My Support My Choice:

Black and Minority Ethnic People's Experiences of Self-directed Support and Social Care

Thematic Report, December 2020

Self Directed Support Scotland
the organisation of choice

ALLIANCE
HEALTH AND SOCIAL CARE ALLIANCE SCOTLAND
people at the centre

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Acknowledgements and Dedication

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

About this Report

This report uses data[1] about Black and minority ethnic people[2] who participated in "My Support, My Choice: User Experiences of Self-directed Support in Scotland" (MSMC), a research project run by the Health and Social Care Alliance Scotland (the ALLIANCE) and Self Directed Support Scotland (SDSS), funded by the Scottish Government.

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

COVID-19

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

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

Executive Summary

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

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

This document is part of a suite of MSMC reports and focuses on the experiences of Black and minority ethnic people who use SDS/ social care in Scotland. Between November 2018 and February 2020, MSMC heard about the experiences of 25 Black and minority ethnic people via a survey and focus groups. Research took place prior to the appearance COVID-19 in Scotland, and this report does not reflect people's experiences during the pandemic.

Black and minority ethnic people who participated in the research acknowledged SDS/ social care as important to achieving a higher quality of life and independent living. However, it is clear from the research that there are barriers that prevent Black and minority ethnic people from enjoying equitable access to culturally appropriate SDS/ social care. Improvements can be made that would respond to people's concerns, build on 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.

Data Gathering and Analysis

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

Information About SDS

When exploring how people first found out about SDS, it was evident that the majority of Black and minority ethnic participants did not have a clear understanding of SDS, although they did know what support they received in practical terms and whether it met their requirements or not. None of the Black and minority ethnic survey respondents received information about the four SDS options in advance of their needs assessment, and many focus group participants said they had never heard of a needs assessment. Those who said they felt best prepared for an assessment usually credited an independent organisation for providing the information. Several people said they struggled to access documents and information in their first language, even after requesting accessible materials from social work or medical professionals.

The majority of Black and minority ethnic research participants recounted mixed experiences of their needs assessments. Only one Black and minority ethnic survey respondent stated that they had discussed all four SDS options with their social worker during their needs assessment; most of the focus group participants stated explicitly that either none, or some but not all, of the four options were discussed with them.

Recommendations include ensuring that people have access to face-to-face communication with social work and high-quality information at an earlier stage, to find out about SDS/ social care and before deciding how their support will be arranged. Information should be provided in multiple languages, and a range of accessible formats, and people should have ready access to independent advocacy and foreign language translators for meetings with health and social care professionals.

Informed Choice and Control

Black and minority ethnic participants indicated a preference for shorter waiting times. Many focus group participants had waited longer than six months for a needs assessment or a review, and some had waited over a year. Timely support would help Black and minority ethnic people avoid reaching crisis point and the need for more intensive and expensive intervention later on.

Only one Black and minority ethnic survey respondent said they chose the way their support was arranged and who managed their budget; the rest said that social workers or medical professionals chose the way their support is arranged. Most Black and minority ethnic people we spoke to were not aware that they were able to choose a specific SDS option, or indicated that they were offered a reduced range of options, or reported that they had no choice at all and were simply informed about their care arrangements. Based on these findings, more work is needed to ensure Black and minority ethnic people have a meaningful choice of all four SDS options and are supported to make this decision rather than having it made for them.

The research also suggests that more work could be done to ensure Black and minority ethnic people receive adequate, person centred and rights based care and support.

Conversations and Relationships with Social Work

Participants highlighted that good, consistent, trusting relationships with social workers and clear lines of communication are all essential for positive and effective experiences of SDS. Black and minority ethnic research participants who were happy with their conversations and relationships highlighted the importance of social workers having a breadth and depth of knowledge of SDS and local services, and praised the listening skills and empathy of professionals who took the time to listen and become familiar with their requirements.

Some participants, however, described less positive experiences, reporting that conversations felt rushed and that social workers did not explain the process around SDS clearly to them in a way they could understand.

Cultural Awareness and Equality

Some Black and minority ethnic research participants reported that a lack of cultural awareness and accommodation was an important concern. Issues were highlighted in relation to social and care workers' lack of understanding of people's cultural contexts and assumptions based on people's ethnicity. Specific examples that were given included lack of awareness that some cultural practices discourage explicitly indicating what assistance is required; eating and food preparation; personal care; and communication gaps. Although rare, some people shared troubling stories of being treated with disrespect by social work or social care professionals, including racism. Work is required to ensure that Black and minority ethnic people have equal access to cultural appropriate SDS/ social care. No-one should have to deal with racist or discriminatory attitudes or behaviour and appropriate training in equalities, human rights and bias should be provided to professionals on an ongoing basis.

Black and minority ethnic participants indicated their desire for greater transparency about what to expect from SDS and social workers, SDS eligibility criteria, how care decisions are made and by whom, alongside inclusive communication and easy access to information. People reported difficulty obtaining paperwork and documentation concerning their care arrangements, even after repeated requests to social work departments, and difficulty obtaining information about how to lodge formal complaints. Social work professionals should ensure they proactively gather feedback from service users and their families, and inform people about how they can challenge decisions, and access independent support and complaints procedures.

Impact of SDS on Family / Relationships

Adequate person centred, rights based support via SDS can be instrumental in improving people's family life and relationships. Several Black and minority ethnic focus group participants emphasised the positive aspects of SDS for their whole household. However, others shared experiences of negative impacts, particularly when there was not enough support in place to meet the service user's requirements. Black and minority ethnic participants highlighted the importance of social workers not assuming that family members can and will provide unpaid care – or that the service user wishes to be reliant on family members and friends.

Care Staff Recruitment, Training, and Quality

Black and minority ethnic participants reported mixed experiences of support worker recruitment, training and quality, and several indicated difficulties finding and retaining personal assistants and care workers that were suitable for their requirements, as well as the positive impact of good support workers. Participants suggested that they would welcome more support to arrange staff training and recruitment from the local authority or relevant support organisations – particularly around questions of diversity and cultural sensitivity training. Black and minority ethnic research participants also indicated their desire for a more culturally diverse social care workforce.

Independent Advocacy and Support

Black and minority ethnic participants value and benefit from the provision of independent advocacy, independent advice and peer support networks. As well as ensuring that these services continue to be sufficiently resourced to carry out their vital work, participants said they would welcome greater signposting to support organisations working with Black and minority ethnic people.

Recommendations

As this research highlights, there are key areas where improvements could be made to respond to Black and minority ethnic people's concerns, build on existing good practice, and increase the effectiveness and reach of positive SDS experiences.

Data Gathering and Analysis

1. 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 SDS/ social care.

Information About SDS

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

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

4. Work should be done to dismantle communication barriers faced by Black and minority ethnic people and older people. People in specific ethnic minority communities would benefit from targeted initiatives on information.

5. People's socioeconomic status should help inform tailored communications.

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

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

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

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

10. Black and minority ethnic people should be informed about all four SDS options, rather than being given information about a more limited list of options.

11. People should be supported to consider the advantages and disadvantages of each SDS option before making decisions.

12. Parent/guardian unpaid carers, who often need support with accessing and understanding information about SDS, should be

encouraged to complete carers' assessments and support plans.

13. If emergency support is put in place following hospital discharge, people should receive follow-up information and conversations to ensure that the original arrangements continue to suit their needs and preferences.

14. Professionals should (be able to) spend more time reviewing case notes before meetings and reviews/assessments and getting to know the people they support.

15. Professionals should proactively check back in with people after assessments to ensure any outstanding concerns are addressed.

16. Black and minority ethnic 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.

17. Black and minority ethnic people should always have access to independent advocacy and support, including translators, for assessments and review meetings, if they desire.

18. 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.

