



My  
support  
my  
**choice**

My Support My Choice:

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

March 2022



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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 Highland. 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<sup>[1]</sup> 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 Highland, 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.<sup>[2]</sup> Subsequent chapters explore people’s experiences of SDS/ social care across Highland. Key findings are highlighted throughout, with a separate chapter on recommendations. The report concludes with a response to the research from the Highland Health and Social Care Partnership.

Due to relatively low survey return rates in Highland, we are not including quantitative analysis in this report. Instead, we have chosen to report on the detailed qualitative data provided by participants via written survey responses, focus groups, and interviews.

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.<sup>[3]</sup>

## 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.

We were unable to publish this report within the same time frame as the national, thematic and other local reports, primarily because of the impact of COVID-19, and the implications on staffing both within our partner organisations and in NHS Highland and the Highland Council. We have been in lengthy conversations across 2021-22 with Highland Council and NHS Highland about the initial findings of the report, and how they are responding to social care change in the current environment. While not part of our original publication plan, this delayed publication presents an opportunity to reflect on recent advances within Highland on how SDS and social care are delivered – including the development of the 2021 SDS Consultation in Highland.<sup>[4]</sup>

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 Highland, 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 39 people in Highland who received SDS (or had been assessed in the previous 12 months) via a survey and interviews. Research took place prior to the appearance of 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 qualitative analysis of the data from Highland within that larger context.

Research participants in Highland 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.<sup>[5]</sup>

## Poverty and SDS

An estimated 24% of Scottish households with a disabled person live in relative poverty after housing costs. MSMC found that most research respondents in Highland 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 Highland 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 Highland found out about SDS from a range of sources, and many reported positive experiences. People highlighted the value of face-to-face communication with social work and independent advice and support organisations, and many recommended that those wanting to know more about SDS should get in touch with independent advocacy and independent advice services as soon as possible. People also highlighted the value of healthcare staff being informed about SDS.

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

This pattern of variable information about the four options continued into people's needs assessments. A minority of people reported that they had "all four options" discussed with them during their assessments, with around half 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, although the substantial minority who disagreed invite improvement work in that area. Most people did not feel that all

their questions had been answered during their needs assessments.

Most of the respondents in Highland indicated that they had received information about how much money they could spend on their care and support. The remainder 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, many participants in Highland 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.

Almost all of the respondents in Highland indicated that they are on their preferred SDS option and most felt involved in all decisions and arrangements about their care and support. While this is encouraging, the finding that several people were either not fully involved or unsure, and many did not feel they had a say in their care arrangement, invites further targeted work to improve people's involvement in decisions about their care.

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 most of the respondents in Highland were offered the choice of who would manage their personal budget, it is concerning that several 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. A few people highlighted instances of being pressured into moving home or entering residential care against their wishes.

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 Highland 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 Highland – 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 Highland highlighted that good, consistent, trusting relationships with social workers and clear lines of communication are all essential for positive and effective experiences of SDS. Many participants reported positive and favourable experiences of assessments and reviews with professionals, providing a range of good practice examples. However, several people also 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. Supported decisions making, rather than substitute decision making, was also highlighted as key to good SDS. A minority people reported significant experiences of intimidation, bullying and harassment.

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. 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.

Several respondents also raised concerns about the so-called “gagging clause” in Option 1 contracts in Highland. We recommend that any Option 1 contracts in Highland that included a so-called “gagging clause” should be reissued, without any attempt to restrict people's ability to discuss the contents of their SDS package should they wish to do so. Future blanket alterations to the terms of people's support arrangements should only take place following meaningful consultation with service users and the people in their support networks.

## 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. Highland 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 Highland 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 Highland 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 Highland.<sup>[6]</sup>

## 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.
3. Highland would benefit from the Health and Social Care Partnership (HSCP) being more open to supporting research into people's experiences of health and social care, to give independent insights into people's experiences and improve

data collection in Highland. This could include learning from other HSCPs and local authorities about streamlining systems for ethics approval for distributing research calls for participants (for example, Glasgow City HSCP have an external research application process for social research which is publicly available on their website).<sup>[7]</sup>

## Information About SDS

4. 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.
5. 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.
6. More information should be publicly available for people about what to expect from interactions with social work, and about their rights.
7. People should be provided with timelines for each stage of the process for accessing SDS, and transparency about where and when decisions about support are made. Transparency would be improved

by sharing more publicly available information in accessible formats.

- 8.** Sufficient time must be allocated for needs assessments and review meetings, to allow for detailed questions and consideration of the four SDS options.
- 9.** Further information and training for professionals may be required about the SDS options and supported decision making.
- 10.** 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.
- 11.** 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.
- 12.** People should be offered a variety of ways to contact social work, as best fits their access needs and preferences. Social work departments should consider different opportunities, including online chat functions, a freephone support line, and direct email addresses so that people can communicate effectively with social work professionals.
- 13.** People should always have access to independent advocacy and support for assessments and review meetings if they desire.
- 14.** 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.

- 15.** Everyone must have access to information about the budget available to them for their care and support.
- 16.** People should be able to have several conversations with social care staff, if desired, to support informed decision making about care charges, budgets and how they interact with other income like social security
- 17.** 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

- 18.** 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 well-being.
- 19.** Targeted efforts are required to ensure that people living in rural areas of Highland 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.
- 20.** 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.

- 21.** Professionals should be trained in supported decision making (and co-production methods more broadly) to help reduce the number of cases of substitute decision making where they choose the SDS option and/or who manages person budgets instead of the service user.
- 22.** People must be treated with dignity and respect in all interactions with health and social care professionals and assessments and support must be adequate and tailored to people's requirements and way of life, taking into account all clinical, dietary, religious, cultural, or any other considerations based on protected characteristics and other self-identities.
- 23.** 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.
- 24.** 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.
- 25.** 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.
- 26.** People – particularly those living in more rural areas – require more acknowledgement and accommodation of travel costs in their SDS budgets.
- 27.** Professionals should fully incorporate equality assessments into their processes for service users and families.
- 28.** No-one should feel or be pressured to share their support with others or move into residential care against their wishes – particularly not as a result of a desire to reduce funding for support via SDS. All resources should be maximised to enable people to enjoy tailored social care and remain – with appropriate support – in their own homes for as long as possible, if that is what they want.

### Communication and Relationships with Social Work

- 29.** 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.
- 30.** 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.
- 31.** 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.

- 32.** 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.
- 33.** 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).
- 34.** Social work professionals should be provided with appropriate training and ongoing support on equalities, human rights, intersectionality, conscious and unconscious bias and anger management at regular intervals.
- 35.** 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.
- 36.** Professionals should ensure that all unpaid carers are offered carer’s assessments/Adult Carer Support Plans and have their rights explained to them.
- 37.** 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.
- 38.** 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.
- 39.** We encourage NHS Highland and Highland Council to indicate document publication dates and web page timestamps. The respective websites 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, NHS Highland and Highland 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.
- 40.** Any Option 1 contracts in Highland that included a so-called “gagging clause” should be reissued, without any attempt to restrict people’s ability to discuss the contents of their SDS package should they wish to do so. Future blanket alterations to the terms of people’s support arrangements should only take place following meaningful consultation with service users and the people in their support networks.

### Care Staff, Recruitment, Training and Quality

- 41.** 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.

**42.** 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

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

**44.** 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.

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

**46.** Local peer networks should be encouraged and supported by NHS Highland and the Highland Council, with social work professionals able to signpost people to relevant networks.

# 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."<sup>[8]</sup> For more information about the national context of SDS/ social care in Scotland, please refer to the MSMC national report.<sup>[9]</sup>

## Local Context

Highland is a council area with an approximate population of 235,540 people across 108,878 households.<sup>[10]</sup> Highland is a large rural area in the north of Scotland, and people live in rural areas, island communities, and urban areas, including one small city (Inverness). Highland is situated between Moray and Aberdeenshire to the east and Argyll and Bute and Perth and Kinross to the south. Highland is also the nearest mainland local authority to Orkney and Shetland to the north, and Na h-Eileanan Siar (Outer Hebrides/ Western Isles) to the west.

Highland is unique in Scotland in that adult social care (including SDS) is managed by NHS Highland, while children and young people's social work is managed by Highland Council.<sup>[11]</sup> Due to the relatively small number of children and young people who responded in Highland (seven respondents), we have not indicated where respondents accessed services via NHS Highland or the Highland Council, in order to preserve participant anonymity. As

such, some findings may be more relevant to adult social care services (managed by NHS Highland) than to children and young people's services (managed by the Highland Council).

Highland Council and NHS Highland publish a range of information for people who access or wish to access SDS on their websites (searchable via the search bar on the council website under the keywords "Self-directed Support", "SDS" and "direct payments").<sup>[12]</sup> At time of writing the NHS Highland website does not support internal searches and directs users to use Google search results for NHS Highland's website.<sup>[13]</sup> The Highland Council SDS web page does not specify in the opening page that it only relates to children and young people, and there are no direct links from the homepage directing people enquiring about adult access to SDS to NHS Highland's SDS web pages.

The Highland Council SDS web pages offer information on employing a personal assistant via SDS, examples of how it is used, eligibility criteria, answers to FAQ, and links to possible sources of help and advice, locally and nationally – including independent advocacy and/or advice services. A range of telephone contact details for regional decision-makers across Highland children and young people's social work are provided. There is no option to call a freephone number, which would enable people from low-income households to call without being charged. This consideration is particularly important given the number of people in Highland – and respondents to MSMC specifically –

who live below the poverty line. There are no direct links to other resources for people who are not deemed eligible for SDS, and the opening page would benefit from a clearer definition of SDS and outlining of the four options.

The equivalent web page for adult social care and SDS within NHS Highland's website provides a definition of SDS and outlines the four options. Option 2 is defined as allowing payment to "a service provider that is currently contracted with NHS Highland", rather than a free choice of provider.<sup>[14]</sup> Anyone wishing to request an assessment is advised to contact their NHS Highland Integrated District Team, but links to regional teams are not provided. Email addresses and telephone numbers for NHS Highland SDS Officers and review team are provided at the bottom of the information page. Anyone with queries about prepayment cards are directed to a specific administration team (via email, post or an 01463 number). There is no option to call a freephone number, which would enable people from low-income households to call without being charged.

We encourage Highland Council and NHS Highland to include more integrated and direct links between their SDS web pages, and to indicate document publication dates and web page timestamps. The respective web pages 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, Highland Council and NHS Highland 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.

