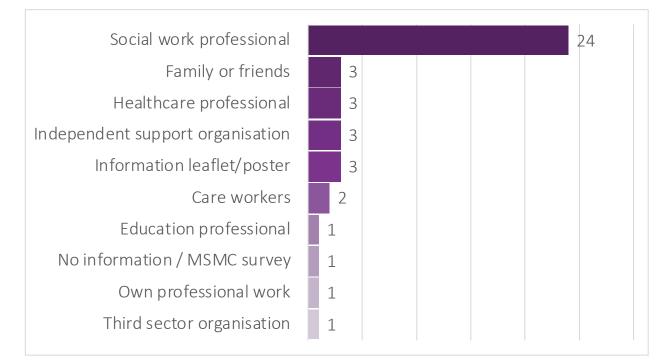
Finding Out About SDS

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

24 survey respondents (57%) first heard from a social work professional (e.g. a social worker/social work assistant or an occupational therapist), three (7%) heard from friends or family members, and three (7%) from NHS health staff, including nurses working in the community. A further three people (7%) first head about SDS from an independent support organisation, three (7%) from an information leaflet/ poster, two (5%) from care workers, one from an educational professional, one from a third sector organisation, and one from their own work.

One survey respondent reported that they had never received information about SDS and that they first heard about SDS via this research project. Two 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.

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, NHS staff, an advocate, an independent support organisation, or their own work. Several people mentioned the Moray Resource Centre as a useful community resource for signposting people to SDS and a first point of information. One participant highlighted that they acted as a peer supporter and advocate, using their experiences of SDS to help others.

It is worth noting that while only five participants (three survey respondents and two interviewees) heard about SDS from NHS staff, when participants engaged with healthcare staff who were familiar with SDS they reported that this had been very helpful in arranging support for themselves or the people for whom they care. One person had been referred to social work for home support by their GP (who they had known and trusted for many years) and reported that the long-standing relationship with their GP made it easier for them to accept that they needed social care support. They stated that "the GP has been a great support" throughout the process, as well as providing the initial referral.

Two other interviewees described broader positive interactions with hospital staff who knew about SDS. One person recounted that hospital staff understood SDS and allowed the SDS user's PAs to carry out their daily personal care (e.g. feeding) and helped with communication between the interviewee and medical professionals. This was very helpful, as the PAs knew the interviewee's communication methods and preferences better than any hospital staff, and were able to use that expertise, following the interviewee's wishes.

These findings echo the 2018 Care Inspectorate thematic review of SDS in Moray and demonstrate the value of engaging a wide range of professionals with SDS, including health professionals. The Care Inspectorate review concluded that there is a "gap in awareness and training for health staff to equip them to support the delivery of self-directed support"^[30]; a finding supported by the low proportion of respondents who had found out about SDS from a health professional.

Finding Out About SDS: The research indicates that people in Moray generally had good experiences finding out about SDS from social work professionals and local independent support and advice organisations. There are some people in Moray 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. This recommendation aligns with the Care Inspectorate recommendation that "the partnership should develop health colleagues' knowledge of and confidence in self-directed support to enable them to support its ongoing delivery".

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 Moray received "all the information [they] wanted" (respectively, 70% for Option 1, 66% for Option 2, 64% for Option 3, and 58% for Option 4). However, it is concerning that around a quarter of people for Option 1, Option 2, and Option 3, and over a third of people for 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: 23% of respondents said that they received "some, but not enough" or no information, and 7% received "enough but wanted more".

Option 2: 29% of respondents reported that they had "some, but not enough" or no information, and 4% received "enough but wanted more".

Option 3: 28% of respondents said that they had "some, but not enough" or no information, and 8% received "enough but wanted more".

Option 4: 38% of respondents said they had received "some, but not enough" or no information, and 4% received "enough but wanted more".

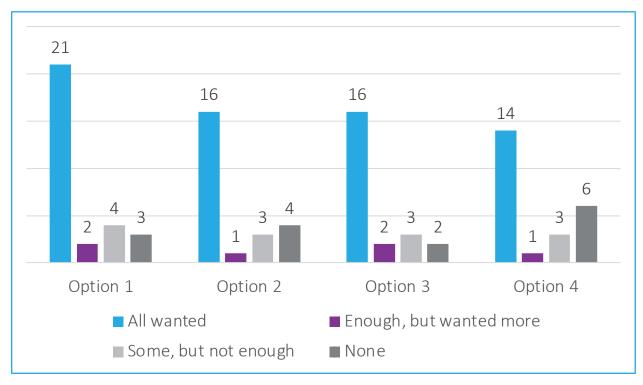


Chart 10: Information received before discussing support (Survey)

Most interviewees had been fully informed about the options prior to their assessments, but a minority had not been told about all four options when they started the process of accessing SDS, which had made it harder to make informed decisions. One interviewee stated that they had no access to information about SDS before their needs assessment was carried out:

Interviewer: Did you receive any information about SDS before that meeting?

Participant: No, I didn't.

Interviewer: Was that first meeting referred to as a 'needs assessment', or was that something that happened later?

Participant: That was a needs assessment.

We also asked survey respondents whether they felt prepared for their needs assessment. Of the 41 participants who answered the question, 27 (66%) strongly agreed or agreed, six (15%) disagreed or strongly disagreed, and eight (20%) were unsure. While it is encouraging that two-thirds of respondents in Moray 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.^[32]

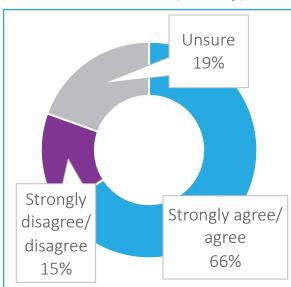


Chart 11: "I felt prepared for my needs assessment" (Survey)

Most interviewees in Moray 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, with they said had made it harder to make informed decisions.