19. Everyone must have access to information about the budget available to them and specific work may be required to ensure this extends to all population groups including women and people living in areas of deprivation.

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

Informed Choice and Control

21. Systems could be improved to guarantee short waiting times – for a needs assessment, review, or for support to be put in place – to help Black and minority ethnic people avoid unnecessary stress and anxiety, deteriorations in their physical and mental health and wellbeing, and from reaching crisis point and the potential for more serious and expensive intervention later on.

22. People have the right to expect a reasonable notice period for needs assessments or reviews.

23. More work is needed to ensure everyone is offered and can make their own meaningful choice between all four SDS options.

24. Professionals should be trained in supported decision making to help reduce the number of cases of substitute decision making where they choose the SDS option and/or who manages personal budgets instead of the service user.

25. Targeted efforts are required to ensure people of all ethnicities enjoy equal decision making about their SDS option and support.

26. Professionals should provide people with up to date lists of service providers in the local area, as well as contact details for other forms of support (e.g. housing assistance, occupational therapy). This list should be provided in accessible formats.

27. Black and minority ethnic 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.

28. Health and social care staff should consider the possibility of mental health crisis if changing packages and eligibility criteria and be able to arrange reassessments and signpost support services where needed.

29. People need flexible budgets and a focus on outcomes to enable them to live as independently as possible. Flexibility is required in a range of ways: from the flexibility to change SDS option, to being able to choose how and when to spend personal budgets, with different amounts of spend and support at different times of year.

30. Flexible, regular access to respite should be strongly encouraged because it is an essential element of SDS that results in good personal outcomes for people who access social care, families and unpaid carers.

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

32. Professionals should consider equality assessments in their processes – both for service users and their families.

Communication and Relationships with Social Work

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

34. 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.

35. People should be informed if their social worker changes and have a right to request a new social worker if trust breaks down.

36. 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.

37. Appropriate training and ongoing support on equalities, human rights, intersectionality, conscious and unconscious bias and anger management should be provided to social work staff at regular intervals.

Cultural Awareness and Equality

38. Targeted initiatives are required to ensure that Black and minority ethnic people have access to culturally appropriate SDS/ social care.

39. Existing equalities and human rights training and (Continuous Professional Development (CPD)) for social work and social care professionals should be reviewed to ensure that diversity and cultural sensitivity training is provided and includes hearing first-hand from Black and minority ethnic people (as well as theory).

40. Action is required to ensure that no-one experiences racist or discriminatory attitudes or behaviour from social work professionals, and Black and minority ethnic people should be treated with dignity and respect.

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

42. 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).

43. 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.

Impact of SDS on Family/ Relationships

44. Professionals should ensure that all unpaid carers are offered carers’ assessments and have their rights explained to them.

45. Professionals should not assume that family members and friends are able or suitable to provide unpaid care.

46. Professionals should respect service users’ preferences if they do not wish to be reliant on family members and friends for their care and support.

Care Staff, Recruitment, Training and Quality

47. Some people need more help from local authorities and health and social care partnerships to recruit and train care staff. Local authorities 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.

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

49. Social care and social work professionals should be trained to support and acknowledge the concerns of people who have had traumatic or poor experiences with social care in the past.

Independent Advocacy and Support

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

51. Focused efforts are required to ensure older people and Black and minority ethnic people are aware of – and can access – independent advocacy and support services.

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

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

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

55. Local peer networks should be encouraged and supported.

Research Participants

The MSMC project heard about the experiences of 25 Black and minority ethnic people. Nine people completed the survey and 16 participated in focus groups.

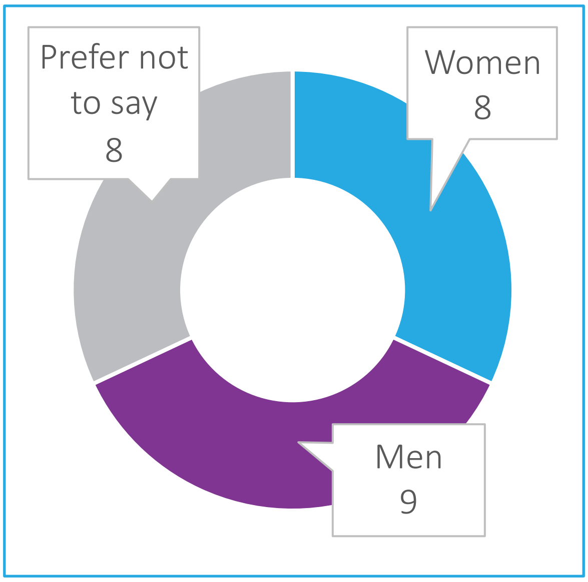
Throughout this report some participant details (e.g. age) have been changed slightly to preserve participant anonymity, while maintaining the most important information. Where changes have been made to quotations those alterations are indicated via square brackets (e.g. "My advocate, [Name], has been great").

Where possible, we have compared our participant data to figures from Information Services Division's (ISD) experimental statistics on social care in Scotland.[4]

Gender

Overall, eight women and nine men from Black and minority ethnic groups participated in MSMC. Eight people preferred not to disclose their gender.

Chart 1: Respondents' gender

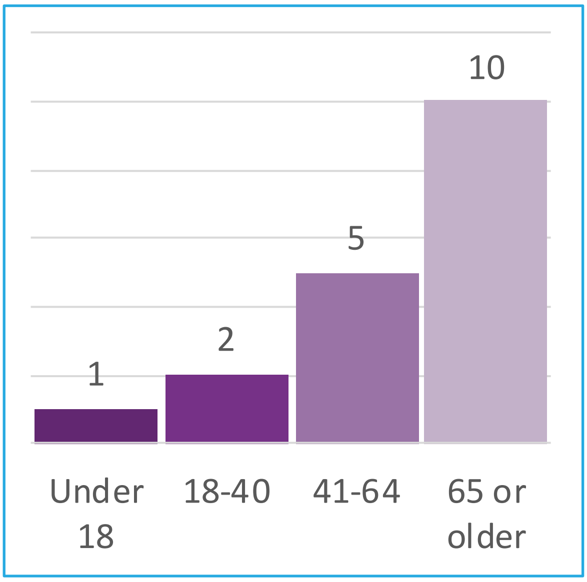


ISD figures for 2017-18 are not available for women and men accessing SDS, however they do publish statistics on the number of women and men accessing social care support services more generally – of whom an estimated 45% access SDS – although not every local authority submitted gender disaggregated data. ISD report that in 2017-2018 62% of people accessing social care support were women and 38% were men.[5] Gender disaggregated data of Black and minority ethnic people who access SDS for 2017-18 is not available on the ISD dashboard.

Age

We asked all participants to share their age. Of the participants who chose to answer the question, one respondent was under 18 years old, two were between 18 and 40 years old, five were between 41 and 64 years old, and ten were 65 or older. Seven people preferred not to share their age.

Chart 2: Respondents' age



ISD do not provide an overall breakdown of age groups accessing SDS for 2017-18, although age group data is provided by SDS Option Chosen and Client Group Profile. ISD provide age disaggregated data on people receiving social care support services more generally (of whom an estimated 45% access SDS) – although not all local authorities submitted data on age to ISD. ISD report that in 2017-2018, 77% of people accessing social care support were over 65 years old, 20% were aged 18-64, and 1% were aged under 18 years.[6]

Ethnicity

In the MSMC survey, people were asked to identify their ethnicity using the following descriptors: white, Asian, Asian Scottish, Asian British, African, Caribbean, Black, Black Scottish, Black British, mixed or multiple ethnic groups, other ethnic group, and prefer not to say.

429 people who completed the MSMC survey identified as white, four people as "Asian, Asian Scottish, or Asian British", three as "mixed or multiple ethnic groups", one as "African, Caribbean, Black, Black Scottish or Black British", and one as "other ethnic group". 22 people chose not to describe their ethnicity.