## Sturrock Review

In 2019, John Sturrock was asked by the Scottish Government to undertake a fully independent external review into allegations of a bullying culture at NHS Highland ('Sturrock Review'). Given that the MSMC data gathering and Sturrock Review periods overlapped, the report's observations and conclusions provide potentially useful context to some of the experiences related by MSMC participants, so social care findings are summarised here. The Scottish Government published John Sturrock's report in May 2019,<sup>[15]</sup> in which 66% of the 340 participants reported experiences that they described as "bullying, in many instances significant, harmful and multi-layered, and in various parts, at all staffing levels, and in many geographic areas, disciplines and departments of NHS".<sup>[16]</sup> The report notes that:

*"Staff [...] feel they are not valued, not respected, not supported in carrying out very stressful work and not listened to regarding patient safety concerns, with decisions made behind closed doors. They feel side-lined, criticised, victimised, undermined and ostracised for raising matters of concern. Many described a culture of fear and of protecting the organisation when issues are raised."<sup>[17]</sup>*

While the Sturrock report covers the full range of NHS Highland services and activities, primarily focusing on staff experiences within NHS Highland, the sections on social care are potentially relevant to MSMC. Here, participants reflected on the negative

impact of budget cuts, pressure from management to reduce spending, and problems with management and frontline staff communication within integrated health and social care. The following statements from the Sturrock Review report provide a staff perspective on some of the common themes raised later in this MSMC report by service users:

*“The lack of openness and denial that services have been cut without significant consultation or risk assessment is contributing to the disconnect between staff and senior managers and leaving the staff feeling that cost saving is the only priority of the Health and Social Care Partnership”*

*“At the highest level we have a government which is advocating financial prudence and value for money and rightly so; however there is no allowance made to rural health and social care boards for the higher cost per person in delivering these services. This immediately places a relatively greater financial burden on rural health boards and their senior management team.”*

*“Being managed by someone that does not know or understand job role, comes from a different background. Most obvious when Social care and Health care joined forces.”*

*“This profession has had a bit of a hard time with managers put in due to integration, who do not understand the profession.”<sup>[18]</sup>*

The Sturrock Review report concludes that “a significant number of employees [...] resigned, moved to other jobs or retired as a direct result of their experiences in NHSH and inability to achieve a satisfactory resolution”.<sup>[19]</sup> The section on social care concludes with the statement that “there seems to have been and may still be significant misalignment between expectations within NHSH and Highland Council over social care, at least in some areas”, and that while “this aspect is beyond the scope of this review” it “may be important to address.”<sup>[20]</sup>

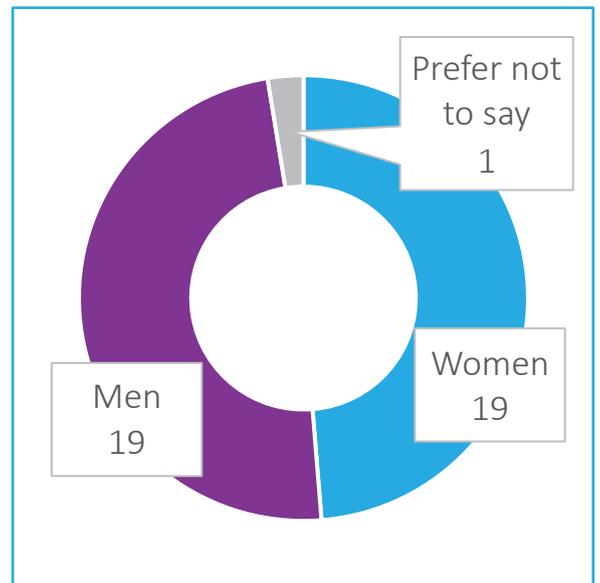
We hope that Highland’s ongoing efforts to address links between these experiences will improve people’s experiences of SDS and social care.

# Research Participants

MSMC heard about the experiences of 39 people who use or were being assessed for SDS in Highland. We interviewed 11 people who spoke about their own experiences or the experiences of other members of their household (spanning the experience of nine people who use SDS or who were being assessed for SDS). A further 30 people from Highland completed the survey. Throughout this report some participant details (e.g. age) have been changed slightly to preserve anonymity, while maintaining the most important information. Where changes have been made to quotations those alterations are indicated via square brackets (e.g. “My advocate, [Name], was great”).

Where possible, we have compared our participant data to local data and figures from Public Health Scotland’s (PHS, formerly Information Services Division) 2017-2018 experimental statistics on social care in Scotland. While not comprehensive, PHS have demographic statistics on people using SDS, and accessing social care support services more generally, that is provided by local authorities, including Highland Council and NHS Highland. 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, 19 women (49% of respondents) and 19 men (49% of respondents) participated in MSMC in Highland. A further one person (3%) preferred not to disclose their gender.

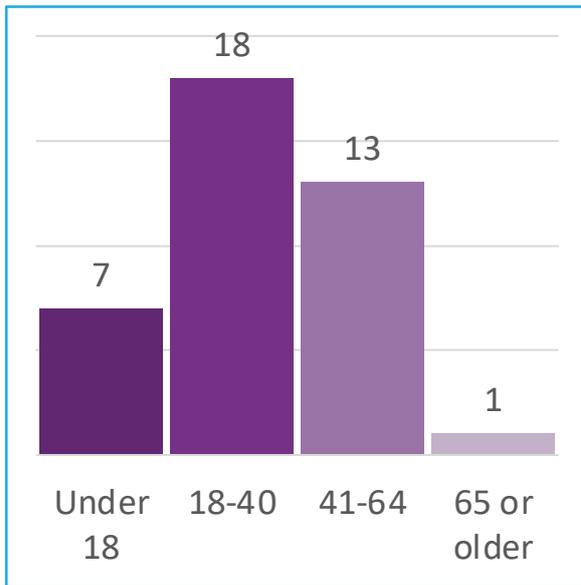
While PHS figures are not available for the division of men and women accessing SDS (nationally or in Highland), they do publish statistics on the number of men and women receiving social care support services more generally (of whom an estimated 99% in Highland access SDS). PHS reported that in 2017-2018 62% of people accessing social care support in Highland were women and 38% were men.<sup>[21]</sup>

## Age

We asked all participants to share their age. Of the 39 people who chose to answer the question, seven (18%) were under 18 years old, 18 (46%) were between 18 and 40 years old, 13 (33%)

were between 41 and 64 years old, and one (3%) was 65 years or older.<sup>[22]</sup>

**Chart 2: Respondents' age**



In mid-2018, 78% of the population of Highland was 64 years old or younger (lower than the Scottish average of 82%), with the average age expected to increase, especially in the 75 and over age group.<sup>[23]</sup>

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 Highland (of whom an estimated 99% access SDS). PHS reported that in 2017-2018 in Highland, 76% of people accessing social care support were over 65 years old, 22% were aged 18-64, and 3% were under 18 years old.<sup>[24]</sup> As such, the MSMC respondents in Highland are younger than the average demographics in the area.

### Ethnicity

28 MSMC survey respondents in Highland identified as white. One respondent selected “Mixed or multiple ethnic groups”. A further

one person chose not to describe their ethnicity. Most interviewees did not disclose their ethnicity when self-describing themselves, and the majority of those that did described themselves as “white”.

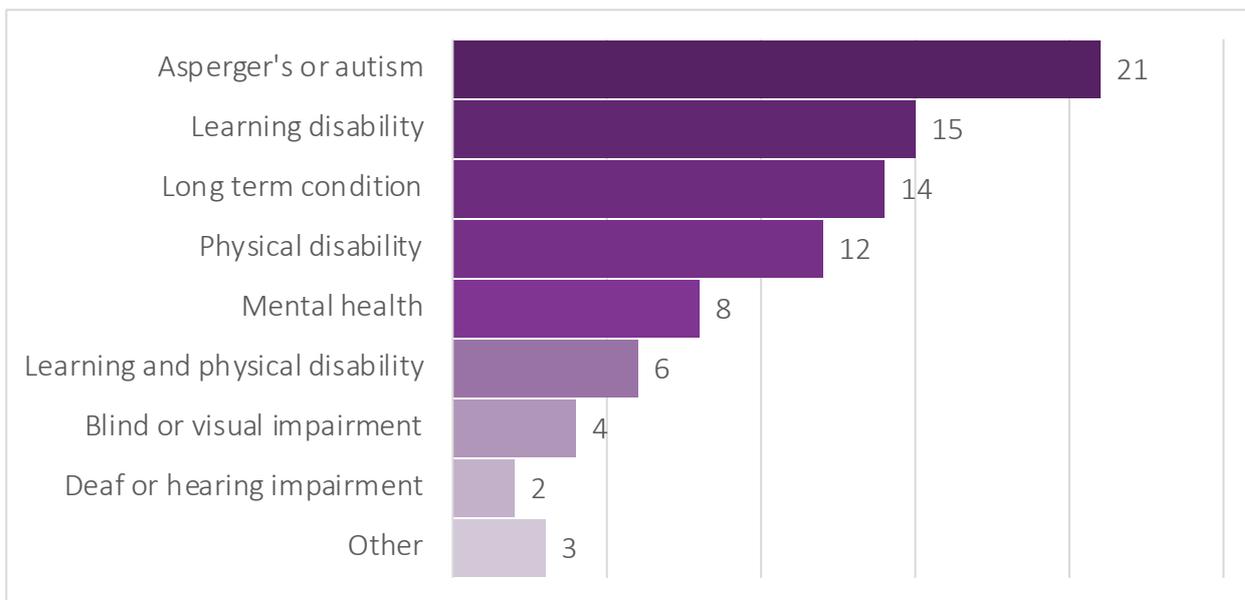
The 2011 Scottish Census indicated that 94.6% of the population of Highland identified as “White: Scottish” (79.9%) or “White: Other British” (14.7%), with a further 4.1% selecting “White: Irish” (0.6%), “White: Polish” (1.5%), or “White: Other” (2%). The remaining people identified as being part of minority ethnic groups: 0.8% of the population identified as “Asian”, “Scottish Asian”, or “British Asian”, and 0.6% as belonging to “other ethnic groups”.<sup>[25]</sup>

PHS do not provide a disaggregated breakdown of the ethnicity of people accessing SDS. They have some disaggregated data on the ethnicity of people receiving social care support services more generally (of whom an estimated 99% access SDS), using the limited categories of “White”, “Other”, and “Not provided/Not known”. PHS reported that in 2017/2018 in Highland, 66% of people accessing social care support were “White”, 34% were listed as ethnicity “not provided/not known”, and 41 people (0.5%) were categorised as “Other” (including “Caribbean or Black, African, Asian and Other Ethnic Groups”).<sup>[26]</sup>