Information and Preparedness Before Assessments: The findings indicate both existing good practice in Moray, and that improvements could be made to ensure everyone 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 about Option 4 – carers' assessments and support plans, and what to expect of a needs assessment. This recommendation supports the Care Inspectorate statement that "the partnership should regularly evaluate the effectiveness of communication about self-directed support and its impact within self-directed support delivery in the partnership."

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 42 survey respondents, 21 (50%) stated that the professional discussed "all four options" with them, five (12%) that "some but not all" options were discussed, and seven (17%) that "none" of the options were discussed. A further nine respondents (21%) indicated that they were "unsure" which options were discussed with them. These findings indicate that more work is needed in Moray to ensure that all four SDS options are outlined and discussed with people during needs assessments and reviews. Most – although not all – interviewees had had all four options discussed with them during their needs assessments. One interviewee recounted that when SDS was first introduced to them:

"[The social worker] discussed with me everything, you know, sort of what help I needed. She discussed with me the options and it just seemed a good way to go. At least have a go with it and see how I'd get on."

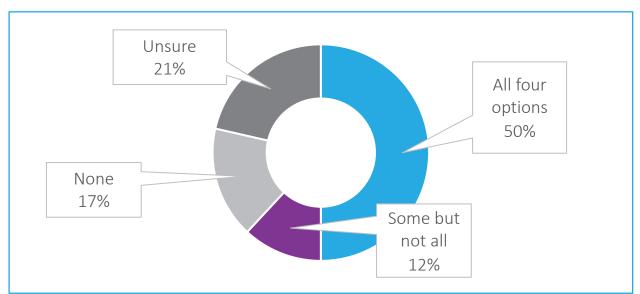
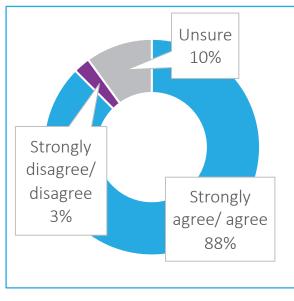


Chart 12: Discussing SDS options with professionals (Survey)

In the survey, we asked whether people agreed with the statement "The person I met with explained things clearly to me". Of the 40 respondents who answered this question, 35 (88%) strongly agreed or agreed, one (3%) disagreed or strongly disagreed, and four (10%) 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.^[34]

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 41 respondents, 28 (68%) strongly agreed or agreed, six (15%) strongly disagreed or disagreed and seven (17%) said that they did not know. Interviewees indicated similar experiences. That a high proportion of respondents in Moray 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 Moray felt their questions had been answered than was typical across Scotland.[35]

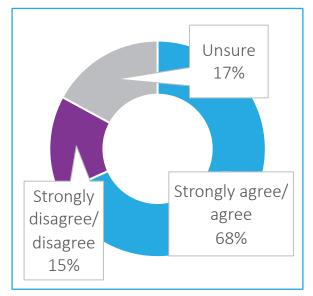
One interviewee, an unpaid carer, outlined how they and the person for whom they cared benefited from clear explanations from their social worker when they started accessing SDS:

"I was being assisted through this process with the senior social worker. [They were] very good, [they] came and interviewed with me, [they] gave me all the paperwork to understand what my role was in all this and [they] chatted quite a bit with [SDS user]. It seemed that everyone was gearing up that this was the right approach."

Another participant recounted a similarly positive experience, with a social worker who provided assistance throughout and took a strengthsbased rather than deficits approach to the assessment process:

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

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



Several interviewees reflected on positive experiences during their needs assessments and reviews. One person reported that the "options were clearly explained." Most interviewees said that they had been able to ask questions during assessments and received satisfactory answers from social work professionals. For example, one interviewee outlined that they had queries concerning administrative aspects of their SDS package:

"I was worried about keeping paperwork for a while. But my social worker said that all I have to do is have a receipt book and get my cleaner [to] sign the receipt book. That's straightforward, she does that. [...] And since then I have had another assessment and they said that the paperwork is okay."

A different interviewee reflected on the importance of being able to ask social work professionals questions:

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

This point was demonstrated in another account, where an interviewee asked if they could take part in crafting classes to help with their mental health - thinking this would be unlikely to be approved. However, their social worker knew their circumstances. was able to empathise and see the value in the suggested activity and supported the participant's choice. The participant reported a significant improvement in their mental health following the implementation of their SDS package, which combines occasional social activities with assistance with household tasks.

However, another interviewee reported feeling confused after their most recent review. They were told that the best approach for them going forward would be to have a managed account for their SDS package (Option 2). While they agreed to this change, the interviewee was left uncertain as to how this would operate in practice, and who would be their new contact person. They would have welcomed more information in order to feel confident about how their support was being managed.

Overall, interviewees indicated that their questions to social work professionals covered a range of concerns, including how support package decision making processes worked, what services they could access, and how to become an employer of PAs.

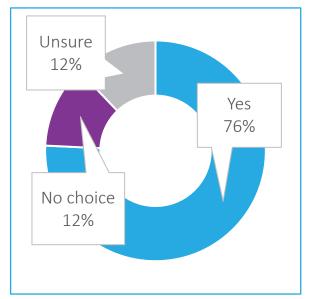
Information During Assessments:

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 Moray. However, further work is needed to ensure that everyone is fully informed about all four SDS options during assessments, all questions are answered, and that social work professionals consistently practice supported rather than substitute decision making.