The representation of MSMC respondents is slightly less diverse than the overall Scottish population. The 2011 Scottish Census indicated that 92% of the population of Scotland identified as "White: Scottish" (84%) or "White: Other British" (8%), with a further 3.3% selecting "White: Irish", "White: Polish", "White: Gypsy/ Traveller" or "White: Other white". The remaining 4.7% of the population identified as being part of minority ethnic groups: 3% of the population identified as "Asian", "Scottish Asian", or "British Asian"; 1% as "African, Caribbean, or Black", 0.4% as "mixed or multiple ethnic groups", and 0.3% as belonging to "other ethnic groups".[7]

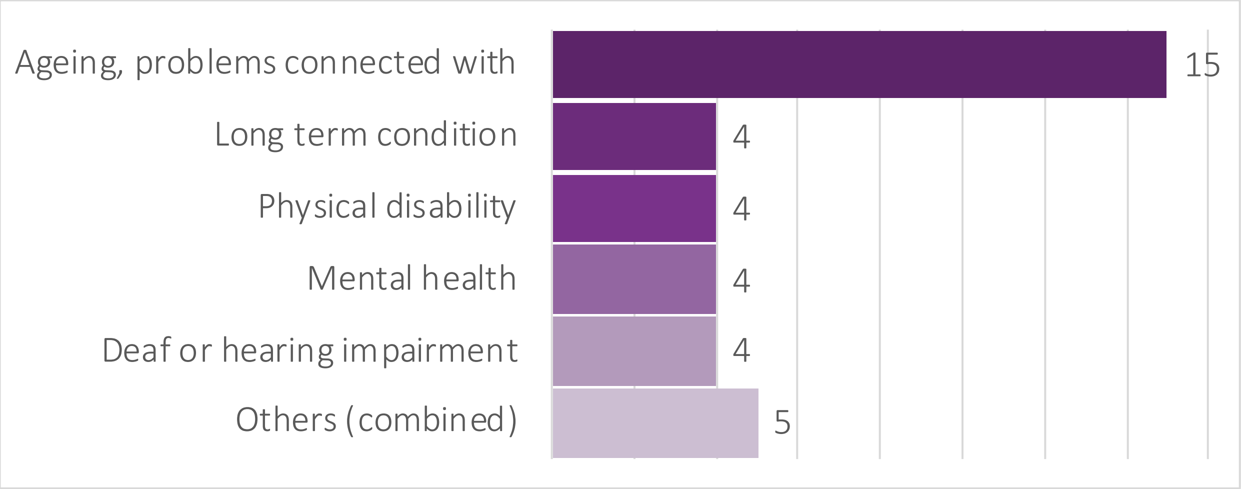
ISD do not provide a disaggregated breakdown of the ethnicity of people accessing SDS for 2017-18. They have some disaggregated data on the ethnicity of people receiving social care support services more generally (of whom an estimated 45% access

SDS), using the limited categories of “White”, “Other”, and “Not provided/ Not known”.[8] Not all local authorities submitted data on ethnicity to ISD. Of those local authorities that did submit information, ISD report that in 2017-2018 71% of people accessing social care support were “White”, 28% were listed as ethnicity “not provided/not known”, and 1% categorised as “Other” (including “Caribbean or Black, African, Asian and Other Ethnic Groups”).[9]

Client Group/Disability/ Long Term Condition

Black and minority ethnic research participants indicated that they live with a range of conditions, with the majority reporting that they live with multiple conditions. 15 people stated that they live with age-related conditions, four selected “mental health”, four are D/deaf, four people described themselves as physically disabled, and four reported that they live with a long term condition. The majority of the 25 Black and minority ethnic research participants indicated that they access SDS in part due to multiple conditions.

Chart 3: Respondents’ client group/ disability/ long term condition



ISD list the following client groups for people accessing SDS in 2017-2018: frail/elderly, physical and sensory disability, learning disability, dementia, mental health, other, and not recorded.[10] These broad categories do not directly align with those tracked in MSMC, and not all local authorities submitted data to ISD. As with MSMC, people could feature in more than one client group simultaneously. Overall, ISD estimate that 47% of people accessing SDS did so because they were “elderly/frail”, 35% due to a physical or sensory disability, 10% because of a learning disability, 8% due to dementia, 7% as a result of their mental health, and 17% for “other” reasons. A further 8% did not have their reason for accessing SDS recorded by the local authority (not including those that did not submit data).

Religion

When asked about their religion (if any), survey respondents were fairly evenly divided between Church of Scotland, Roman Catholic, other Christian, Muslim, no religion, and those who preferred not to say. Focus group participants referenced care and social workers' understanding of a range of world religions as important to their experiences of social care but did not explicitly disclose personal religious beliefs to the research team. These results are slightly less diverse than 2011 Scottish Census data for Scotland.

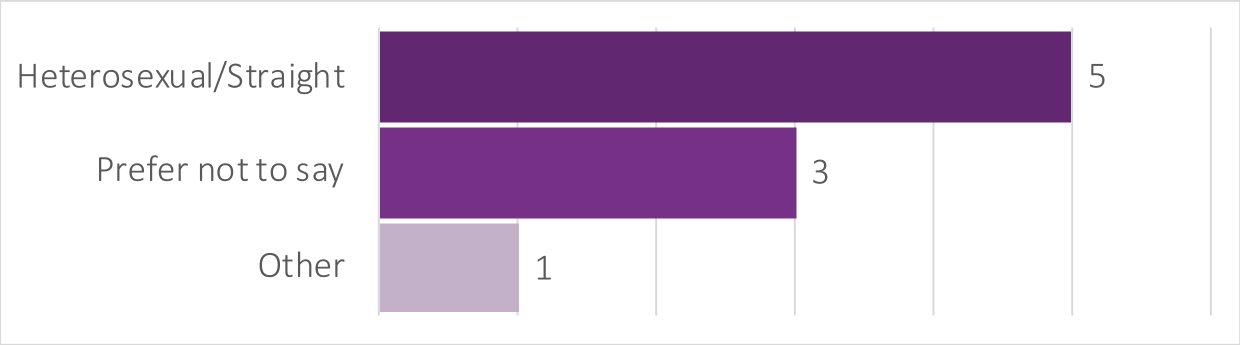
Data on people's religion for 2017-18 is not available on the ISD dashboard.

Sexual Orientation

Five Black and minority ethnic survey respondents described their sexual orientation as heterosexual or straight, one person selected "other sexual orientation", and three people preferred not to answer the question. None of the focus group participants explicitly disclosed their sexuality when self-describing themselves. The 2011 Scottish Census did not record data on sexual orientation at local authority level (although the 2021 Scottish Census is expected to); as such, we do not have local statistics on sexual orientation available as a comparison.

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

Chart 4: Survey respondents' sexual orientation



SDS Option

Most of the Black and minority ethnic focus group participants did not know which SDS option they used, if any (although they did receive social care support); and several expressed considerable confusion about the four options. One person stated that they used Option 1, one person reported they used Option 3, and one person was appealing the outcome of their latest assessment. A further four people were awaiting a decision following a recent needs assessment; when asked which option they would prefer, one person stated Option 1, one Option 2, one Option 4, and one person did not specify their preferred option.

Figures from ISD indicate that in 2017-2018 there were 8,390 people in Scotland using SDS Option 1, 7,435 using Option 2, 78,054 using Option 3, and 4,257 using Option 4.[11] 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 on the SDS options chosen by Black and minority ethnic people is not available on the ISD dashboard.