### Client Group/Disability/Long Term Condition

MSMC survey respondents in Highland self-identified as living with a range of conditions, with the majority reporting that they were living with multiple conditions. 21 people (70%) selected Asperger’s or autism, 15 people (50%) selected learning disability, and 14 people (47%) stated that they live with a long term condition.<sup>[27]</sup>

**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’

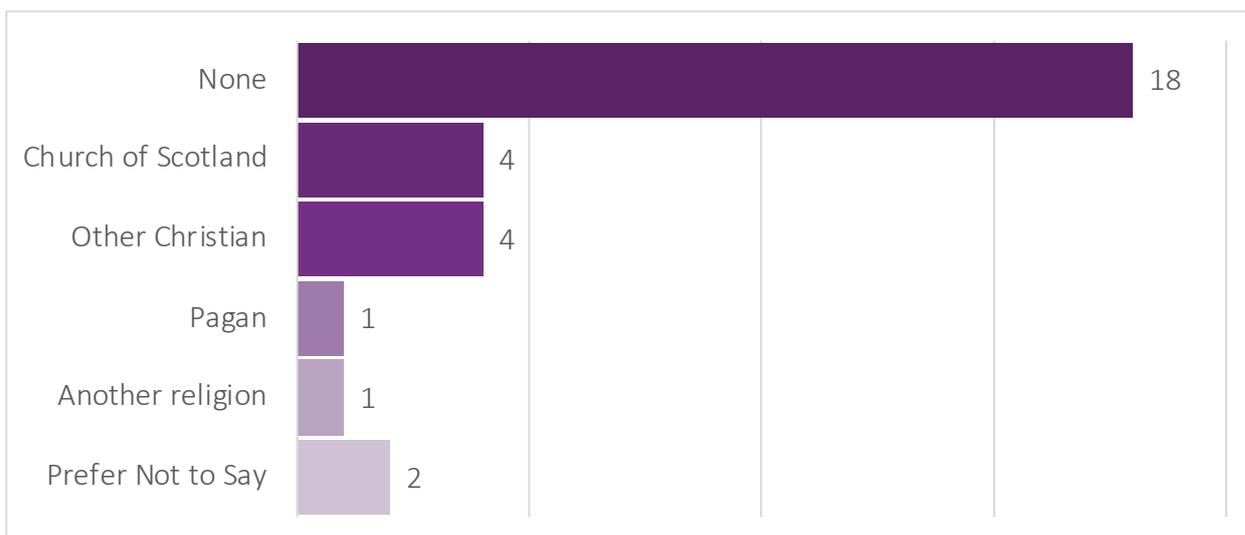
### Religion

When asked about their religion (if any), 18 survey respondents stated “none” (60%), four were part of the Church of Scotland (13%), four described themselves as “other

Christian” (13%), one was pagan (3%), and one selected “another religion not otherwise specified” (3%). Two people (7%) preferred not to answer.

Most of the interviewees chose not to explicitly disclose their religion when self-describing themselves; one stated that they were Roman Catholic. The overall spread of MSMC respondents is slightly less diverse than the 2011 Scottish Census data for Highland.<sup>[28]</sup> Data about people’s religion is not available on the PHS dashboard.

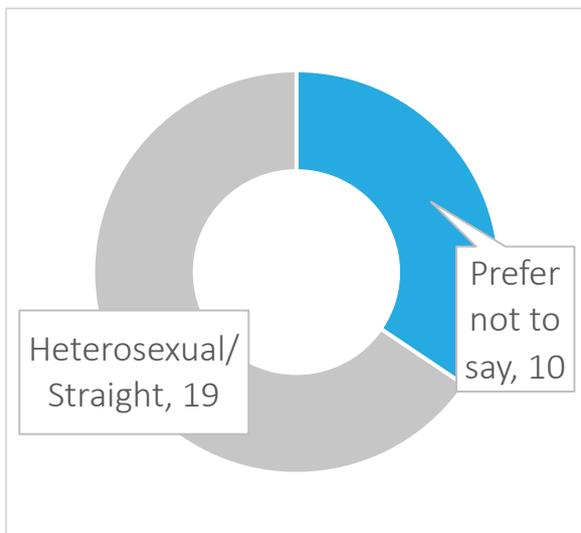
**Chart 4: Survey respondents’ religion**



## Sexual Orientation

19 survey respondents described their sexual orientation as heterosexual or straight. A further ten people stated that they preferred not to disclose their sexual orientation, and one person 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**

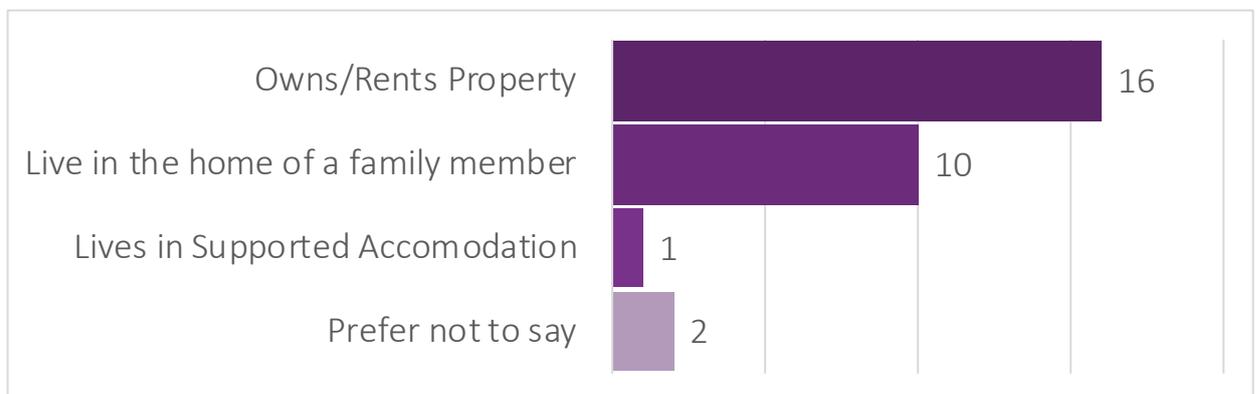


## Housing

16 survey respondents (55%) either rented or owned their own home, ten people (34%) reported that they lived in the home of a family member, and one person (3%) lived in supported accommodation. Two people selected "prefer not to say" (7%). Data on people's housing situations (other than residential care) is not available on the PHS dashboard.

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

**Chart 6: Survey respondents' housing arrangements**

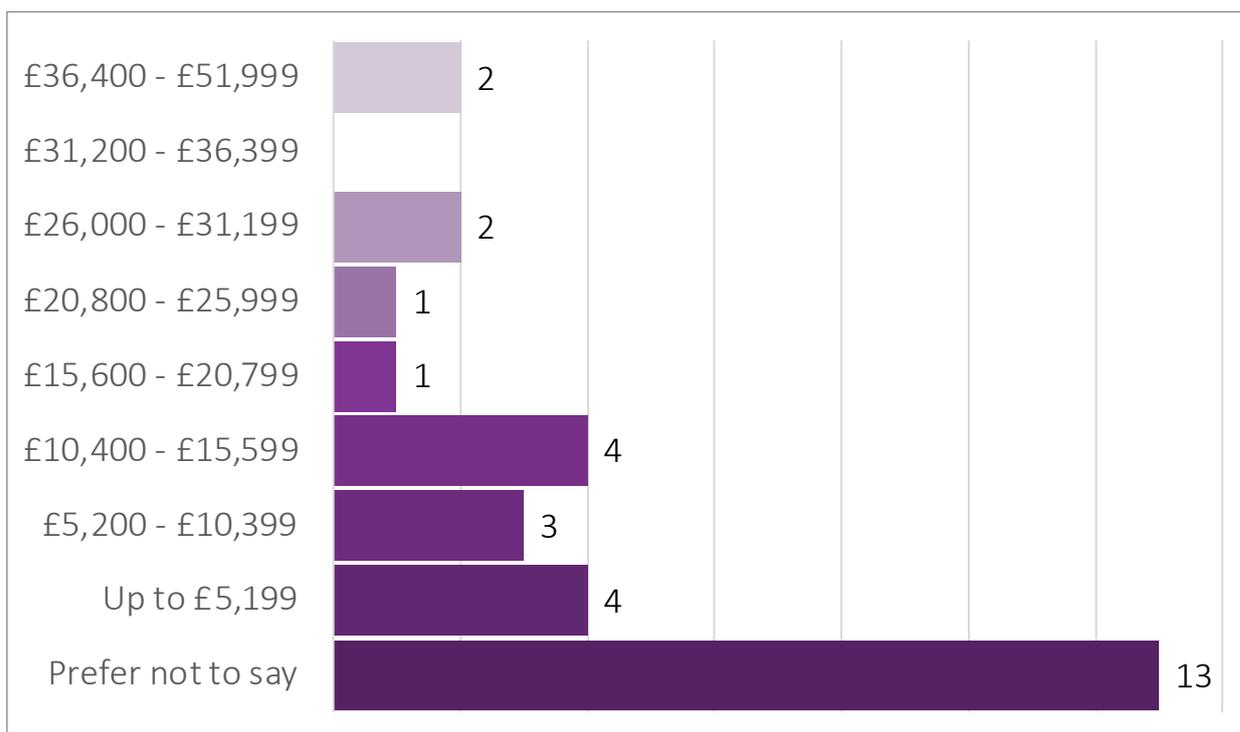


## Household Income

We asked survey respondents about their household income. We were interested in this information because in Scotland an estimated 24% of households with a disabled person live in relative poverty after housing costs, compared to 17% of the population with nobody with a disability in the household.<sup>[29]</sup>

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).<sup>[30]</sup> 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).<sup>[31]</sup> Based on this definition, eleven (65%) of the respondents in Highland 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. While SDS is not a source of income, it is the only way many people can access support to live independently and participate in their communities. As such, reductions in SDS budgets can result in people having to manage without support, risk deterioration in physical and mental health, and place unacceptable demands on family and friends to assume roles as unpaid carers.

### SDS Option

Of the 29 participants in Highland who shared which SDS option they used, 15 people indicated they used Option 1, seven used Option 2, three used Option 3, and two used Option 4. Two people stated that they did not know what option they used.