Information 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 33 respondents, 25 (76%) said yes, four (12%) said no, and four (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 a substantial majority of respondents in Moray had received information about how much money was available to them is a positive finding. However, that nearly a quarter of respondents either had not received that information or were unsure indicates further work can be done in this area to expand existing good practice. It is vital for informed decision making that people are given full information about their personal budgets. Respondents in Moray were more likely to have been told how much money they could spend on their support than people in other parts of Scotland.^[36]

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 41 respondents, 30 (73%) had no concerns, three (7%) had outstanding issues, and eight (20%) 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 care charges, difficulties communicating with social work professionals, and slow introduction of care packages. One respondent stated that the "care package for [family member] should have been arranged before [they were] discharged from hospital", and that delays caused considerable problems for the family. Another discussed the burden of care charges as a disabled person with limited income and high living costs, stating that they are "facing a brick wall with this problem". A different participant reflected on problems and delays when social workers are not able to approve decisions. They summarised their experience as follows:

"Any time I've had to contact them you get social work, then the manager, and it's up and down a ladder and I'm at the bottom. [The] social worker can't make a decision – [they are] disempowered. Sometimes you have to make a split [second] decision and they can't do it."

Some people highlighted that living in a rural area of Moray 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 35 respondents, one person in Moray indicated that they were in the process of appealing the outcome of their last social care assessment or review. They reported that they were being supported in their appeal by an independent advocate. Respondents highlighted that unresolved issues had direct and negative impacts upon their health and the health of the people for whom they care. **Outstanding Concerns and Appeals:** The research invites further work in Moray 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.

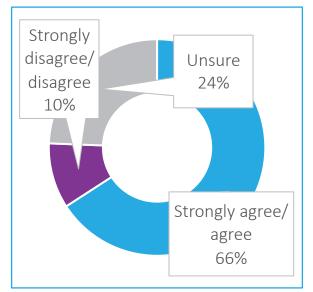
Informed Choice and Control

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 41 respondents, 27 (66%) agreed or strongly agreed, four (10%) disagreed or strongly disagreed, and ten (24%) stated that they did not know. While it is encouraging that most respondents in Moray 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.

Overall, most participants felt they had enough time to choose their preferred SDS option. However, some people would have liked more time before deciding – a result that overlaps with those people who wanted more information about their options. Two of the respondents who wanted more time to decide said that they had received no information about SDS options at their needs assessment, while two reported that all four options were discussed with them. Of the latter two participants, one stated that they had received "some, but not enough" information about each of the four options, while the other did not answer those questions. These results indicate a correlation between the provision of clear information and people feeling able to make prompt decisions about their support.

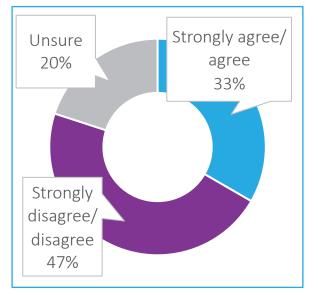
Chart 16: Enough time to choose SDS option (Survey)



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 30 respondents, ten (33%) strongly agreed or agreed, 14 (47%) disagreed or strongly disagreed, and six (20%) 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.

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. 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 Moray if they were on their preferred SDS option. Of the 32 participants who answered, 27 (84%) were on their preferred option, two (6%) were not on their preferred option, and three were unsure (9%).

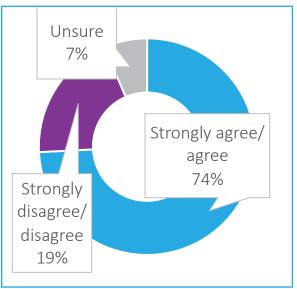
A similar pattern was found with interviewees. Out of the ten households interviewed, eight were on their preferred SDS option and two were unsure which SDS option they were on. One interviewee who was unsure of which SDS option they used outlined that they had been moved on to a managed SDS account. They were unsure if this meant they were using Option 2, and expressed considerable confusion about how they could use their SDS budget. A different interviewee, who was on the SDS option they had originally preferred, was now contemplating a change as they were no longer happy with the care they were receiving. The interviewee wanted greater control and choice over the people providing their care – and as their care provider would not allow them to request or decline specific care workers, they would like to move to an alternative SDS option. They explained that:

"There are just one or two carers who are rather difficult, and I would like to have a little bit more say about that frankly. I don't mind my care being arranged, I'm quite happy for the council to do my care, but it would just be kind of quite nice to say, you know, 'Please, [...] two or three people out of the many that I see, I'd rather they didn't come'. But I've got no say, I've got no choice."

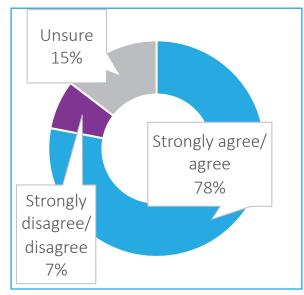
The proportion of respondents in Moray indicating they are on their preferred SDS option is encouraging. These people described how support arrangements enable them to do a diverse range of activities. These included (but are not restricted to): personal care, assistance with household tasks and shopping, 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 31 respondents, 23 (74%) strongly agreed or agreed, six (19%) disagreed or strongly disagreed, and two (6%) stated that they did not know.

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

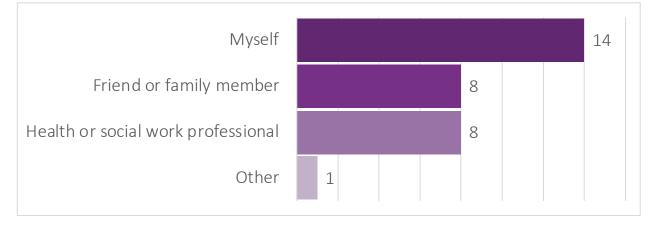


In the survey, we also asked people to respond to the statement "I had a say in how my help, care or support was arranged." Of the 41 respondents, 32 (78%) strongly agreed or agreed, three (7%) disagreed or strongly disagreed, and six (15%) stated that they did not know. These findings are encouraging, 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 32 respondents, 14 (44%) said that they chose the way their support was arranged. Eight (25%) said that a social worker chose their support for them. A further eight people (25%) stated that a friend or family member chose for them. One person (3%) selected "other". These findings invite further work to embed supported decision making (instead of substitute decision making) in SDS/ social work practice.