Data Gathering and Analysis

As this chapter demonstrates, there are concerning gaps in SDS data gathering and analysis. Information Services Division (ISD) have reflected on difficulties gathering disaggregated data on people's use of and experiences of SDS/ social care in their experimental statistics publication Insights into Social Care in Scotland.[12] 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.[13] Data gaps are also in part due to existing patterns of data collation – leading, for example, to the ISD Social Care Information Dashboard tracking ethnicity via the limited and problematic categories of "White", "Other", and "Not provided/ Not known".[14]

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

Information About SDS

Finding Out About SDS

In the survey and focus groups we asked respondents how they first found out about SDS. In exploring this topic, it was evident that the majority of the Black and minority ethnic people who took part in MSMC did not have a clear understanding of SDS – although they did know what support they received in practical terms, and whether it met their requirements or not.

One participant reflected that uncertainty about SDS/ social care was common amongst Black and minority ethnic people, stating that:

> *"The first question is that people don't even know how to get in touch with social work or find a social worker. Most ethnic minority people do not know who to contact and where."*

A different respondent also framed these difficulties explicitly in terms of cultural context and ethnicity. They concluded that:

> *"I think mostly, especially for ethnic minority people, nobody knows, nobody gets in touch with them, nobody asks them. There are different barriers and different issues – that needs to be highlighted. When you do the [MSMC] report, it needs to be part of that. These are people who are English speaking – there are many, many people who do not speak the language, they will never know who to contact,*

> *where to phone, what they get or don't get. Just think about it, their situations, where they're just left, in such a dire situation sometimes. I think there are very extreme cases as well. These are people who can speak on behalf of their communities as well as themselves, but it has to be highlighted."*

Several older Black and minority ethnic people spoke of their confusion regarding the overlaps between Free Personal Care and SDS, and what was covered within social care support more broadly. Key questions that people raised are as follows:

> *"Some people, like dressing and toileting, that's free. But if you need somebody to cook a meal or clean, that you have to pay for, is that right?"*

> *"I wonder, is social care providing toileting services? If people have double incontinence, it's very hard for the carer, the lifting and changing. Can you get toileting services from the social work?"*

> *"It's only for over 65s. If they're fit enough, they don't get anything. When do you decide? It seems that you have to decide at some point Self-directed or whatever choice, [but] none of us know what life will be like in our future. Is it to be decided before it happens? I am almost 79. Is this the time, or when my ability goes really low, I can decide then? Will it be changeable, or once I decide I have to stick to it?"*

Those that had been knowingly introduced to SDS had first heard about it via a range of information sources: social workers, medical professionals, friends and family members, information leaflets and posters, and social media.

Amongst older participants, several offered input on how they would seek information about social care support. Friends and family (including extended family living outwith Scotland) were many people's first port of call, followed by medical professionals. One ethnic minority respondent, whose spouse accessed SDS (which they described as "very, very good"), first engaged with social workers for their own care following a referral from their doctor. Several other participants also stated that their first action should they need social care support – specifically in times of crisis – would be to contact their GP. One participant summarised their approach as follows:

> *"You can also ask your GP, because there will be a social work team connected to them, your doctor. When I have problems, my [spouse] is very ill, and I just saw the doctor and said, 'this is a crisis we're in and I don't know where to go'. And I don't think it's my responsibility to search the internet to find help."*

However, the same person reflected that following contact with a GP, accessing information to obtain support is not easy. They went on to explain that in their experience, "you speak to ten people and they all tell you, 'it's not me, it's somebody else.'"

Finding Out About SDS: The research indicates that work is needed to ensure Black and minority ethnic people, including those currently accessing social care, are fully informed about services and support. It would be helpful to widen the pool of professionals who are informed about SDS and can encourage Black and minority ethnic people to access it. Making more use of health and education professionals would be particularly valuable, as well as building on the existing expertise of social workers, independent advice and support organisations. Greater use of health professionals in the process would also help to strengthen the integration of health and social care.

Information and Preparedness Before Assessments

We asked survey respondents how much information they received on each of the SDS options before meeting with a professional to discuss their support, and whether it was enough information for their needs. None of the Black and minority ethnic survey respondents had received advanced information about the four SDS options before meeting with a social work professional.

Many Black and minority ethnic participants who currently access SDS stated that they had never heard of a needs assessment. In terms of getting in touch with social work, one person who received social care support stated that they "don't know what it means to have a social worker."

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

One focus group participant summarised their thoughts on the information provided on SDS as follows:

> *"Sometimes I don't understand the logic. The government, the local authority can support family and friends to care for the person, because some people need 24/7, and we understand nobody is going to be there 24/7, but there are other people who want to help, and can provide that help, but they're not supported. So, it would be helpful if they explained to us the four options, because people get confused about that. Somebody I know was told that they need to be an [Option 1] employer, and they said, 'I can't manage all that paperwork.'"*

People spoke eloquently about receiving insufficient information about SDS – even when in receipt of services – stating that "there's a lack of clarity on what people want and what people are given. It's not clear, what they get, and what they want or need." Another person stated that the process for accessing support was unclear, but that this was compounded by variance across different geographical areas:

> *"I get the impression that there's a stage before that sometimes with us understanding what this is all about. It depends on the local authority you're in, the services*

you get – so we all get pieces of information, but to put them together like a jigsaw I think we need more distance. For example, people who stay with families, who are looked after by families, don't have the same kind of people coming in to help them, and in some cases there is no support at all. Because you have to fit in with the final package – as in, it doesn't have to be appropriate for you, it's the same one that's decided for everybody and you kind of have to fit in with that. So I don't know – […] I find it very confusing."

Another participant, who is over 65 years old, echoed the above comments about some people not having the capacity – or the responsibility – to carry out online research about SDS. They stated that they "don't want a helpline", and that they preferred face to face communication. They went on to point out that:

> *"On top of that many people don't have access for the computer. How then do you check online? Online, not everybody comfortable there. It's very difficult for ethnic people, especially our generation. When we came here we didn't study here, we didn't have access, or very few – so we can't really manage it. We need help. Also language."*

Several people reported that they struggled to access versions of documents and information leaflets in their first languages – even after requesting accessible material from social work or medical professionals.

Information and Preparedness Before Assessments: These findings indicate that Black and minority ethnic people still require better advance information and support to feel prepared for needs assessments. Comprehensive, high-quality information in a wide range of accessible formats and languages should be pro-actively provided to people about the different SDS options, carers' assessments and support plans. The benefits of earlier high-quality information include: early intervention, before people reach crisis point and reduced demands on staff time because people are better prepared for discussion and assessments. Information about SDS for older Black and minority ethnic people should also include clear explanations of social care support more broadly and Free Personal Care. People whose SDS starts following discharge from hospital should receive follow-up information and discussions once support is in place, to ensure that the original arrangements continue to suit their needs and preferences.

Information During Assessments

This pattern of variable information about the four SDS options continued into people's needs assessments. We asked Black and minority ethnic people whether all four SDS options were discussed with them when they met with a professional to discuss their support needs (e.g. a social worker/ social work assistant or an occupational therapist). Only one Black and minority ethnic respondent stated that they had discussed "all four options" with their social worker during their needs assessment. Most Black and minority ethnic participants stated explicitly that "none" of the four options were discussed with them, or – in some cases – some but not all options were discussed, and they would have welcomed more information.

While some people discussed constructive and positive relationships with social workers, the majority of participants recounted mixed experiences with their needs assessments or reviews. Several people reported ongoing uncertainty about how much support would be provided in arranging care packages with the different SDS options, and what choices were available to them.

Information During Assessments: Social workers and other professionals play an important role in informing, influencing and implementing decisions about social care, and they are often many people's first port of call for information about SDS, including eligibility criteria, wait times and available support. The research indicates that further work is needed to ensure that Black and minority ethnic people are fully informed about the four SDS options during assessments and given the opportunity to consider them. For some people, information is best provided face-to-face, more than one conversation may be needed, and people should have access to independent advocacy and support and foreign language translators during these meetings if they want. People should always have access to information in a range of accessible and inclusive communication formats in advance of and during meetings.