Figures from PHS indicate that in 2017-18 there were 674 people in Highland using SDS Option 1, 252 using Option 2, 7,389 using Option 3, and 27 using Option 4.<sup>[32]</sup> 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*.<sup>[33]</sup> 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.<sup>[34]</sup> 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”.<sup>[35]</sup>

### 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 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.

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."*

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

*"It's great – I am now living my life to its full potential."*

*"It's definitely worth applying for, it can make all the difference to your quality of life."*

*"It's been the best decision – I now have a lot more freedom to go out and about."*

*"I would say [...] it can be a really, a really wonderful thing, and for the person who is receiving the support, it can open a lot of doors, and [...] it can give the person a chance to experience lots of new things, or to access services which might have been difficult for them to access before. It can also take pressure off families."*

*"If they want full control or choice, if they're wanting full control of their life then the way to do it is get SDS. It's got its problems, but you can do an awful lot more than when you don't have support via SDS."*

*"The context of SDS is fantastic – and when it operates as it should,*

*with support given to people who are directing their support, with appropriate support given to them wherever they need it, then it's a great way of life for people who need support."*

Interviewees identified a range of ways that SDS has positively impacted their lives, with one interviewee (an unpaid carer) summarising their experience and that of the person for whom they care as follows:

*"It's really helped [Name]; it's given [them] a new lease of life. [Name] can go and [...] work, and [Name] doesn't need to have me there all the time. [...] And also the PA is brilliant because [they] can get [Name] to do things that I can't get [them] to do, you know? 'It's mam, so I'll no do it.' Whereas the PA [...] isn't mum, and they have a good laugh. It's been one of the best things we've ever done."*

Participants discussed the ways that having SDS enabled them to have more autonomy. One interviewee remarked that control over the budget meant that the SDS user could be sure what expenditure was spent on which activities – rather than residential settings with limited variety and trips out. According to a different participant, having control over their SDS budget also increased their overall access to independent living. Another respondent commented that they felt empowered by being able to manage their finances. A different interviewee shared that they enjoyed having increased control over their care providers.

However, some people were more cautious or explicitly negative about SDS, particularly relating to recruitment difficulties, budgets, and inflexibility:

*“Don’t waste time trying to get it.”*

*“Forget it, it’s not worth the hassle. Honestly, [...] it is disappointing.”*

*“It isn’t worth the stress and judgemental interference in your life.”*

*“It’s very stressful and time consuming, and hard to recruit carers.”*

*“It’s not as flexible as advertised. Staff recruitment is problematic in [a] small community.”*

*“It’s a money saving exercise and the support you identify [...] they are reluctant to give. It’s not flexible, regardless of what they say.”*

*“Very challenging, takes up a lot of time and isn’t the solution that it’s portrayed as. Very restrictive in terms of what SDS can and can’t be used for.”*

# Information About SDS

## Finding Out About SDS

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

Survey respondents most commonly heard about SDS from social work professionals (e.g. a social worker/social work assistant or an occupational therapist). A few heard from friends or family members, or from NHS health staff. People also heard about SDS from an independent support organisation, from social media, and from an independent advocate. One person contacted social work when they “needed help” following their own research.

One of the survey respondents who heard about SDS from NHS professionals reported that the

individual informed them about SDS “in secret” as they were “not supposed to share” information about it.

Among the interviewees, social work was the most common method through which people first heard about SDS. Two interviewees first heard about SDS from friends; one stated that “we knew absolutely nothing about it up here, and [Name] told me to look into it, which I did.” Two more interviewees stated that they were informed about SDS via educational professionals. Another participant mentioned that they had seen a poster about SDS prior to their disabled child transitioning to independent living in a flat, while a different interviewee was directed to SDS by an independent support organisation.

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

## Information and Preparedness Before Assessments

We asked 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. Most people did not feel that they received “all the information [they] wanted” about all four options,

with people least likely to have had enough information about Options 2 and 4. It is concerning that most respondents either had no information or were left wanting more in advance of their assessment.

A minority of interview participants had been fully informed about the options prior to their assessments, but most 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 reported that they had sought information about SDS by themselves, as no information was provided by NHS or social work professionals prior to their needs assessment. Another participant also discussed the lack of information provided before their needs assessment and the limited choice concerning the different SDS options. They explained that they received:

*“Absolutely nothing, [the social worker] came in and she showed me a sheet which she took away, and she said this is what type 1 care is, type 2, type 3, type 4. She said, ‘but we can discard type 3 and 4 because they’re not available here.’”*

Another interviewee stated that they had not received any information in advance of their needs assessment – and that despite the social worker knowing that they have a learning disability, none of the forms or paperwork used during the needs assessment were provided in Easy Read format. They stated that “what didn’t work is that they didn’t explain the process properly. They didn’t make it easy to understand.” The interviewee stated that Easy Read documents would have made their needs assessment easier.

We also asked respondents whether they felt prepared for their needs assessment. Several people stated that they felt prepared for their assessment, but most people disagreed. While it is encouraging that many respondents in Highland felt prepared for their assessment, it is concerning that most either felt unprepared or were unsure.

Most interviewees in Highland had not been fully informed about the

options prior to their assessments, which they said had made it harder to make informed decisions.

Many of the respondents stated that the professional discussed “all four options” with them, with several reporting that “some but not all” options were discussed, and an equal number that “none” of the options were discussed. Several respondents also indicated that they were “unsure” which options were discussed with them. These findings indicate that more work is needed in Highland to ensure that all four SDS options are outlined and discussed with people during needs assessments and reviews.

### **Information and Preparedness**

**Before Assessments:** The findings indicate both existing good practice in Highland, 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 Options 2 and 4 – carers’ assessments and support plans, and what to expect of a needs assessment.

## Information During Assessments

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

In the survey, we asked whether people agreed with the statement "The person I met with explained things clearly to me". Most survey respondents report clear explanations, which is encouraging, but several people stated that they did not receive clear explanations.

We also asked people to respond to the statement "All my questions were answered", regarding their meeting with a professional. Several people agreed, while most participants disagreed. That several respondents in Highland indicate that all their questions were answered is welcome; the finding that most people felt their questions were not answered or were not sure indicates further work is needed in this area.

Several interviewees reflected on positive experiences during their needs assessments and reviews. Some interviewees said that they had been able to ask questions during assessments and received satisfactory answers from social work professionals. Others would have welcomed more information or more detailed responses to their questions.

One interviewee stated that they felt their questions were not answered, and their concerns not listened to during their needs assessment. They stated that they asked questions about the assessment process (for example, "how long is the assessment going to take, and what is it going to do for me?") and did

not receive a proper answer or explanation of what to expect.

A different interviewee recounted that their social worker did not have sufficient depth of knowledge to advise them properly on SDS, and made mistakes in the process, causing delays to the interviewee's support. They summarised their experience as follows:

*"But they should be trained better than that. This should have not been the case! This should have been done straight away. They [the social workers] should have been trained! [...] And it is still happening today."*

Overall, interviewees indicated that their questions to social work professionals covered a range of issues, including how decision making processes worked, budgets, and the availability of suitable support options in their area.

One interviewee also commented on the difference it makes to service users when social workers are well informed about SDS, versus when they are working with insufficient information. They recommended that people:

*"Make sure that your social worker is trained, [...] is experienced with assessing these things. I know you don't always get to choose right enough, but it's worth really knowing yourself, because [sometimes] the service user's family [...] knows more about the different options than the social worker."*

A different interviewee echoed this theme and stressed the importance of properly equipping staff to work with service users around SDS. They stated that:

*“I don’t think SDS is well-known”, and even though “it has been going since 2013 it is still not recognised.”*

### **Information During Assessments:**

Social work 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 some positive examples of good practice in Highland. 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 respondents if they had been told the amount of money they can spend on their support (sometimes called an estimated or a personal budget). The majority of respondents stated that they had been given a budget.

Most of the interviewees we spoke to in Highland described their SDS budgets in terms of a specific number of hours per week, rather than a budget. One participant said that they had “no idea” what their budget was, stating that “I got some information [from social work], but not very much”, and that “it would be nice to know how much budget I’ve got.”

That most respondents in Highland had received information about how much money was available to

them is a positive finding. However, the small minority of respondents who 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.

### **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 those respondents with outstanding concerns, the main issues were budgets, lack of information about the four options, and limited support to access care. One respondent stated that they found that “very few options [were] available – [it’s] ‘find your own’”. Another participant stated that they were “left in the dark as to whether the budget would be approved or how much we would be allocated”, while another noted concerns about “restrictions and clarifications on use of budgets” against their agreed outcomes. One

respondent simply stated that “none of my concerns were addressed”.

Some people highlighted that living in a rural area of Highland 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. These issues are explored later in the report.

We also asked participants whether they were in the process of appealing the decision made in their last review or needs assessment. 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 Highland 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

We asked if people agreed with the statement “I had enough time to choose the option of SDS that suited my needs.” Many people reported that they had enough time to choose – but nearly the same number indicated that they did not, with a few people stating that they were unsure. While it is encouraging that nearly half of respondents in Highland had enough time to choose an SDS option, the findings suggest that work is required to increase the number of people who feel they have enough time to decide on the best SDS option for them.

One participant summarised their concerns about now having enough time to make their decision as follows:

*“I didn’t feel I got enough time to think about what options really met our needs. Does feel rushed, the decision to get it to panel. Also [there are] very little options available – either limited council respite or find your own.”*

The issue of respite, or short breaks, is explored later in the report.<sup>[36]</sup>

Overall, nearly half of respondents felt they had enough time to choose an SDS option. However, a similar proportion would have liked more time before deciding – a result that overlaps with those people who wanted more information about their options. Five of the respondents who wanted more time to decide said that they had received no information about SDS options at their needs assessment, two stated that “some but not all” options were discussed, and three were unsure. Finally, two

reported that all four options were discussed with them. These results indicate a correlation between the provision of clear information and people feeling able to make prompt decisions about their support.

## Waiting Times

Participants reported variable wait times for assessments and support to be put in place; some waited three or four months, while others waited more than a year before the start of support provision. In one case, the practical consequences of delays meant that one family paid for essential support for several months before an SDS user’s budget was approved, causing financial hardship.

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 Highland if they were on their preferred SDS option. Most people were on their preferred option, with one person stating that they were not on their preferred option, and two reporting that they were unsure.

The proportion of respondents in Highland 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.

A similar pattern was found with interviewees. Seven people interviewed were on their preferred SDS option, and one person was not on their preferred SDS option. A further interviewee had changed their SDS

option following problems finding suitable care provision in their area. Their preference would have been to use Option 2 with a choice of suppliers, but this was not available to them.

We also asked survey respondents to agree or disagree with the statement “I am fully involved in all decisions about my care and support”. Most people strongly agreed or agreed, while a minority disagreed or strongly disagreed, or stated that they did not know. The finding that most people are fully involved in decisions about their care is encouraging, but the fact that several respondents either did not feel involved in decisions about their care or were unsure invites further work in this area.

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.” Respondents were evenly divided between those who felt that they had a say, and those who felt they did not. That many respondents did not feel fully involved in all decision about their care is troubling. These findings invite further work to embed supported decision making (instead of substitute decision making) in SDS/ social work practice.