Chart 20: Who chose support arrangements? (Survey)

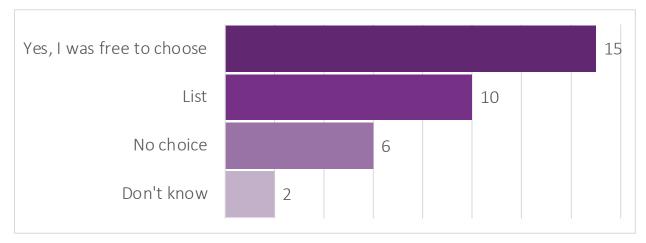


We also heard from interviewees about their SDS option choice. One interviewee reported that their social worker restricted what SDS they could use. Other interviewees highlighted the importance of access to information to make informed decisions. Choice Over SDS Options and **Support:** Although the majority of respondents in Moray 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. People should also be able to choose care workers even when their support is organised by others - and this should be reflected in local commissioning processes.

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 33 respondents, 15 (45%) said that they were free to choose who they wanted to manage their personal budget, ten (30%) chose from a set list of providers given to them by a social work professional, six (18%) said they were not given a choice, and two (6%) were unsure whether they had a choice.

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



Of the 15 people who were given free choice of who would manage their personal budget, one selected the council, one chose a third sector provider organisation, one opted for a private care agency, and one selected an independent support organisation. A further 11 people (73% of those who were free to choose) selected an individual person (this response could include themselves).

Of the ten people who chose from a list, two people selected the council, five chose a third sector provider organisation, two opted for an individual broker, and the final person selected "unknown".

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

It is encouraging that nearly half of respondents in Moray were offered an unrestricted choice of who to manage their personal budget. However, it is concerning that nearly a quarter of respondents reported that they either had no choice or 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).

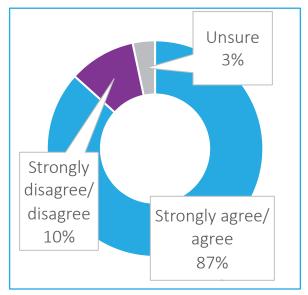
Budget Management: The

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

Adequate Support

We asked survey participants to respond to the statement "Enough budget to meet my outcomes makes Self-directed Support easier for me". Of the 30 respondents, 26 (87%) strongly agreed or agreed, three (10%) disagreed or strongly disagreed, and one (3%) was 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 shared their distress at realising that their new social worker had not taken the time to carry out their needs assessment properly, and had recorded incorrect information about them, leading to a reduction in their support. They stated that:

"Well [the social worker] didn't really go through everything. I mean, on the sheet – I couldn't read it, but I had a friend come over from [location] and [they] bullet-pointed, and there must have been about what, 13 or 14 things that [social worker] got wrong. [They] had put that I could go out on my own, I could do my own shopping, I could do my own cleaning, [...] [they] had even taken out – [...] I'm supposed to have somebody with me [due to specific medical condition], in case anything else happens because I'm confusable afterwards, disorientated. And I'm supposed to have someone

with me [...]. And [social worker] had even removed that."

A different interviewee discussed problems with spending their approved SDS budget on a specific service. They require regular health interventions to help maintain their health and wellbeing. However, their SDS budget was only approved for a specific level of that health intervention, which they did not feel met their needs or outcomes. They also struggled to find somebody at that level within their local area. The interviewee felt that a more flexible approach to who was approved to provide the health intervention would have made the process easier. In the meantime, they are paying for the specific health interventions themselves from a more highly qualified provider, with limited personal funds. The interviewee reflected that this intervention "really is a physical necessity, a great necessity", but that there's a "clear gap [that they] have to compensate for" within the integration of health and social care.

As well as reporting on the negative impacts of cuts to social care support, some respondents described care arrangements that were not suitable. 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.

Some interviewees reflected that part of the future planning of care depends on people realising that they need to hold conversations, including with their social worker, to put support provision in place for changed circumstances. One person summarised their perspective as follows:

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

People also indicated that they would welcome more future planning in discussions about their care – both in terms of flexibility around contingencies, and in planning for futures where people might require more care (including scenarios where unpaid carers are no longer able to provide support). Adequate Support: The research reinforces the need in Moray 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 most people in Moray 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. Professionals should not assume that family members and friends are able or suitable to provide unpaid care, and future planning should be supported by professionals. Such actions would be in keeping with the Care Inspectorate finding that only 12% of records in Moray included mention of contingency arrangements, and suggested that this remained "an area for improvement".

Flexibility

Many research participants commented on the value of and need for flexibility for the effective use of SDS – particularly around budgets. 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. Several people spoke of positive examples of flexible funding and approaches to SDS that prioritised their choices and enabled individuals to make their own risk assessments when trying new activities. Two interviewees discussed the advantages of flexibility in their SDS packages, and that having a contingency fund to pay for additional support enables them to vary support depending on their health needs from one month to another.

While there were several examples of good practice with regard to flexible use of SDS in Moray, one interviewee outlined the need for greater flexibility in how they could access and use SDS. They stated that:

"SDS is offered [...] at the moment from Moray Council. My understanding and their understanding of SDS seems to differ. My understanding is that there would be money available for [Name], so that [Name] is able to choose what's best for [Name] to do. That's my understanding. What I think Moray Council have done is that they have set up boxes and put people into a particular box [...] regardless of what's best for [Name]. I also tried to go down the route of taking the money and organising everything myself, but I was told that would also have to be with their approval. [...] The problem I have is not so much the money, it's the choices and how they are made. And what's further irritated me is that some of these choices this year have been made without a social

worker or anybody from that department actually visiting."