Outstanding Concerns and Appeals

We asked Black and ethnic minority participants whether they have any concerns that were not addressed during their last assessment. One person indicated they are currently appealing a decision about their support, while others said that they had done so in the past. Of those people with unaddressed concerns, budgets, delays in implementing care, and a lack of information about SDS and wider social security entitlements were the main issues – with people highlighting that these 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 to strengthen and embed existing good practice to ensure that Black and minority ethnic people are not left with unaddressed concerns following needs assessments. People should be provided with alternative, accessible communication routes, in multiple languages – like online chat functions, a freephone support line, and providing direct email addresses – that would allow them to follow up and have questions answered at a later date if it is not possible during meetings. Social work professionals should proactively check in with people after assessments to address any outstanding concerns.

Informed Choice and Control

Waiting Times

Black and minority ethnic focus group participants indicated their preference for short waiting times and commented on problems caused by long waits for needs assessments or access to support. Many Black and minority ethnic focus group participants had waited longer than six months for a needs assessment or review, following a request for support, and some had waited over a year. Some people commented on additional waiting times that they did not expect – between initial phone contact with social work and assessments; between assessments and decisions on packages and finances; and between decisions and the eventual start of support.

One person reflected on their difficulties in both accessing information about available services, and receiving support:

> *"You're not looking for something for free, you're looking for a trustworthy person. I want the authority to give me a list or anything – even that, of such and such provides this service. But even with that […] it's a long wait. So that's the kind of thing that's frustrating."*

Waiting Times: Short waiting times are important 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 also lead to a deterioration in people's physical and mental health and wellbeing. Timely support can help Black and minority ethnic people avoid reaching crisis point and the potential for more invasive and expensive intervention later.

Choice Over SDS Option and Support

We asked people if they were on their preferred SDS option. Most Black and minority ethnic people we spoke with were not aware that they were able to choose a specific SDS option, or indicated that they were offered reduced choice, without all four SDS options being offered, or reported that they had not had any choice about how their support was arranged and were instead simply informed about their care arrangements. One person summarised their experience as follows: "we didn't have any choice in the matter, as [we] were told it was happening and that was that." Another person reported that in their locality they and their family had been told that SDS was not suitable to support people with dementia, "because people who suffer dementia seem to decline", and were unsure of their options for support after receiving that response from social work.

Only one Black and minority ethnic survey respondent stated that they chose the way that their support was arranged; the remainder reported that social workers or medical professionals chose the option they use and the way their support is arranged. Similarly, only one person (the same individual who chose the way their support was arranged) chose who managed their budget.

Choice Over SDS Option and Support: The research suggests that more work is needed to ensure Black and minority ethnic people are offered a meaningful choice between all four SDS options. Although many people indicated they were happy with their support, Black and minority ethnic people – particularly older Black and minority ethnic people – would benefit from targeted initiatives to ensure that they are fully involved in all decision making processes about their social care and support, and to make sure their questions are answered. While health and social care professionals play an important role in helping people access appropriate services, that should not extend to making decisions on people's behalf – the principles of choice and control are clearly embedded in SDS legislation and policy, and extend to all population groups, including Black and minority ethnic people (with targeted initiatives into individual communities). Staff could be given more training about how to support decision making rather than lead it, and on co-production methods more broadly.

Adequate Support

Several Black and minority ethnic people spoke in detail about the impact on their physical and mental health of substantial reductions to their SDS budgets and support.

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

One participant outlined that after being directed towards Option 3, they then realised how limited the care options available were in terms of timings. As a result of provider availability, they were expected to have care workers get them up and showered at 6.30am each morning and be put to bed at 5pm. The respondent did not feel that this was suited to their lifestyle or their family structure; when they raised this concern and asked for alternative arrangements, their social worker "wrote that [they] declined the service". The respondent went on to state that they "had to fight" this cessation of SDS, stating that "I want you to write that the service you provide is not appropriate. Declining is a different thing altogether from not appropriate."

Another person reflected on experiences of at 12pm still not receiving breakfast or help to get out of bed: "getting the provision, but in a very inappropriate way". Another recounted an experience of a care worker arriving to put someone to bed in the middle of winter, and that it was only on being asked why she had arrived so early that the care worker realised it was 2.30pm. Her response was "oh, blimey, I never realised, I've already put another lady in bed!" While the individual relayed this story with good humour, they outlined the underlying problem with inflexible care provision, and – crucially – a lack of awareness that they had other options.

Other respondents recounted similar experiences ("they used to come for the breakfast at 10am, and at 12pm they'd come and say 'have your dinner now"). People also spoke of how delays and irregular timings caused problems with medications that had to be taken with food, or at set intervals. Some people also linked reporting problems with this sort of service provision to social workers removing SDS, on the basis that the people had declined support – rather than discussing other care options. One respondent summarised their conclusions as follows:

> *"I think when they write the planning service they should write the timings, for at least a week, so that would make it clear that the person hasn't declined, it's the services that are not up to it."*

Several participants stated that once SDS packages were agreed there were still problems for Black and minority ethnic people in terms of the provision of day to day care. One carer outlined their situation as follows:

> *"Even when the services are provided by the local authorities, they're chosen by the person who uses SDS, but the local services it seems they are ignorant about other issues, like the culture and routine. [In specific location] the local authority insists that the elderly must have a shower in the morning. So, the staff comes round about 7am, 7.30am, but the elderly totally feels helpless because [in] our culture, normally we have a bath before we go to bed. So even though she received the service, it seems against her will. But from her point of view she has no choice, because it's provided by the LA."*

Another person spoke from their own experience, where after several months of service provision that did not suit their lifestyle they said "I don't want this service, I will try to manage. Wrong timings, wrong people!" – and they stopped using SDS. A more culturally sensitive approach may have been more successful in providing the respondent with a sustainable pattern of support.

Adequate Support: The research suggests that some Black and minority ethnic people are not receiving adequate or appropriate person centred support. Good quality, adequate support via SDS can be instrumental in improving people's quality of life and plays an important role in helping people enjoy their right to independent living and equal participation in society. The impact of not providing rights based, person centred care can be devastating and it is therefore vital that people are treated with dignity and respect in all interactions with health and social care professionals and that assessments and support are adequate and tailored to people's requirements and way of life, taking into account all clinical, dietary, religious, cultural, or any other considerations based on protected characteristics and other self-identities.

Communication and Relationships with Social Work

Good Conversations and Consistent Relationships

Black and minority ethnic focus group participants indicated that good conversations require effective communication, access to information, prompt decisions, and good future planning. Those who were happy with their conversations highlighted the importance of social workers having a breadth and depth of knowledge about SDS and local services. They also praised the listening skills and empathy of their social workers as key to their positive interactions, along with social workers having the time to listen to them and become familiar with their needs. Some examples of people's positive experiences of conversations with social workers are as follows:

> *"I feel I have a good working relationship with an excellent social worker who does her utmost on our behalf."*
>
> *"If you have a helpful OT or other professional then it's a good system."*
>
> *"It depends on the social worker. Someone nice, sympathetic, [they] listen to you carefully. My social worker was good, but then she left."*

Good Conversations and Consistent Relationships: The research demonstrates the vital importance of good conversations and communication between Black and minority ethnic service users and social work professionals, and there are 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 relationships with social workers, including direct and varied lines of prompt communication available. Overall, we would recommend that work to ensure positive conversations and meaningful, consistent engagement with people should continue, with ongoing planning to guarantee high quality practice for all people using SDS – especially around clear and accessible communication.

Poor Communication and Relationships

Some Black and minority ethnic people described less positive experiences of communication and relationships with social work professionals. Several people reported that they felt that the conversations they had with social work professionals during their needs assessments were rushed, and many stated that social workers did not explain the process around SDS properly to them in a way they could understand.