We also asked survey respondents who chose the way that their support is arranged now. We found that most people made their own decisions about their care or were supported by their friends and family in those decisions. A minority of people reported that social work professionals or others made decisions about their care; a finding that invites further work to embed existing good practice and supported decision making (instead of substitute decision making) in SDS/ social work practice.

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 in order to make informed decisions.

A lack of choice of care providers across Highland meant that in several cases participants reported having no choice concerning who provides their support (even if they were on their preferred SDS option). One interviewee went further and stated that in their experience there is pressure from some social work staff to choose Option 3. They outlined their concerns as follows:

*“They are telling people that there is no money for SDS. [...] Not just about the options but about that there is no money for SDS. And [...] they are not explaining the options properly. They are just giving one option and they are not giving people the chance to decide what option they’d like to have. Basically, there is only Option 3 because that’s the easiest option to do.”*

### **Choice Over SDS Options and Support:**

Although the majority of respondents in Highland 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 also indicated that they would welcome more choice of providers, in order to be able to meaningfully access all SDS options.

### **Budget Management**

We asked respondents whether they chose who manages their personal budget, and if so, who they chose to manage it. Just over half said that they were free to choose who they wanted to manage their personal budget, but several people said they were not given a choice, and one person was unsure whether they had a choice.

Of the people who were given free choice of who would manage their personal budget, most people selected an individual person (typically either themselves or a family member). One person selected the council, one chose a third sector provider organisation, one opted for a private care agency, and one selected an individual broker.

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

It is encouraging that most respondents in Highland were offered an unrestricted choice of who to manage their personal budget. However, it is concerning that several 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 Highland 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”. Most people strongly agreed or agreed with that statement.

Several participants spoke in detail about the impact on their physical and mental health of substantial reductions to their SDS budgets and support. One survey respondent stated that their “budget was cut because of service needs and not any changes to my needs – which impacted negatively on my life in a big way.” An interviewee who also experienced substantial budget cuts stated that:

*“I wrote to them outlining the [...] risks of reducing my package,*

*but they went ahead and cut it anyway. Within three months my life was impacted on in a very negative way. I did not have the support available to help as it was removed. Now support has to be sourced [...] from elsewhere to fill the shortfall from my SDS.”*

Another interviewee discussed the challenges in obtaining 24/7 support in Highland. Although their SDS budget was approved, they were being pushed into a potential shared support situation to reduce overall costs (where a single care worker is shared between several different SDS users, from different households). The participant explained that they were dissatisfied with this approach and did not feel it was person centred.

One interviewee had recently moved to Highland from another local authority area. Although their support needs had not changed, the interviewee struggled to access the same SDS package and faced an attempt to reduce their budget. A different participant remarked that the general pressure from social work to reduce budget expenditure dissuaded them from asking for further assistance.

Several respondents outlined how the person for whom they cared, before transitioning from children’s to adult services, was able to use SDS for support with social activities. Adult respondents were less likely to be supported for social and community engagement – although several had previously had support for social activities (now reduced). One respondent commented on what they saw as inequality of provision:

*“I was told I couldn’t have this; this isn’t covered. In some areas they say yes – because I can’t wash on my own, because [of*

*specific condition], going to the hairdressers isn't a luxury. But I don't want somebody in the shower with me washing my hair, I have a bit of dignity I want to keep, you know what I mean? And so, I said, 'I go to the hairdressers twice a week'. 'What an extravagance!' said the occupational therapist [who was part of the review team]. I said, 'How often do you wash your hair?' [They said], 'Well, how often I do mine isn't what's in question here, it's whether we think this is reasonable.'"*

In the above instance, the interviewee felt that there was very much a divide between the assessment team and themselves; washing daily was seen as acceptable for the social worker and occupational therapist, but being able to wash twice a week was seen as an extravagance for the interviewee, as a disabled person.

Another interviewee outlined similar problems accessing even basic care – and frustration with perceived differences in what some people were able to access, as opposed to their care:

*"I'm a little bit intrigued when I hear that nowadays people can spend their SDS on this or that, theoretically. Because we've barely got enough to pay the 24/7 [personal] care, and we have to go into the contingency all of the time."*

Another interviewee was offered short-term support via SDS Option 3 with a specific care provider, who would send carers to assist the interviewee. The description offered sounded similar to a targeted reablement intervention. The interviewee would have preferred to use Option 2, and requested as

much from their social worker during their needs assessment, so they could select an agency that would let them request a small rota of female carers they could get to know and feel comfortable with. They were informed by social work that this was not possible in their area. Furthermore, the interviewee was informed that the carers would report back if they felt that the interviewee genuinely required the support supplied, and this would feed into social work's decision to continue or end support at the end of the six week "trial" period. The assessors also asserted that somebody would visit separately to assess what the interviewee was "capable" of in the kitchen. Given that the situation did not concern a discharge from hospital or substantial change to the person's conditions and requirements, and related to support for chronic and long-term conditions that had been known to NHS Highland for several years, this decision to remove the choice of Option 2 and enforce a six-week trial period is counter to the best practice guidelines for SDS.

Some survey and interviewee participants indicated that they were happy with the support they were receiving. However, the findings indicate that further steps are needed, particularly to ensure that people are not being forced into care pathways against their wishes (and the legislation around SDS). While care and medical professionals play an important role in providing support for people to 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. We recommend that staff should be given more training about how to support decision making for service users and unpaid carers rather than lead it, and on coproduction methods more broadly.

**Adequate Support:** The research reinforces the need in Highland 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 some people in Highland were happy with their care, we found that many 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.

### Relocation and Residential Care

The MSMC research team heard from a few people in Highland who felt that their local authority and social workers had pressured them to move to urban areas or consider residential care rather than remain in their own home with support via SDS. One participant reported that they were informed by social work that they would need to move from a rural location to an urban centre if they wanted to access SDS. There was no financial assistance offered for their eventual relocation.

Another participant shared that their SDS option had changed recently, but not by choice. Previously, they had a SDS package that meet their support needs using an agency. The SDS package was reduced to 20% of the original amount, and this reduction in the SDS budget meant there was not enough to pay the existing care provider's rate of pay per hour and respond to their care needs. Instead of retaining the budget, or identifying an alternative care provider (which was a challenge in the rural area in which the interviewee lived), the

interviewee's social worker pressured them to moving into a residential care home, away from their family, and recommended that they use emergency hospital admission in lieu of accessing care or short breaks. These options caused the interviewee and their family considerable stress and distress and were not in keeping with their preferred choices or rights (to continue to live at home, in their community, with their family).

### Relocation and Residential

**Care:** No-one should feel or be pressured to move or enter into residential care against their wishes – particularly not as a result of a desire to reduce funding for support via SDS. All resources should be maximised to enable people to remain – with appropriate support – in their own homes for as long as possible, if that is what they want.

## Flexibility

Many research participants commented on the value of and need for flexibility for the effective use of SDS. 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 benefits of more flexibility in SDS budgets – and particularly if support hours can be used on a variable week by week basis. One respondent, an unpaid carer, summarised their experience as follows:

*“The initial social work assessment was okay, ‘we’ve assessed [Name] as needing [X] hours support per week.’ But then, you know, it was discussed that it was actually a little bit flexible, and we could use some of these hours [...] to have a longer day at another time, you know, so [...] there’s a degree of flexibility.”*

Some interviewees experienced inflexibility with the ways that SDS budgets could be spent. One participant recounted a stipulation that a PA must be paid to take them to and from activities. To increase the interviewee’s independence, a request was made for the travel to be unaccompanied, via taxis. This request was turned down, even though the taxi journeys would cost less money than paying a PA’s wages. Another participant described how funds from a disabled young person’s

SDS budget were returned to the local authority, because authorisation was often not forthcoming for certain items or activities in time to spend the budget. The interviewee felt that these items or activities would have helped the SDS user to achieve their personal outcomes.

**Flexibility:** The research suggests that there is good practice with regards to flexible approaches to SDS in Highland, which positively impact’s people’s lives and those of the people for whom they care. However, many people in Highland 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 Highland – for SDS users and unpaid carers alike. 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. Short breaks were also mentioned by several interviewees as an important chance for people to have breaks and relax.

One interviewee, who was an unpaid carer, highlighted that their child was refused support for participation in specific social activities. Instead, their social worker suggested alternatives that the unpaid carer felt “wouldn’t work” for the SDS user. The interviewee felt that there was a lack of empathy shown towards the SDS user’s needs, particularly regarding access to suitable short break facilities. The interviewee, in conjunction with a local SDS advocacy service, prepared a costed support plan whereby the SDS user could access short break facilities which they felt were suitable for their needs. However, despite the proposed option being cheaper than a traditional short break at a residential facility, this was refused, as the proposal did not use a recognised care provider.

Other interviewees reflected on difficulties accessing short breaks, and the negative impact this had on their health and well-being. Several respondents stated that they had struggled to get approval to access short breaks, even when they were approved as part of their outcome or budget. Some reported that the short break sections of their budget were cut completely with no warning, and in contrast to what was outlined in assessments or reviews. One respondent recounted that “I was told I would get more respite and nothing else would change, and instead had [specific health intervention] taken away and no increase to respite.”

**Access to Short Breaks:** Flexible, regular access to short breaks should be strongly encouraged in Highland 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 Highland. 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. One person had to move to an urban location in order to access services appropriate for their needs – which meant living a significant distance from their family and support network and resulted in corresponding travel costs.

Finally, one interviewee recounted the impact of other entitlements upon the use of SDS. They explained that a potential loss of Personal Independence Payments (PIP), for instance, would prevent them accessing a mobility car – and in a rural location, this would greatly impact upon their ability to travel, even with support from SDS. They would have appreciated more support from social work in navigating these overlapping areas of disability access.

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

# Communication and Relationships with Social Work

## Good Conversations and Consistent Relationships

The importance of productive conversations in arranging appropriate social care support was highlighted in the 2019 Care Inspectorate thematic review of SDS.<sup>[37]</sup> 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).

Participants 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 well-being more generally. They also reflected on the positive impact of social workers who could signpost resources.

One interviewee noted that their social worker often suggested pieces of equipment or activities to enhance independent living. They commented that sometimes it is difficult to know when to ask for further assistance and what to request, so the social worker's suggestions were welcome. A different interviewee, speaking on behalf of a SDS user for whom they provide unpaid care, remarked that the social worker spent time to fully include the SDS user's views in the review process. They stated that "there are time now we will have social work reviews, and [Name] seems, you know, very relaxed

talking to social workers, [they're] pretty at home with that process."