The interviewee went on to say that they felt that the overall approach was not sufficiently flexible or person centred enough. They gave an example of a specific social activity being cut from a personal outcomes plan and SDS budget – although said activity had been funded previously and had a positive health impact on the SDS user. Instead of having the choice of social activities, they were informed that they could only receive funding for one, specified, activity – which the SDS user was not interested in.

Another interviewee noted that their social worker had informed them that no support was being funded towards social activities, shopping or domestic tasks. However, they knew of other SDS users who received social support in Moray. The interviewee felt confused and let down by these conflicting messages and pointed out that people do require support for occasional tasks beyond personal care. In particular, the interviewee had requested support from social work to complete their postal vote, as without assistance they would not be able to vote. They were informed that support with post and administrative tasks was only available via a third sector organisation. However, that organisation did not have the capacity to assist the interviewee before the voting deadline. The interviewee felt that the assumption is that disabled people and people living with long term conditions have a network of unpaid carers who can fill in the gaps in their care – and that without that additional support, they were substantially disadvantaged. They called for a more flexible approach to support, which could respond to occasional need as well as regular personal care (e.g. voting).

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

"[We need] flexibility. [...] Allow money to leave Moray to go to Aberdeenshire if you're not able in Moray to provide a service that would be beneficial to somebody both mentally and physically."

Another participant commented that, "when we first got SDS, I was told it was flexible. But it's not flexible. You have to be quite specific about what you use it for."

Flexibility: The research suggests that there is good practice with regards to flexible approaches to SDS in Moray, which positively impact's people's lives and those of the people for whom they care. However, some people in Moray 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 Moray – for SDS users and unpaid carers alike.^[38] 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. One survey respondent stated that "SDS enabled my wife to plan short breaks away, knowing I will be cared for well."

Short breaks were also mentioned by several interviewees as an important chance for people to have breaks and relax. One interviewee explained that funding for short breaks enabled long-distance visits to the SDS users' relatives without needing to stay at their houses enabling the SDS user to both see their family and have privacy and personal support for their personal care needs.

Some interviewees reflected on difficulties accessing short breaks, and the negative impact this had on their health and wellbeing. Two interviewees shared that they were only allowed to use their short breaks budget at specific resorts or locations, which often had long waiting lists or restricted availability which did not overlap with their annual leave. 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 Moray 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 mentioned as a concern, especially for people living in more rural areas of Moray. 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. 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.

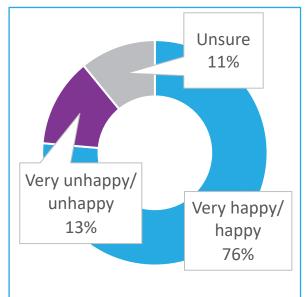
Travel Costs: People – particularly those living in more rural areas of Moray – require more acknowledgement and accommodation of travel costs in their SDS budgets.

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.^[39] 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 23: "How happy are you with the conversations you have had about your support with professionals?" (Survey)



Of the 41 respondents, 28 (68%) were happy or very happy, six (15%) were very unhappy or unhappy, and seven (17%) didn't know. Respondents in Moray were notably more satisfied with their conversations with professionals compared to people in other parts of Scotland.^[40] Interviewees highlighted that good conversations required 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 stated that their conversations with social work were "simple and effective". Others commended the assistance and efforts of proactive social workers - for example, social workers who raised the rate of pay for PAs with their managers, following the interviewee having recruitment difficulties or annual increases in costs.

One interviewee discussed the attention to care and support demonstrated by their social worker:

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

Similarly, another interviewee outlined that their positive relationship with their social worker was crucial for their wellbeing. They shared that:

"When it comes to the SDS, we have a really good relationship. When I have a dip in my mental health mood, I shut everybody out - but [social worker] perseveres, and [...] phones me or chaps on the door or things like that. [Social worker] is there for me for everything really. I would say our relationship is really good [...]. When I used to go downhill, I never ever got in touch with him and [social worker] is the person I should have gotten in touch with. [...] If I refused the phone calls, [social worker] would knock on the door. And if I didn't answer the door, [social worker] would come the next day again. [They] certainly knows [their] job. [Social worker] cares about the people [they] looks after. [They are] a good social worker."

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

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

Another participant commented that their social worker recognised that they required additional help with the accountancy and administrative tasks surrounding SDS. They were supported by their social worker to move to a managed account. A different interviewee reported that they felt reassured by their social worker's ability to take on board their need for future planning. The interviewee has responsibility as an unpaid carer, but due to their own health conditions they have coordinated with social work to develop a support plan for the SDS user for whom they care if they need to step back from the caring role with limited notice. The interviewee described this sort of future planning as beneficial for both the interviewee's mental and physical health and that of the person for whom they care.

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

"Social work were extremely helpful and kind."

"Explanation was clear on all aspects of the meeting."

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

"I was happy with the support I receive, and I feel that I am listened to."

"The structure of the conversations [...] ensured the most immediate problems and tasks were talked about."

"[The social worker had] an understanding of my situation and consideration of my needs."

"The social worker took time to talk to [SDS user] and get to know [them]. They were experienced and confident and focused on [SDS user's] needs."

"Being treated as equals, respecting each other's position and views."

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.

Good Conversations and Consistent Relationships: The

research demonstrates that people in Moray 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 Moray. Of the 41 people who answered the survey questions about how happy they are with the conversations they have had about their support with professionals, six (15%) indicated they were either very unhappy or unhappy, and seven (17%) were unsure. 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", reported that that their needs assessments were rushed, 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:

"Not enough [information] about options available – council firmly in charge!"

"The meeting was restricted by how busy [social worker] was, restricted to 30 minutes."

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

"The inability of the bad system to allow staff to do the right thing. Instead of assisting us they now treat us as though they work for the Department of Work and Pensions."

"Bloody awful – they couldn't care less. It's not always to do with money."