One person stated that their social worker is “utterly clueless in how to communicate with me”. A different respondent outlined a difficult situation where, during their needs assessment, the social workers did not engage with their views:

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

Similarly, another person found communication with social work difficult when attempting to arrange support. In that instance, the participant’s daughter “phoned the social work, and she asks why I’m not getting it, and waiting and waiting and waiting.” Despite intervention from family members, they found that there was “nobody there to listen to the complaint”, and the individual faced several months of waiting without a support, or the means by which to agitate for assistance.

Poor Communication and Relationships: Examples of poor communication raise concerns about decision making and autonomy; if people’s opinions (spoken or written) are not recorded and acknowledged during assessments, then they cannot be said to control or choose their support. Options for assisting this process may include further training for professionals in communication skills, supported decision making and the SDS options, and ensuring more time is allocated to assessments/review meetings.

Cultural Awareness and Equality

Cultural Awareness and Understanding

Some Black and minority ethnic people reported that a lack of cultural awareness and understanding was a substantial concern – with people highlighting issues with social workers who did not understand people’s cultural contexts, or, in the more extreme examples, social workers who made assumptions about people’s circumstances based on their ethnicity.

Participants discussed the direct and negative impact of miscommunication and assumptions upon their health and the health of the people for whom they care. They offered a variety of examples where social workers’ lack of awareness or understanding of their needs, preferences, and culture caused problems with the implementation of SDS.

For example, people discussed situations where it was not culturally typical or appropriate for them to explicitly state what they needed assistance with – and that this reticence caused problems for them when answering social workers' questions. One person summarised their perspective on this issue as follows:

> *"I think a lot of people do not understand how to answer questions. I think they're so used to saying, 'I'm OK, I'm OK, I can manage'. And if you can't do it, talk about your worst day – don't say 'I can manage'. Social worker comes, they [the person being assessed] start waking up, they start wearing socks, they – I think they feel that they need to show because some stranger comes to the house, they start doing everything they can't do."*

Another person relayed mixed experiences with social workers:

> *"It all depends on the social worker – they can give you [a] good report or [a] bad report. So how can justify? Depending on the social worker, sometimes it's good, somebody come in, and say, 'yes, OK, OK'. And sometimes – this does happen, for religion, culture – the person doesn't agree with that."*

Another person reflected that much of their difficulties in accessing support stemmed from problems accepting and verbalising that they need help:

> *"[My son] said, 'mum, why don't you say when you need help? Ask, don't do things just for your ego. But you're living alone, you need help, you ask someone. We are not here, but you can get help.' But our culture says, 'I'm fine. I'm dying, but I'm still fine.' […] That's how we're acting in our culture."*

Several respondents also referred to their eating and food preparation habits in discussions about choice over support arrangements. One person outlined that they were offered a range of dietary choices by their care provider each week – but that none of them were geared to food commonly eaten by people from their ethnic community:

> *"In the afternoon, I get afternoon tea, the service they have, to give you sandwich or soup or whatever it is. There's a lot of options, and they ask me, 'what do you want?' I give them a week before what I would want that particular day. […] But the point is that if you look at the things that they have written down, the food is not ethnic minority at all. Nothing to do with ethnic minority. The potatoes and veg that you get is all mashed up. Chips are also all mashed up! So, it's very difficult."*

In another example, a lack of cultural awareness was directly connected to reductions in someone's support. During their needs assessment, a disabled Black person was asked by their social worker about their personal grooming – "your hair, is it a wig or not?" Embarrassed by the framing of the question, the individual said "it's my hair", rather than stating that they were wearing a wig. The social worker then commented that "if you've got hair, it looks beautifully combed, so how do you get your hand up?" Embarrassed, the person did not respond to explain that they used a wig and could not raise their arm to arrange their hair. As a result of this interaction, the disabled person had their SDS package removed, as the social worker concluded that if they could carry out hair care tasks they did not require assistance with personal care. The respondent reflected that this problem stemmed from the social worker not knowing enough about Black hair care, framing their question poorly, and "not knowing that sometimes people in self-respect and dignity, they won't say a few things."

Some respondents reflected on the power imbalance between social workers with decision making powers about people's social care support, and Black and minority ethnic people who may not have the language or feel safe enough to challenge decisions. One person stated that there was a lack of awareness amongst social care professionals about systemic inequality:

> *"I think understanding from the community, but also staff, social workers, service providers, this is a big gap. I think they think they're the powerful party and decision making rather than thinking they're providing a service."*

The respondent went on to state that solutions to communication gaps could be found by closer working and consultation between social work professionals, governing bodies, and Black and minority ethnic people. However, they were keen to state that the responsibility for change lies with social work, local authorities, and Scottish Government, not Black and minority ethnic people; it is the State's duty to provide equal service for all people in Scotland, irrespective of their ethnicity (or any other form of intersectionality):

> *"But it is [...] their problem, they need to resolve it. But you can only learn from practice when you meet with them, and understand them, and have empathy with them. This is different, the approach has to be different. There are many problems, but I always say to them it is your problem, sort it out."*

Several Black and minority ethnic participants commented on the need for increased diversity amongst – and training for – social work and social care professionals. One participant reflected on the difficulties of providing effective diversity and cultural awareness training for social care and social work professionals and highlighted the need for in-person training with a diverse body of people, rather than just relying on theory.

A different respondent agreed with the importance of face-to-face training for social work and social care professionals and outlined some examples of good practice that could be usefully extended to other training programmes across Scotland. In particular, they highlighted how some universities assign student social workers to a multicultural family base for a year as part of their placements, so "they do have some idea of equality". However, they also reflected that "if there are specifics, like the bathing, which we know [are culturally specific], then in fact what we've got to say that within social work training for their degrees [...] that these are aspects that need to be considered on the course."

This statement was met with broad agreement from other focus group participants, who also concluded that it was important that social workers – at all stages of their career and training – should "learn to ask", in order to constantly improve their awareness of people's cultural contexts, as "they have to learn from their experiences."

Cultural Awareness and Understanding: The findings demonstrate that work is required to ensure that all Black and minority ethnic people have access to culturally appropriate SDS/ social care. Existing equalities and human rights training and Continuing Professional Development (CPD) for social work and social care professionals should be reviewed, with a view to ensuring that diversity and cultural sensitivity training is provided and includes hearing first-hand from Black and minority ethnic people as well as studying the theory.

Racism and Discrimination

While several Black and minority ethnic people shared their experiences of social workers appearing not to empathise or understand the extent of their requirements, other experiences demonstrated unacceptable behaviour and discrimination. While these accounts were rare, in contrast to the majority of people's experiences, they were important enough to include within this report as examples of poor practice and as part of efforts to improve and ensure high quality care for Black and minority ethnic people across Scotland.

One respondent outlined problems they experienced with social workers, going beyond well-intentioned ignorance or poor training and into discrimination and racism. They summarised that sometimes, in their experience, "it's even more simple; you deal with a social worker who thinks that black people shouldn't be in this country in the first place." They went on to ask: "what mechanism does the department have to detect that, and what role does that have within the service provision?"

Another respondent outlined how their social worker had assumed that because they were part of an ethnic minority community, they must have family networks available nearby who could and would provide unpaid care. They stated that "social workers should judge the situation" on an individual basis, rather than relying on racial stereotypes: "if somebody is living alone, that person needs more help than other people living with their families."