One participant highlighted good practice during their SDS review. They outlined that the social worker took into consideration a person centred approach and approved the expenditure of the SDS budget on some new activities. The interviewee also reported that after they lodged a complaint with social work about the standard of care provided by an agency, their social worker assisted them in ensuring that the care provided was changed and improved.

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, and good communication skills – including following up on outstanding queries. 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:

*"My initial social worker was brilliant and really did the best for me."*

*"The social worker listened carefully to what me and [family member] said about my independent living. They asked good questions and had good ideas."*

*"Lots of listening, note-taking, recapping, offers*

*of feedback to questions unanswerable at meetings.”*

*“I felt that a professional understood my illness and circumstances for the first time in three years.”*

*“I have a social worker for really wants me to have a happy life and sees value in what I choose to do. [My social worker] works hard to secure my budget for me.”*

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 many people in Highland felt 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 improvement work to ensure positive conversations and relationships, with ongoing planning to guarantee high quality practice for all people using SDS.

## Poor Communication and Relationships

A substantial minority of participants described less positive experiences of communication and relationships with social work professionals in Highland. Several 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.

*“I felt that a professional understood my illness and circumstances for the first time in three years.”*

*“I have a social worker for really wants me to have a happy life and sees value in what I choose to do. [My social worker] works hard to secure my budget for me.”*

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.

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

*“No one ever called me back.”*

*“Never heard from any professional.”*

*“My two [...] social workers have felt disinterested.”*

*“The initial conversation was good but not seen anyone regarding SDS*

*for years, so just stuck with what services we originally agreed on.”*

*“They are utterly clueless on how to communicate with me – despite them having files on me 5 feet thick.”*

*“Always feels rushed. Feels like we need to fit the boxes rather than what works well for child.”*

*“Made to feel some care aspects were not to be discussed, especially those most relevant to my needs.”*

*“Felt [social worker] didn’t care, wasn’t interested. Even though I was in crisis there was no emergency back-up plan available.”*

*“Social workers were very secretive and would not return calls during the assessment process. [...] Carer advocate got things moving again and SPAEN explained the process of employing someone in more detail.”*

*“It’s all to do with funding, I don’t feel my or my [family members’] feelings, health, and concerns are taken into account.”*

*“The social worker does not keep in touch and keep me informed with what is happening. I contacted social work [...] saying I was in crisis and couldn’t cope and nothing has changed. No communication leaves me feeling unimportant and that we don’t matter; I’m at my wits end.”*

Other respondents expanded their comments to experiences with health and social care more broadly. One person stated that they are “unhappy with health professionals’ attitude; [...] they don’t see me as an individual.”

One interviewee remarked that during their needs assessment they felt that their social worker made assumptions about what SDS option they would use, because the interviewee has a learning disability. The interviewee summarised the experience as follows:

*“[The social worker] put words into my mouth. [They] thought I wasn’t capable to choose what I wanted and what outcomes I wanted. And I said, ‘no, I can choose what I want, I’ve got a voice. Why are you putting things into my mouth?’ So, that was the difficult part of it.”*

When asked what they would recommend to improve communication between social workers and people seeking to access SDS, the interviewee stated that social workers – whether working with people with learning disabilities, or anyone else – should:

*“Just be with the person and go through the complete assessment. If people struggle then yes, I can understand that [social workers supporting a decision]. But if you are capable of saying what you want to do with that budget and what outcomes you need, then that is completely different – you can do that! I was really shocked [...] I mean [the social worker] took ten months to have my assessment finished. Unbelievable, I was so angry! That assessment could have been done in a week.”*

The interviewee then spoke strongly in favour of supported decision making, ensuring that staff and service users have plenty of time to discuss options and outcomes in needs assessments and reviews, and of the value of peer support networks

A different interviewee suggested that the geography of Highland leads to specific challenges when it comes to effective communication and relationships with social work – particularly at senior management level. They had been invited to meet with decision-makers in Inverness, but the travel time between Inverness and their home rendered this impractical – and they stated that many people across Highland would be in similar positions. They suggested that the SDS support team should hold regular meetings in different parts of Highland, to enable people to bring queries to the team from within a local area:

*“Quite honestly you can’t get a hold of the SDS support team here anyway. They’re up in Inverness, they don’t answer us phoning, they won’t come to [location]. I said, ‘could you not just have a sort of surgery down here once a month?’ All of us could speak to you, and have a personal interview and that, so they can travel down once and then all of us don’t have to travel up to Inverness for advice. We’d be better informed if you regularly came down, finding out, if somebody has popped in to ask them a question – ‘Oh, you’re getting SDS too?’, you know. Without [it] they’ll tell you nowt, so we don’t know half the time.”*

Several participants reported that they felt that frontline social workers were unable to secure approval from NHS Highland managers for SDS packages. In some cases, this led to frontline social workers revisiting respondents to determine where reductions in support could be made. One participant summarised their perspective as follows:

*“There’s been a mention of social workers – they’re not really there for you. The only time we see them is when they have to come out [...] to cut something off.”*

Interviewees also commented that high staff turnover within social work made conversations with social work professionals difficult – and particularly lack of regular access to a social worker with a person centred approach. One interviewee reported that their social workers changed due to ill health and work-related stress, while another remarked that their social worker, who had a person centred ethos, moved to a different local authority area. These concerns match the problems with staff turnover highlighted in the Sturrock Review, which concluded that “a significant number of employees [...] resigned, moved to other jobs or retired as a direct result of their experiences in NHS and inability to achieve a satisfactory resolution”.<sup>[38]</sup> Here, we see the direct impact of that staff turnover on disabled people, people living with long term conditions, and unpaid carers.

### **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 in Highland 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. Cumulatively, the research findings highlight the importance not only of good communication with social workers during needs assessments, but the need for transparency, sustained and trusting relationships, and depth of knowledge about SDS.

## Intimidation, Distrust, and Bullying

Some people shared their experiences of social workers appearing not to empathise or understand the extent of their requirements, to the extent that they felt intimidated and bullied. Other experiences demonstrate unacceptable behaviour. While these accounts were rare, they were significant enough to include within this report as examples of poor practice and as part of efforts to improve and ensure high quality care for people in Highland.

One interviewee described an experience of their needs assessment that highlighted a variety of problems with the behaviour of the social work professionals involved. Having received support for several years, their recent needs assessment was carried out by two social work professionals. The interviewee provided the professionals with information about the development of their compound health conditions and the need for more care, as their unpaid carer was no longer able to provide the level of support they required. During the assessment, the social work professionals stated that they needed to observe the interviewee carry out daily tasks that they found difficult to complete. The interviewee carried out these tasks as requested.

The social work professionals then required the interviewee to demonstrate how they cleaned themselves, and what parts of the process they found difficult. The interviewee was expected to take off their clothes and underwear and shower in front of the social work professionals, then get dressed again. The interviewee was extremely uncomfortable but did not feel that they were able to refuse. They feared that if they did not comply then they would be denied the support they needed. They described the experience as follows:

*“The [social work professional] says, ‘well I need to see you stripped off and how you do it and wash. Now what do you do for soap and things, if your [specific body parts] are that bad?’ So, I got my shower gel [...] and swooshed it round and got a face cloth, you know, and – so I had to re-wash myself totally, in front of the [social work professionals]. The pair of them standing taking notes and here’s me trying to kid on I wasn’t – it felt –’ [interviewee unable to continue].”*

The interviewee queried whether it was necessary to undress in front of the social work professionals in order to demonstrate their personal hygiene process.

They stated that the social work professionals responded to their query by saying, “and what’s the problem with somebody seeing you like this?” The interviewee replied that their discomfort with nudity in front of people they did not know stemmed from their religious and cultural background.

This reason was not deemed an acceptable justification by the social work professionals; the interviewee felt sufficiently pressured that they then complied and showered in front of the two social work professionals. They stated that they were crying throughout the process of showering, but the social work professionals did not allow them to stop, nor did they attempt to reassure the interviewee or make them feel more comfortable.

The needs assessment that this interviewee described was not person centred, did not respect their autonomy or preferences, demonstrated misuse or misunderstanding of the

imbalance of power, and at points violated their human rights.

Another person recounted how their social worker attempted to insist that they move from 24/7 support to a combination of paid carers and telecare. They pointed out that telecare was not possible for them, due to their rural location (any mobile carers driving to the service user would take a considerable amount of time to arrive) and their physical range of movement. They recalled their interaction with their social worker as follows:

*“And they were both virtually shouting at me, the social worker [...] saying I was quite capable of pressing a button. And [the social worker] then said, ‘I spoke to you on the phone earlier, you answered the phone, how did you manage to do answer the phone when you can’t press a button?’ I said, ‘but I’ve got a carer, and [they] place the phone on my shoulder and I speak into the phone that’s on loudspeaker – that’s how it works. [...] But [phone company] who provide that system will not guarantee it and will not put in emergency numbers because they can’t guarantee it’s 100%.’ So [the social worker] wouldn’t believe that, so I said, ‘fine, I’ll phone up [phone company representative]’ [...] and he explained that we cannot put in emergency numbers, and it cannot be used as emergency equipment. [...] The phone call ended, [the social worker] put the phone down, and [they] said to me, ‘there you are now, nothing wrong with your phone, you can use it.’”*

Two interviewees also experienced a breach of General Data Protection Regulations (GDPR) during their interactions with social work. This involved health and social work

professionals accessing the medical records of one of the interviewees (an unpaid carer, who did not access SDS) without their permission, to check the SDS user’s statement during a needs assessment that the unpaid carer was no longer physically capable of carrying out some care-related tasks. This inappropriate accessing of data would not have been possible in most social work departments. The interviewees felt that this action constituted a breach of trust.

Similarly, another interviewee stated that their social worker contacted their GP without consultation with the SDS user and arranged for their medication to be altered without their consent or consultation – or considering why this approach was inappropriate and disempowering. These examples of inappropriate communication and substitute decision making pose clear problems in terms of the treatment of disabled people, assumptions made and respect for people’s choices.

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

**Intimidation, Distrust, and Bullying:** No-one should have to deal with discriminatory, intimidatory or bullying language, attitudes or behaviour from social work professionals and people must be treated with dignity and respect. Appropriate training and ongoing support on equalities, human rights, intersectionality, conscious and unconscious bias and anger management should be provided to staff at regular intervals. Training and guidelines should also be developed for staff to help them prioritise supported decision making (rather than substitute decision making). Social work staff should pro-actively gather regular feedback – good and bad – from service users, families and unpaid carers as a way to support continuous improvement. Social work professionals should also pro-actively inform service users, families and unpaid carers on a regular basis about how they can challenge decisions, access independent advocacy and support, local authority complaints procedures and the independent oversight of the Scottish Public Services Ombudsman (SPSO). Health and social care staff should be trained in prioritising service user’s autonomy, choice, and control, and in appropriate GDPR compliance. They should not access the medical records of service users’ family members without permission, and they should practice supported decision making in all conversations around people’s health and social care. Greater signposting of independent advocacy and independent support and advice organisations may also help to reduce conflict and rebuild trust.