"Attitude. [Social worker's name] – stranger to the truth and totally unreliable; should not hold a social care position." One interviewee recounted that after a reduction in their support hours during a review, they felt that their new social worker was not on their side. The lack of consistent communication, and their difficulties in chasing for further information also enforced their feeling of powerlessness. As they explained:

"I've been miffed from the word" go, and nobody has been able to give me any answers. I [...] talked to some of the people in the local SDS team, and again I get promises [that] somebody will contact me [...] but have I heard from any of them? No, unless I keep on and keep on and keep phoning – that's hard for me because I can't use my hands to make phone calls, if somebody does use my phone I can't phone them, you know, it's just hard work and this is where I could do with somebody coming round to help me."

Another interviewee relayed a troubling account of being treated with disrespect by a social work professional. They had previously had a comprehensive SDS package that covered regular personal care throughout the day, which enabled them to be active in the community and have a good quality of life. However, following a reassessment by a new social worker their package was cut substantially, to one third of the original provision – despite no changes to their needs or stated outcomes. This means that they no longer have assistance to use the toilet during the day; as a result, they cannot participate in social activities or community life. Their PA was also unable to afford to work for them on reduced hours. They had also had serious health complications because of the reduced care available to them. When the interviewee sought further

support and clarification from social work, the same social worker visited, and dismissed their concerns about the reduction in support and its impact:

"My [PA] said that [they] soon will have to look for another job and that [they don't] know how I'm going to manage. And that has taken me over the edge. I just feel like ending it all. I am constantly in tears. [...] I'm not proud of the fact, but I have attempted suicide before, because of the pains and that, it just gets too much for me. And [the social worker] turned around, [they] just turned around and said, 'don't be silly'. [They] said, 'don't be silly, it's not that bad.' And I thought, but you aren't in my position, you aren't in my position, you aren't getting the pain, you can't see how I am, how I live my dayto-day life. Now [they've] taken those hours off me I can't get out. I'm stuck in the house day in day out, and I'm going to be stuck for appointments. [...] I've never ever been treated that way before; I'd always been treated with respect."

At time of interview the participant was appealing the decision and awaiting a reassessment with a different social worker, with support from independent advocacy. **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 Moray to ensure that people's experiences of conversations and relationships with social work are consistently good. 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, expected wait times, and how to challenge decisions.

Transparency: The research indicates that while there are good examples of transparent process in Moray, 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 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 their trusted PA "see[s] what needs to be done without me saying anything. And that's nice that they know what needs to be done and they know where everything is."

Two other interviewees reflected that before a SDS package was

put in place, the SDS user used to live in a care home, where their social life disappeared. However, the interviewee's SDS package has enabled them to work with a team of care providers of their choice, communicate affectively, and have an active social and family life. One of these two interviewees provided more details about their current care arrangements, with a team of trusted personal assistants:

"We have a rota system. We've got quite a wide range of different carers, but the key for the carers that work for us is they've got to want to care. It's not about just [...] physical needs, subsistence needs, it's about being able to deal with everything from [...] moods to [Name's] need to be able to communicate. I mean, communication is really time consuming and very exhausting for carers, and not all carers can cope with it – and we have had a turnover of carers who for whatever reason haven't really fitted in with what we need. And it's not good for them and it's not good for [Name]. [...] [The current team] like the predictability, they've got predictable shifts. We care for the carers and the carers care for us, and that seems to work."

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.

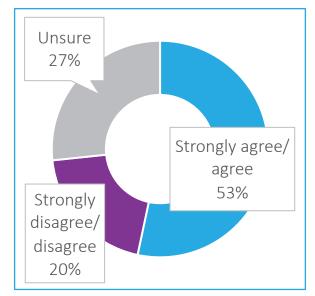
Some respondents also reported that they would like to have more choice

over which care workers provide their care when receiving support from third part organisations via Option 2 and Option 3. As discussed earlier in this report, people should be able to choose care workers even when their support is organised by others – and this should be reflected in local commissioning processes.

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 30 respondents in Moray, 16 (53%) strongly agreed or agreed, six (20%) disagreed or strongly disagreed, and eight (27%) were unsure.

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



These findings are supported by comments by interviewees about the importance of, and difficulties finding and retaining, care workers who are appropriate to their requirements. Some interviewees commented on concerns with PA recruitment, specifically linked to their experiences using Option 1 in Moray, 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 "it took nearly nine months" for them to recruit PAs – although they also stated that once they had located suitable people, "all three have helped [...] and they are all very reliable and professional." The interviewee outlined that when using SDS for the first time, some people may need additional time and support. The elderly person for whom they cared, for instance, was reliant on a specific, known routine, and struggled to accept paid carers. However, once the interviewee had recruited a small, regular team of PAs, they felt that the SDS user's quality of life improved and the system worked well.

One interviewee shared their experience of setting up a rota with their team of PAs, where members of the team agreed their own shifts between them, depending on availability – leading to greater choice for the PAs, and less administrative work for the service user and their family. The interviewee asserted that their PAs choose which shifts to do and that this aids flexibility for everyone, instead of having a fixed work pattern.

Some interviewees voiced concerns in relation to the rate of pay for PAs. They felt that the rates were too low to attract good candidates. One interviewee supplemented their PA's wages from their own funds; another (an unpaid carer) had increased the hourly rate but reduced the amount of support hours covered for the person for whom they care – increasing their workload as an unpaid carer. In the latter example, this means that the SDS user does not have enough support in place to meet their identified needs.

Some people also commented on the need for care workers to receive appropriate specialist training. Some respondents suggested they would welcome more support from Moray Council regarding PA recruitment, training and continued professional development.

Care Staff Recruitment, Training and Quality: Some people would welcome more support with PA recruitment, training and continued professional development. Moray should work with people who access SDS and unpaid carers to improve systems and processes related to care staff recruitment, training and quality. People would also welcome the ability to choose their care workers even when their support is organised by others – and this should be reflected in local commissioning processes. 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 Moray 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.