Another participant agreed and raised the same problem. They summarised their experience and perspective as follows:

> *"What strikes me is that [for] people who are poor and are medically poor who start off in trying to access this minefield of services, as you demonstrate, then it becomes more and more cumbersome. The question I have from my own experience is the assumption that you're going to get social workers, a certain number of social workers, who may have racial tendencies – then that will play a part in the level of service they provide. And that's an issue that not only applies to social work but applies to service provision across the board; in courts, in situations and employment with service provision and so on. And I would like to see that issue addressed. For example, are the social workers vetted anywhere along the way as to their attitudes to ethnic minority communities?"*

Another participant raised the issue of structural inequality:

> *"In theory in their training they are supposed to practice equality. They will have read a lot of books, and they will have heard a lot of debates. But in practice it doesn't quite work like that. Studies show that there is embedded racism within the structure, whether they are actually even aware of it, and to what extent any organisation actually takes the trouble to deal with it, or is it two, three tier – not in the mainstream to deal with it. […] Who deals with inequality, like major inequality, in the end?"*

Some Black and minority ethnic people stated that when they requested other social care options, they were often labelled as "troublemakers":

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

Several respondents stated that they would welcome more empathy and respect during their interactions with social work. Furthermore, a small but important number of Black and minority ethnic people discussed the limitations of available feedback and complaint options when they were unhappy with their interactions with social work. Others highlighted the need for complaints processes to be more transparent.

One person stated that "it's important to complain in the higher authority" when social care professionals act in an inappropriate or discriminatory fashion. However, as another person pointed out, complaint is sometimes only possible from a position of (relative) security or privilege:

> *"To be able to challenge, and to complain, you need to be a strong-minded person. In my present state of affairs I can do that very well. But ten or twenty years down the line, when I'm not well, how can I do that?"*

Another participant echoed this point, stating that "people who are capable, can do it, no problem. It is for those who are most vulnerable who are not able to, they won't even know where to start. I think that's the challenging part."

Other people commented that a complaint takes energy and time – and that in addition to that fact, in some cases Black and minority ethnic people also have to deal with being presented as angry stereotypes when they complain or challenge decisions:

> *Respondent 1: Complaining takes a lot out of you. You just get so tired that you just give up. And it's also the fact that you pick up the phone and, 'oh, it's that [Name] again.' So you are aware of that – you reach a point where you have ten cups of tea before you call somebody to complain! […] But I think you have to recognise that complaining is not easy. We give up because the whole process – the energy. By the end of a day […] you're so tired, you don't*

have an ounce of energy left to pick up the phone to somebody.

Respondent 2: And the possibility of being victimised.

Respondent 3: Discrimination as well.

Respondent 4: Yes. So that is why it is far better for somebody from the family, other people, beside you, to complain about it. It's much better.

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

Transparency

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

One key theme around transparency was the need for greater clarity on eligibility criteria for accessing SDS. People noted that while some local authorities share eligibility criteria publicly (either in information leaflets or via local authority websites), this is not the case across Scotland.

In keeping with the reported confusion about which SDS option they used, several Black and minority ethnic people indicated that they would welcome greater clarity around their social care arrangements – in terms of documentation about outcomes, how care is arranged, and how decisions are made (and in what time period). Respondents felt that transparency of process is particularly important when specific types of support are declined, or care arrangements need changed:

> *"When somebody declines [a type of support], and they know their need, there should be in the process why it was declined. The person should be signing, the person who declines. They should be able to see the reason of decline, rather than… it becomes very easy for [social work] to say they declined, they don't need to say why they declined, they can manage. But they don't manage."*

Another participant recounted how when their white spouse had support through SDS, they received a detailed list and rota of what to expect in terms of their support package. In contrast, the participant (who now receives SDS themselves) reported that they have no control over their care arrangements (which sounded to the research team like Option 3). They find it difficult that their care providers keep detailed records of what they have done in terms of care work each day, but that documentation is not shared with the respondent – even though they are expected to sign off on it:

> *"They do that, but I don't see that. They should always get a signature from me to say that they have done that. […] It's very important to have something written down, and you manage to read that, to see when somebody is coming to see you or is somebody not."*

One respondent outlined how:

> *"People don't complain enough, they don't complain about providers. They can say 'we done one thing' and you don't know what they said in their report. I think if you start challenging, if you start saying things, things will only start changing then – not before."*

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

Impact of SDS on Family/Relationships

Black and minority ethnic participants identified a range of ways that SDS has enhanced their lives, including beneficial impacts on family relationships. However, the picture is mixed, with some people reporting that SDS has had a negative impact on family life.

Several focus group participants emphasised the positive aspects of SDS for the whole household, for example family of SDS users able to enjoy retirement or doing activities associated with their own interests, knowing that the SDS user had suitable support. However, not all respondents were positive about the impact of SDS on family life. Those that highlighted problems tended to centre these concerns around budget cuts, which led to increased responsibilities for friends and family as unpaid carers.

Several people shared the negative impacts when there was not enough support in place to meet the requirements of a SDS user. These issues were particularly acute when social workers assumed that family members would be able to provide unpaid care without properly assessing whether that was feasible or desirable for the people involved.

One respondent stated that "even living with the families, the families are working, that can be worse sometimes" – particularly when, as another person pointed out, family members "can't be there all the time" due to other commitments. Another person said that "it's OK when the carer isn't working, but when they work full time, and they have children, and caring responsibilities – it doesn't work."

Several older Black and minority ethnic participants reported that the family ethos found within many of their communities meant that many people required extra help when they took on caring roles – but that this wasn't always provided by local authorities. They summarised their experiences in the following discussion:

> *Respondent 1: I think […] within the ethnic minority community there is an extended family ethos, where we tend to try to look after each other, whereas within the standard system you put your parents away, it's quite normal. So, there's this kind of movement, from the extended family. And the Government has really got to have a good look at that, where it applies, because there's confusion, and people could be suffering because of that.*
>
> *Respondent 2: That's right. It's cultural change which we're not noticing.*
>
> *Respondent 3: I keep saying it, they do not look after anymore, the children are not there anymore, they are working full time – remember, children are going to be in their 50s or 60s, they have grown up children, and they are working full time. They don't have time, they live somewhere else, they have full time jobs, and then they are expected to start. Joint family looking after, it doesn't happen as much. If it does happen it's a lot of strain for families, and for relationships, to do all the work, look after their family, grandparents who do not live with them. So, there are many situations like this.*
>
> *Respondent 1: Actually, you find that elderly people, grandparents, are looking after children, because childcare doesn't work. I know that's across the community, but it's a major issue for elderly people – especially when most of us keep working, your body is already knackered. […] And most people, we're not asking for much – for example, my husband, the budget for him to be in a home is massive. So, he is in our home, because we want him there, but the additional work of looking after him is actually the problem. You know, I can be a cleaner, and cook, and everything – but beyond the duty, the job we normally do as husband and wife, as families, sons and daughters, is the additional job of caring. And that is what the government should be looking at. Someone says the wife is doing it, or the daughter is doing it, there should be a package for that person. […] I think that's really a scandal. I feel that we want to give because we care, and we love the people we're looking after – but they're exploiting us!*

Impact of SDS on Family/ Relationships: Adequate person centred support via SDS can be instrumental in improving people's family life and relationships, however serious problems can arise if support is inadequate or inappropriate. It is essential that social work professionals do not assume that family members will be able to provide unpaid care – or that service users wish to be supported by friends and family. It should not be assumed that Black and minority ethnic people are able or content to move out of their own home and into the home of another family member so that they can be supported via unpaid care. It is also important for professionals to consider conscious and unconscious racial bias when assessing people's right to access support.

Care Staff Recruitment, Training and Quality

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

Staff Recruitment, Retention and Turnover

Several Black and minority ethnic people commented on concerns with care worker recruitment and retention. Many commented specifically on difficulties recruiting people who could understand and respect the needs of Black and minority ethnic people, and their specific cultures (and, more broadly, the limited number of Black and minority ethnic carers and social workers currently working in Scotland). Key comments are as follows:

> *"The problem is there are no ethnic minority carers at all. It's very difficult, challenging."*

> *"I think that social work should employ ethnic minority support workers. My [spouse] suffers*

dementia, […] I look after my [them], but I never feel as if I have a break at all. […] I'd like somebody from an ethnic minority group. I've tried to find a support worker, but my [spouse] won't accept that. I'd like an ethnic minority one, a [specific ethnic group] one. You've got to know the person, but they come in for a few hours. It's very difficult. I tried to get the service but social worker says it's impossible, nobody wants that kind of job."