## 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.

Participants reported that they would like access to copies of all documentation concerning their social care provision, including copies of their agreed budget and personal outcome plans, but struggled to obtain these documents from social work. Several respondents also raised concerns about the accessibility of information; one respondent stated that they process written information better than verbal communication, and they requested printed information on SDS and their options, but that this was not provided. The respondent was also not given a written record of their needs assessment when they requested it.

Several respondents also referenced a “gagging clause” in Option 1 contracts in Highland. The research team were shown a contract which stated that signatories are not allowed to discuss their support package and budget with any parties outwith the NHS Highland social work teams. Some participants felt pressured into signing this contract, as otherwise they would not receive support, while others were challenging its validity. As one respondent asserted, this clause has a range of potential negative consequences:

*“It would be good, to know and support each other, if you’re finding something difficult. And as I say, when I asked them what their reason was for this gagging clause, as I’ve called it, they said, ‘well, we don’t want people hearing what other people are getting, and thinking that they should get the same.’”*

A focus group on people’s experiences of SDS in rural areas took place

in Highland, with the majority of participants resident in Highland. Several participants mentioned the so-called “gagging clause” as a point of concern (although this was not an explicit question in the research). One person stated that they found that the language of “gagging clause” and “secrecy document” causes “a lot of confusion and aggression”, as people felt threatened. Another participant outlined their concerns about the clause:

*“What I was going to say about the secrecy thing is – I used to be trained as a peer, as someone with lived experience, as a SDS advisor. And when SDS came out there was a lot of blue sky thinking – people were telling people you could spend it on this, or spend it on that thing. Which actually in the spirit of the legislation was correct. However, the secrecy thing bothers me because [...] one of the things that will really make SDS flourish in our communities is being able to share good practice and good experiences. So, I went along to [example of SDS-supported activity], and it was brilliant, and I was able to use my money to do that. The reason they’re putting the secrecy clause in is because they don’t want people to discuss not just the amount, but how they’re spending the money. Because if one person’s spending the money on one thing, and another person’s been told they can’t spend their money on that, they’ll get endless complaints. But I don’t think they’ve served themselves well by doing that and it’s actually not going to help SDS work.”*

The participant’s comment about the impact of a “gagging clause” on peer support and advice on SDS was echoed by other members of the focus group. Another person summarised their experiences as follows:

*“Just one topic, to reinforce what you’re saying, I was invited to meet the parents of [...] disabled children at [Name] school. There was a coffee morning, I went along. The parents were all like, ‘SDS, blah blah blah’, and they sort of chatted and they talked about the difficulties and that. And I said, ‘but you’re carers, so you’ll have your carers package for respite?’ And they went, ‘What?’ I counted, and there were 18 people in the room, and one person put their hand up and said, ‘I’ve got it’. I went ‘How long ago did you get it?’ She went, ‘last week’. And I said, ‘have you told anyone?’ And she said, ‘No, I had to sign the secrecy clause’. So 18 people in the room didn’t know about the experiences of SDS for a carer, because of that.”*

While reducing peer support for people using SDS was presumably not the intention behind the “gagging clause” for Option 1 users, the above experiences outline some of the consequences of this decision. Given how important MSMC participants – in Highland and throughout Scotland – find peer support in helping them with both accessing SDS and everyday life, it is important that people feel free to share lived experience and expertise widely. Anything that restricts that freedom of discussion is to be strongly discouraged.

**Transparency:** The research indicates that 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, web page timestamps, details of Equality Impact Assessments, and the role of people who use support, unpaid carers, and partner organisations in decision making, is encouraged. We also recommend that any Option 1 contracts in Highland that include a so-called “gagging clause” should be reissued with these elements removed, allowing people to exercise their right to discuss the contents of their SDS package, should they wish to do so. Future blanket alterations to the terms of people’s support arrangements should only take place following meaningful public consultation with service users and the people in their support networks.

# 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. Participants summarised the impact of good PA support as follows:

*“My PA is lovely, and they understand my needs and how to help me.”*

*“It is the best thing I have done. I now get support when I need it and my PAs are chosen by my family and I. [...] I would highly recommend.”*

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. 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”. Most people strongly agreed or agreed with that statement.

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 Highland, 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.

Several participants commented that they have found it increasingly difficult to recruit suitable personal assistants and agency care workers alike. Problems with high turnover of staff, especially those employed through agencies, was a key theme when it came to factors that made SDS challenging for people.

Overall, almost every interviewee spoke of a sense of trepidation or fear about being left with inadequate or unsuitable care, due to problems with staff recruitment or retention. Many people also highlighted that they had lost good PAs and care workers to other jobs – in some cases because staff employed by

some agencies were on zero-hour contracts, were not paid for travel time between clients' houses, and did not receive sick pay. Participants expressed sympathy for staff who had moved on to other work, but also reflected on the stress that high staff turnover caused, with correspondingly variable standard of care.

One impact upon participants who were not able to access suitable carers was the pressure this can put on unpaid carers, friends, and family relationships. People spoke of spouses taking on too many caring responsibilities during retirement or while working, and the negative impact this had on their health. Parents of disabled children, in particular, voiced concerns about what would happen when they are no longer able to provide unpaid care, as current levels of support via SDS are inadequate without unpaid care. One stated that:

*"I'm constantly fighting them. All is happening is [Name] is going*

*further and further downhill. It's a waste of time. It is making me ill because I'm constantly worrying about knowing that there is something that could help. The whole point of SDS was [...] that one day [Name] will be able to look after [themselves]."*

Several people also commented on the need for care workers to receive appropriate specialist training. Some respondents suggested they would welcome more support from NHS Highland and Highland Council regarding PA recruitment, training and continued professional development. One respondent spoke warmly of existing support – and highlighted that people should make use of available assistance:

*"Don't be afraid to call brokers or SDS providers and ask lots of questions. Make use of help with interviewing or use established agencies."*

**Care Staff Recruitment, Training and Quality:** Some people would welcome more support with PA recruitment, training and continued professional development. Highland 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. 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. 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 Highland 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 Highland 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 Highland.

## Independent Advocacy

Several survey respondents commented on the value of independent advocacy when accessing SDS. One person stated that others should “definitely access advocacy services to know all the facts” when accessing SDS. Another recommended that people should “make sure that you have a witness and preferably an independent professional with you during all contacts” with social work.

One interviewee stated that making complaints or challenging practices (informally or formally) had been publicly discouraged by NHS Highland. According to the interviewee, NHS Highland was quoted in the local media as stating that service user complaints were negatively impacting upon frontline staff, such as community nurses and health workers.

Many of the respondents shared experiences of using independent advocacy services to challenge needs assessments/review decisions. One participant experienced a substantial reduction in their SDS package, which then failed to meet their support needs

– with very little notice. They were supported by independent advocacy in challenging their treatment by NHS Highland – support which they stated was key to regaining suitable care provision. The interviewee reported that during this period, NHS Highland, social work, and their care provider became hostile towards their advocate.

Other participants also brought up the value of independent advocacy and third sector organisations in accessing SDS. One summarised their advice to others on this count:

*“If you’re having trouble with social work, get yourself an advocate. I think that’s the first thing I would say. I think it’s vital for people to have someone to speak for them, and to research.”*

## Independent Advice and Support

When asked whether access to independent information and support made SDS easier for them, people responded in a positive fashion. 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 “have someone with you for support [during needs assessments], someone who can articulate your feelings/needs.” Another suggested that people seeking to access SDS should “get independent information and raise

concerns if too many ‘limitations’ are put on the direct payment.” A different respondent stated that people should “always have a witness and get in writing what [they’re] offered.”

### Peer Support

Several people in Highland 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, and combats isolation. One participant suggested that it is valuable for people wishing to access SDS to “speak to real people who are going through it, consider all options, [...] and take any help and advice.” Another respondent stated that they highly recommended “speak[ing] to somebody that is already using it if you can and see what works for them.”

In addition to using independent advocacy to challenge decisions, two interviewees discussed their involvement with peer support networks for similar activities. One participant outlined that they participated in a local SDS user support group. This group had assisted various people to access SDS or to challenge decisions to ensure that they receive person-centred support.

### Independent Advocacy and Support:

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

# Response from the Highland Health and Social Care Partnership

Highland Health and Social Care Partnership (HHSCP) welcome the publication of this report into supported people's experience of Self-Directed Support (SDS) in Highland. HHSCP will review the report and its findings to inform important redesign and development work going forward.

Whilst we note the very small sample size which is less than 0.5% of the total number of adults and children in receipt of services within Highland, the report does nonetheless provide valuable insights from people with lived experience of SDS and also highlights some important areas for improvement. The experience of every person counts and we continually learn from all of the feedback we receive.

It is reassuring to hear that research participants acknowledged SDS as important to achieving a higher quality of life and independent living; that several respondents highlighted the positive impact of flexible support; many participants reported positive and favourable experiences of assessments and reviews with professionals; most people felt social work professionals explained matters clearly; many participants felt they had sufficient time to choose their SDS options and most felt involved in all decisions and arrangements about their care and support.

We do note however that budgets, care charges, communication with

social work and waiting times were prevailing themes when respondents discussed concerns with their needs assessments.

We further note that several respondents outlined concerns about their interactions with social work professionals and that a minority of respondents reported practice of significant concern that would warrant further investigation. We treat any allegation of poor practice with the utmost of seriousness. We are aware, from details contained within the report, of two cases that have been subject to complaints investigations and one which was also subject to external review, the learning from which has been shared and has informed social work practice in Highland. Due to respondent anonymity we are not able to follow up with others but we would urge anyone with a concern about the service they or their family has received to come forward with their concerns. Information on how to do so can be found at:

<https://www.nhshighland.scot.nhs.uk/Feedback/Pages/ComplaintsProcedure.aspx>

[https://www.highland.gov.uk/info/670/consultations\\_complaints\\_and\\_compliments/368/make\\_a\\_complaint](https://www.highland.gov.uk/info/670/consultations_complaints_and_compliments/368/make_a_complaint)

The logo consists of a blue speech bubble with the text "My support my choice" in white, bold, sans-serif font. The words "My support" are on the top line, "my" is on the second line, and "choice" is on the third line. There are three small blue circles below the main bubble.