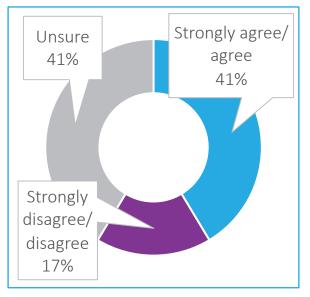
Independent Advocacy and Support

Respondents in Moray 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 Moray.

Independent Advocacy

We asked survey participants to respond to the statement "access to independent advocacy makes SDS easier for me". Of the 29 respondents, 12 (41%) strongly agreed or agreed, five (17%) disagreed or strongly disagreed, and 12 (41%) were unsure.

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



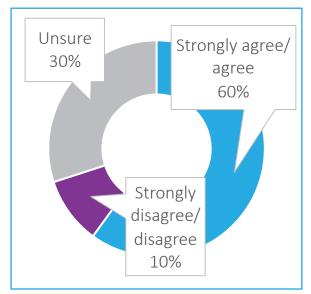
Some survey provided additional comments on the value of independent advocacy when accessing SDS. One interviewee stated that they had not engaged directly with advocacy, but they welcomed the fact that it was available if they ever felt like they required additional support. Another interviewee had experienced a significant reduction in their support hours following a recent review, and sought assistance from independent advocacy:

"I phoned the [social work] duty care manager about it. I said to myself, 'What am I going to do? Because I can't manage on that.' I said, 'I need somebody, I can't go out on my own, I can't go to appointments or anything. I have to have someone with me. [...] I can't go out on my own.' [...] I got the advocacy in and they're going to get it all sorted out and try and get my hours reinstated. [...] They're actually fighting it for me."

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 30 respondents, 18 (60%) strongly agreed or agreed, three (10%) disagreed, and nine (30%) were unsure.

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



Survey respondents and interviewees commented on the value of independent advice and support in accessing SDS. Several people highlighted that they had benefited from the involvement of independent advice and support services during their needs assessment and reviews, and received support from them in challenging decisions about SDS. One person recommended that people should seek independent advice and support as follows:

"They [the person accessing SDS] have to know all the rules and regulations [...] My advice would be to contact some charity [...] outwith the system and know about it and find out what you can first before you even start."

Peer Support

Several people in Moray 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 person recommended that anyone seeking to access SDS should "ask to speak to a current SDS user". However, one interviewee recounted feeling upset while attending a peer support event. They heard from other people with similar support needs who were able to live independently with meaningful support from both SDS and unpaid carers. The difference, the interviewee believed, was that those with appropriate levels of support had assistance from unpaid informal carers to argue their case and fill in any gaps in provision of care.

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. This recommendation is in keeping with the Care Inspectorate finding that "independent advocacy could be used more effectively to support people with selfdirected support choices".

Response from Health and Social Care Moray

Health and Social Care Moray welcomes publication of the "My Support My Choice" research and is grateful to the 54 people who shared their rich experiences of Self-directed Support in Moray.

The report findings and recommendations will be reviewed with stakeholders to inform and influence our ongoing efforts to respond to areas of challenge and concern and build on good practice in order to drive continuous improvement in the quality of our Self-directed Support delivery.

It was encouraging to hear that people have had positive experiences, particularly around good conversations and relationships with social work practitioners, the provision of information and their involvement in decisions and arrangements for their care and support.

It is recognised that some of the core components of the SDS Framework Standards are already in practice in Moray, however the report highlights 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.

Many of these recommendations echo the actions for improvement

we identified and are taking forward in response to the Independent Review of Adult Social Care in Scotland and the SDS Framework Standards, and in line with our strategic planning priority to enable people to have greater choice and control over how they live their life.

We are delighted Moray is one of three local authority areas chosen to work intensively with the SDS Project Team at Social Work Scotland to test out and develop the approved Framework Standards to inform and support future practice across Scotland.

Health and Social Care Moray are committed to making positive changes in Moray, through increasing choice, control and collaborative work with individuals, families and communities to support delivery of better outcomes. Through being a partner in the project with Social Work Scotland, Moray is in a positive place to make improvements locally and influence practice nationally.

The report comes at a time when work is underway in Moray to create an Option 2 Flexible Framework. This will support greater choice for individuals, knowing that the chosen support service has been checked and meets agreed standards. We are aware of not limiting choice to

> My support my choice

just the framework with significant work underway to explore how this can be achieved easily and safely.

There are many challenges around the workforce required to enable people to have the full choice and flexibility they should have. Discussions are taking place with a range of partners to explore how we can attract more people into the care sector, whether that be through working for a provider, or working as a personal assistant.

Planning, designing, procuring and monitoring all care services involves people with lives experience and unpaid carers. We have begun the transformation to a new Outcome Focussed Care at Home service in partnership with an external provider which will enable individuals and their families to take charge of how their care is delivered through collaborative working with their care staff and the provider, putting the individual at the heart of service delivery.

We recognise the importance of ensuring people have good access to high quality information in a format which is right for them. We are working with people to explore the most appropriate way information can be presented and delivered. We are reviewing our information to ensure everyone is informed about SDS, the process of SDS and what it means for them, and how to access independent support or advice. This will support individuals to be fully informed about their indicative budget, their chosen option and the management of their budget, all of which are recommendations from the report.