"Also, when looking for carers, and something we haven't really touched on, is having carers from your own community, who can speak your language – especially if you can't speak the language. There is a lack of ethnic minority community carers. And some people will refuse because they cannot understand, they want to interact with somebody for ten minutes. The only person they see all day! And if that's the case, they come, open the fridge, they make them a sandwich – and they hate eating cold food! And I think there are multiple issues with that as well."

Several research participants spoke of the benefits of being supported consistently by one or two trusted people, and reported problems with high staff turnover.

Staff Training

Another important care consideration for Black and minority ethnic research participants was PAs who are qualified to carry out the specific specialised personal care they need, with appropriate medical training. As indicated elsewhere in this report, several Black and minority ethnic respondents highlighted problems caused by a lack of cultural awareness amongst social workers and carers. People's concerns included service users and carers not sharing a common language, the lack of effective diversity and awareness training for staff, and the practicalities of understanding and accommodating culturally or religiously appropriate food preparation.

Care Staff Recruitment, Training and Quality: Some Black and minority ethnic people would welcome more support from their local authority to arrange PA recruitment, training and continued professional development. It is also evident that some people would welcome improved access to suitably trained and high calibre care workers. While some people are comfortable with the role of employer and have experienced good, long term, working relationships with their support workers, this experience is not universal. This suggests that local authorities should continue to work with Black and minority ethnic people who access SDS/ social care to find ways to improve systems and processes – particularly recruiting a diverse workforce, staff diversity and equality training, and staff retention within the wider social care sector. This support and acknowledgement of variable practice is particularly important when social care and social work professionals are discussing care arrangements with people who have had poor experiences in the past. People have the right to feel safe and respected – particularly in their own homes – and social care workers and professionals across the sector should do all they can to support service users to feel safe, secure, and independent.

Independent Advocacy and Support

Black and minority ethnic research participants 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.

Respondents spoke warmly of the benefits of independent advocacy and independent advice and support organisations – particularly of services centred around Black and minority ethnic people. They also stressed the acute need for people to be able to challenge decisions and inappropriate practices, and to have support in doing so – either from organisations or peer support networks. One survey respondent recommended that people "seek help from an independent support organisation who provide information and support for people looking to get SDS as they are knowledgeable about the process in your area and get support in place."

Another participant stated that advocacy and peer support is "critical" for Black and minority ethnic people accessing social care. They stated that:

> *"I've just helped somebody who'd had their funding removed because of the social worker's report [...] you need somebody there. [...] The matter ended up at the tribunal, and the tribunal decision was based on the – had to negate the social worker's report, because the social worker's report meant that the funding was stopped. And therefore, it is critical that you have some sort of advocacy in order to ensure that the social worker's decisions are valid."*

Meanwhile, some respondents stressed that a further consideration is that "some people don't have anybody" – they may not speak English or have a support network to agitate on their behalf. Similarly, people may feel uncomfortable discussing personal care needs or the details of their health with others – including social workers and staff reviewing complaints. One person outlined this problem as follows:

> *"And self-respect, their dignity! They don't want to share their problems with everybody. So many people who don't have anybody."*

People commented on the value of independent advocacy and having a range of independent advice and support in accessing SDS – but even then they referenced that confidentiality and time to build up trust was important to the success of that support for Black and minority ethnic people. Several people highlighted that they had benefited from the involvement of independent advocacy services during their needs assessment and reviews. Various forms of advocacy were mentioned, ranging from local user-led service organisations to solicitors, and from national legal aid organisations to carers' centres. One respondent made the following statement about their experience of third sector organisations and social care:

> *"I'd like you to put in the report that sometimes we get better care from the voluntary sector than from the government. I am more likely to phone charities than social work if I need even an answer or an explanation. There's so much rhetoric about equality, about diversity – but the gap between the aspiration and delivery is huge."*

Respondents also raised concerns about language within the complaints system, and the need for local authorities to provide translators for Black and minority ethnic people who are challenging decisions or lodging formal complaints – as is the case within the justice system. One participant summarised the need for this service as follows:

> *"At one time we used to get […] a translator in order to help, because people did not understand. I've just had a […] case where the report is that the demeanour and the repetition of questions and answers actually reduced the credibility of the witness. And these are ethnic minority people. So therefore, that has got to be conveyed, that somehow we've got to know what you're putting forward. Also, in fact how can people actually gain redress if something isn't right, or they're not satisfied – where do they go, and to whom? Because we were just talking back and forth if they don't know how to access their rights. Without language, people have no rights. And thus, this is critical."*

Finally, participants also reflected on diversity, representation, and complaint more broadly for Black and minority ethnic people – and on the need for change. One person summarised their position with a call to action:

> *"Ethnic minorities should not be hard to reach. In Scotland, 5 million people. How hard can it be? Especially in a city like [location] as well. I think we need to get over this, establish contact – because it is your job, our job. That area is not touched, care with ethnic minorities is not discussed. We need to get in there; if we don't, nobody will listen to us. It won't change."*

Independent Advocacy and Support: People clearly value and benefit from independent advocacy 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 local authority staff be given more training and information about local independent support and advocacy organisations, so they can more routinely refer people to these resources as part of assessment processes, and recognise the value these independent services can bring to their own work. Focused efforts are required to ensure older people and Black and minority ethnic people are aware of – and can access – independent advocacy and support services. People should always have access to translators if required, and local peer support networks should also be encouraged and supported.

Glossary

Budget / Hours / Package

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

Charging Policy

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

COSLA

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

Direct Payment

See “Option 1”.

Disability

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

Eligibility Criteria

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

Guardian

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

Health and Social Care Partnership / HSCP

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

Independent Advocacy Service / Independent Advocate

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

Endnotes

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

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

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

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

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

6 ISD dashboard, https://scotland.shinyapps.io/nhs-social-care/.

7 2011 Scottish Census, 'Ethnicity, Identity, Language and Religion' (2011). Available at: https://www.scotlandscensus.gov.uk/ethnicity-identity-language-and-religion.

8 https://scotland.shinyapps.io/nhs-social-care/

9 Ibid.

10 ISD dashboard, https://scotland.shinyapps.io/nhs-social-care/.

11 ISD Scotland, 'Social Care Information Dashboard'. Available at: https://scotland.shinyapps.io/nhs-social-care/.

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

13 Ibid, pp. 6, 48-60.

14 ISD dashboard

speak on behalf of people who are unable to do so for themselves.

Independent Living

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

Independent Living Fund / ILF

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

Independent Support Organisation

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

Integration Joint Board / IJB

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

Impairment

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

Local Authority / LA

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

Needs Assessment

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

Option 1 (also called “direct payment”)

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

Option 2

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

Option 3

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

Option 4

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

Occupational Therapist / OT

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

Personal Assistant / PA / Support Worker

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

Personalisation

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

Physical Impairment / Physical Disability

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

Reablement

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

Respite

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

Self-directed Support / SDS

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

Sleepovers

The provision of care and support services overnight.

Social Care

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

Support Plan

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

Support Worker

See Personal Assistant / PA.

Unpaid Carer

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

About the Project Partners

ALLIANCE
HEALTH AND SOCIAL CARE
ALLIANCE SCOTLAND
people at the centre

About the ALLIANCE

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

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

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

The ALLIANCE has three core aims; we seek to:

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

Self Directed Support Scotland
the organisation of choice

About Self Directed Support Scotland

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

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

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