We do consider it important to note that we would have liked to have seen cognisance given to the role of professional assessment. The report highlights the importance of supported decision-making and we recognise that we have more work to do in this area.

Social work is however a complex profession with often competing rights, risks and responsibilities. We work to a number of different statutes and there are times when, for example, although considering all 4 options as part of the assessment process, it may not be appropriate to offer the full range of options according to the criteria as set down in the SDS Regulations or where, for example, to do so would cut across the delivery of other statutory functions such as when we may be operating under Adult Support and Protection, Adults with Incapacity or Mental Health Acts.

In recognition of the challenges and the need to develop practice locally, and taking cognisance of learning from the pandemic, we have, since April 2021, been working collaboratively with a number of partner organisations in the development of an updated SDS Strategy informed by the SDS Change Map, the new SDS Standards and the findings of the Feeley review.

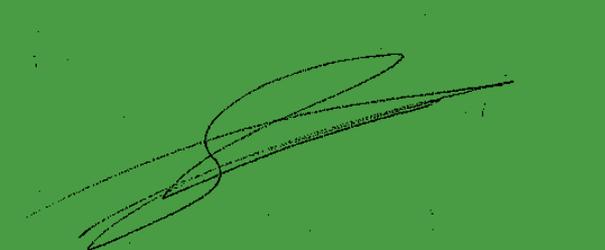
Partner organisations in this work include In-Control Scotland, SDS Scotland, about Dementia and the SDS Project Team from Social Work Scotland in addition to people who had experience of practice locally including a local carer and representatives from Connecting Carers, the Highland Senior Citizens Network, and Community Contacts (our local, SIRD organisation). We undertook significant engagement events with a range of

people including people with lived experience, carers, frontline staff, managers and provider organisations utilising a variety of methods to seek people's opinions and views.

In January of this year Health and Social Care Committee agreed the SDS Strategy for Adult Services and we are now embarking on the important work of realising it and continuing with the collaborative approach that we have adopted to date. This work is progressing alongside other important related initiatives such as the development of Community Led Support. All work is underpinned by important human rights principles and the maximisation of flexibility, choice and control.

In respect of Children's Services, the expectation is that the Draft SDS Strategy will be presented to the Council's Strategic Committee.

Yours sincerely



Louise Bussell

Chief Officer Community Services  
NHS Highland



Fiona Duncan

Chief Social Work Officer  
The Highland Council



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 respondents being discussed in this report (39 participants), we use "a few" to refer to three to five respondents, "several" or "some" to refer to six to ten participants, "many" to refer to 11-19 respondents, and "most", and "the majority" to refer to twenty or more participants.
- 2 Information and documents related to project design and methodology can be found in the national report, available at: <https://www.alliance-scotland.org.uk/blog/resources/my-support-my-choice-peoples-experiences-of-self-directed-support-and-social-care-in-scotland-reports/>. All MSMC reports are also published on the Self Directed Support Scotland website, available at: <https://www.sdsscotland.org.uk/mysupportmychoice/>.
- 3 Health and Social Care Alliance Scotland and Self Directed Support Scotland, *My Support My Choice - People's Experiences of Self-directed Support and Social Care in Scotland - National Report* (Oct 2020); *Women's Experiences of Self-directed Support and Social Care in Scotland - Thematic Report* (Dec 2020); *People with Mental Health Problems' Experiences of Self-directed Support and Social Care in Scotland - Thematic Report* (Dec 2020); *People with Learning Disabilities' Experiences of Self-directed Support and Social Care in Scotland - Thematic Report* (Dec 2020); *Blind and Partially Sighted Peoples' Experiences of Self-directed Support and Social Care in Scotland - Thematic Report* (Dec 2020); *Black and Minority Ethnic Peoples' Experiences of Self-directed Support and Social Care in Scotland - Thematic Report* (Dec 2020). These reports, and an Easy Read version of the national report, are available at: <https://www.alliance-scotland.org.uk/blog/resources/my-support-my-choice-peoples-experiences-of-self-directed-support-and-social-care-in-scotland-reports/>.
- 4 NHS Highland, "Self-directed support consultation to launch" (30 August 2021). Available at: <https://www.nhshighland.scot.nhs.uk/News/Pages/Selfdirectedsupportconsultationtolaunch.aspx>.
- 5 As well as the work of the Care Inspectorate and Audit Scotland noted in the MSMC national report, we note the recent Independent Review of Adult Social Care. See <https://www.gov.scot/groups/independent-review-of-adult-social-care/> and <https://www.alliance-scotland.org.uk/blog/resources/independent-review-of-adult-social-care-in-scotland-engagement-report/>.
- 6 Health and Social Care Alliance Scotland and Self Directed Support Scotland, *My Support My Choice - People's Experiences of Self-directed Support and Social Care in Scotland - National Report* (Oct 2020); *Women's Experiences of Self-directed Support and Social Care in Scotland - Thematic Report* (Dec 2020); *People with Mental Health Problems' Experiences of Self-directed Support and Social Care in Scotland - Thematic Report* (Dec 2020); *People with Learning Disabilities' Experiences of Self-directed Support and Social Care in Scotland - Thematic Report* (Dec 2020); *Blind and Partially Sighted Peoples' Experiences of Self-directed Support and Social Care in Scotland - Thematic Report* (Dec 2020); *Black and Minority Ethnic Peoples' Experiences of Self-directed Support and Social Care in Scotland - Thematic Report* (Dec 2020). These reports are available at: <https://www.alliance-scotland.org.uk/blog/resources/my-support-my-choice-peoples-experiences-of-self-directed-support-and-social-care-in-scotland-reports/>.
- 7 Glasgow HSCP, "Apply for Approval for Social Research". Available at: <https://www.glasgow.gov.uk/article/19154/Apply-for-Approval-for-Social-Research> .
- 8 Scottish Government, *Self-directed Support: A National Strategy for Scotland* (2010). Available at: <http://www.gov.scot/Resource/Doc/329971/0106962.pdf>.

- 9 Health and Social Care Alliance Scotland and Self Directed Support Scotland, *My Support My Choice - People's Experiences of Self-directed Support and Social Care in Scotland - National Report* (Oct 2020). Available at: <https://www.alliance-scotland.org.uk/blog/resources/my-support-my-choice-peoples-experiences-of-self-directed-support-and-social-care-in-scotland-reports/>.
- 10 NRS Scotland, 'Highland Council Profile'. Available at: <https://www.nrscotland.gov.uk/files/statistics/council-area-data-sheets/highland-council-profile.html>.
- 11 Highland is the only Scottish area to adopt the lead agency arrangement for the planning and delivery of integrated health and social care services. For more information, see: <https://hscscotland.scot/integration/>
- 12 Highland Council, 'Self-directed Support'. Available at: [https://www.highland.gov.uk/info/1350/care\\_and\\_carers/425/self-directed\\_support](https://www.highland.gov.uk/info/1350/care_and_carers/425/self-directed_support).
- 13 NHS Highland, 'Search Results'. Available at: <https://www.nhshighland.scot.nhs.uk/Search/Pages/NHSSearchResults.aspx?k=SDS&u=http%3A%2F%2Fwww%2Enhshighland%2Escot%2Enhs%2Euk>.
- 14 NHS Highland, 'Self-directed Support'. Available at: <https://www.nhshighland.scot.nhs.uk/services/asc/sds/pages/welcome.aspx>.
- 15 John Sturrock, *Report to the Cabinet Secretary for Health and Sport into Cultural Issues related to allegations of Bullying and Harassment in NHS Highland* (Scottish Government: 9 May 2019). Available at: <https://www.gov.scot/publications/report-cultural-issues-related-allegations-bullying-harassment-nhs-highland/>.
- 16 *Ibid.*, p. 15.
- 17 *Ibid.*, p. 16.
- 18 *Ibid.*, pp. 70, 73, 76-77.
- 19 *Ibid.*, p. 16.
- 20 *Ibid.*, pp. 76-77.
- 21 Public Health Scotland, Social Care Information Dashboard: <https://scotland.shinyapps.io/nhs-social-care/>.
- 22 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.
- 23 NRS Scotland, "Highland Council Area Profile". Available at: <https://www.nrscotland.gov.uk/files/statistics/council-area-data-sheets/highland-council-profile.html>.
- 24 Public Health Scotland, Social Care Information Dashboard: <https://scotland.shinyapps.io/nhs-social-care/>.
- 25 Scotland's Census (2011), "Ethnicity, Identity, Language and Religion". Available at: <https://www.scotlandscensus.gov.uk/>.
- 26 Public Health Scotland, Social Care Information Dashboard: <https://scotland.shinyapps.io/nhs-social-care/>.

- 27 This was a multiple choice question and some respondents chose more than one option.
- 28 Scotland's Census (2011), "Ethnicity, identity, Language and Religion". Available at: <https://www.scotlandscensus.gov.uk/>.
- 29 Scottish Government, *Poverty and income inequality in Scotland: 2015-2018* (2018), p. 10. Available at: <https://www.gov.scot/publications/poverty-income-inequalityscotland-2015-18/pages/10/>.
- 30 *Ibid.*, p. 1. Available at: <https://www.gov.scot/publications/poverty-income-inequalityscotland-2015-18/pages/1/>.
- 31 *Ibid.*, p. 12.
- 32 Public Health Scotland, Social Care Information Dashboard: <https://scotland.shinyapps.io/nhs-social-care/>.
- 33 Information Services Division (now Public Health Scotland), *Insights into Social Care in Scotland: Support provided or funded by health and social care partnerships in Scotland 2017/2018* (11 June 2019). Available at: <https://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/Publications/index.asp?#2399/>.
- 34 *Ibid.*, pp. 6, 48-60.
- 35 Public Health Scotland, Social Care Information Dashboard: <https://scotland.shinyapps.io/nhs-social-care/>.
- 36 As a term that is still widely used, some MSMC respondents referred to "respite". We use "short breaks" in place of "respite" in this report, following discussion elsewhere by unpaid carers and carer organisations about the unhelpful definition of respite as "a short period of rest from something unpleasant". For example: [www.collinsdictionary.com/dictionary/english/respite](http://www.collinsdictionary.com/dictionary/english/respite).
- 37 Care Inspectorate, *Thematic review of self-directed support in Scotland: Transforming lives* (2019). Available at: <https://hub.careinspectorate.com/media/3676/thematic-review-of-self-directed-support-in-scotland-transforming-lives.pdf>.
- 38 Sturrock, *Bullying and Harassment in NHS Highland*, p. 16.

## 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 individual and community assets, helping people to stay well, supporting human rights, self management, co-production and independent living.
- Champion and support the third sector as a vital strategic and delivery partner and foster better cross-sector understanding and partnership.



## 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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