We welcome feedback from individuals, their families and friends on the report and ideas for improvement. Should you wish to discuss any aspect of the report further, or to put forward ideas for change, please email: <u>SDSConsultation@moray.gov.uk</u>



My support my choice

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), we use "some" or "several" to refer to three or four interviewees, "many" to refer to five interviewees, and "the majority" to refer to six or more interviewees.
- 2 Information and documents related to project design and methodology can be found in the national report, available at: <u>https://www.alliance-scotland.org.uk/blog/resources/my-</u><u>support-my-choice-peoples-experiences-of-self-directed-support-and-social-care-in-scotlandreports/</u>. All MSMC reports are also published on the Self Directed Support Scotland website, available at: <u>https://www.sdsscotland.org.uk/mysupportmychoice/</u>.
- 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-peoplesexperiences-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.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); 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-socialcare-in-scotland-reports/.
- 6 Scottish Government, *Self-directed Support: A National Strategy for Scotland (2010).* Available at: <u>http://www.gov.scot/Resource/Doc/329971/0106962.pdf</u>.
- 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: <u>https://www.alliance-scotland.org.uk/blog/resources/my-support-my-choice-peoples-experiences-of-self-directed-support-and-social-care-in-scotland-reports/</u>.

- 8 NRS Scotland, "Moray Council Area Profile". Available at: <u>https://www.nrscotland.gov.uk/</u> <u>files//statistics/council-area-data-sheets/moray-council-profile.html</u>.
- 9 Moray Council, "Self-directed Support". Available at: <u>http://www.moray.gov.uk/moray_standard/page_77505.html</u>.
- 10 Moray Council, "Eligibility Criteria for Community Care Policy and Procedure" (Dec 2009). Available at: <u>http://www.moray.gov.uk/downloads/file79352.pdf</u>.
- 11 Moray Council, "Community Care Assessment". Available at: <u>http://www.moray.gov.uk/</u> <u>moray_standard/page_79483.html</u>.
- 12 Care Inspectorate, *Thematic review of self-directed support in Scotland Moray local partnership report (June 2019),* p. 10. Available at: <u>https://www.careinspectorate.com/</u> <u>images/documents/5134/Self-directed%20support%20in%20Moray%20June%202019.pdf</u>. Moray Council, "Independent Advocacy". Available at: <u>http://www.moray.gov.uk/moray_standard/page_80974.html</u>.
- 13 Scottish Government, *Self-directed Support: Practitioners Guidance (2014*). Available at: <u>https://www.gov.scot/publications/self-directed-support-practitioners-guidance/pages/6/</u>.
- 14 Public Health Scotland, Social Care Information Dashboard: <u>https://scotland.shinyapps.io/nhs-social-care/</u>.
- 15 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.
- 16 NRS Scotland, "Moray Council Area Profile". Available at: <u>https://www.nrscotland.gov.uk/files/</u> <u>statistics/council-area-data-sheets/moray-council-profile.html</u>.
- 17 Public Health Scotland, Social Care Information Dashboard: <u>https://scotland.shinyapps.io/nhs-social-care/</u>.
- 18 Scotland's Census (2011), "Ethnicity, Identity, Language and Religion". Available at: <u>https://www.scotlandscensus.gov.uk/.</u>
- 19 Public Health Scotland, Social Care Information Dashboard: <u>https://scotland.shinyapps.io/nhs-social-care/</u>.
- 20 This was a multiple choice question and some respondents chose more than one option.
- 21 Scotland's Census (2011), "Ethnicity, identity, Language and Religion". Available at: <u>https://www.scotlandscensus.gov.uk/</u>.
- 22 Scottish Government, *Poverty and income inequality in Scotland: 2015-2018 (2018),* p. 10. Available at: <u>https://www.gov.scot/publications/poverty-income-inequalityscotland-2015-18/pages/10/</u>.
- 23 Ibid., p. 1.
- 24 Ibid., p. 12.
- 25 Public Health Scotland, Social Care Information Dashboard: <u>https://scotland.shinyapps.io/nhs-social-care/</u>.

- 26 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: <u>https://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/Publications/index.asp?#2399/</u>.
- 27 Ibid., pp. 6, 48-60.
- 28 Public Health Scotland, Social Care Information Dashboard: <u>https://scotland.shinyapps.io/nhs-social-care/</u>.
- 29 For more information on Dignitas, see: <u>http://www.dignitas.ch/</u>.
- 30 Care Inspectorate, *Thematic review of self-directed support in Scotland Moray local partnership report (June 2019),* p. 13-14. Available at: <u>https://www.careinspectorate.com/</u> <u>images/documents/5134/Self-directed%20support%20in%20Moray%20June%202019.pdf</u>.
- 31 Care Inspectorate, *Thematic review of self-directed support in Scotland Moray local partnership report,* p. 14. Available at: <u>https://www.careinspectorate.com/images/</u> <u>documents/5134/Self-directed%20support%20in%20Moray%20June%202019.pdf</u>.
- 32 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.
- 33 Care Inspectorate, *Thematic review of self-directed support in Scotland Moray local partnership report,* p. 27. Available at: <u>https://www.careinspectorate.com/images/</u> <u>documents/5134/Self-directed%20support%20in%20Moray%20June%202019.pdf</u>.
- 34 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.
- 35 In the national MSMC report, 52% of survey respondents reported that all their questions were answered, while 12% were unsure and 36% disagreed.
- 36 In the national MSMC report, 52% of respondents agreed they had been told the amount of money they could spend on their support, 36% disagreed, and 12% were unsure.
- 37 Care Inspectorate, *Thematic review of self-directed support in Scotland Moray local partnership report,* p. 16.
- 38 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: <u>www.collinsdictionary.com/dictionary/</u> <u>english/respite</u>.
- 39 Care Inspectorate, *Thematic review of self-directed support in Scotland: Transforming lives* (2019). Available at: <u>https://hub.careinspectorate.com/media/3676/thematic-review-of-self-directed-support-in-scotland-transforming-lives.pdf</u>.
- 40 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.
- 41 Care Inspectorate, *Thematic review of self-directed support in Scotland Moray local partnership report,* p. 10.

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



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.



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.

The ALLIANCE

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