

Older People's Experiences of Self-directed Support

Briefing paper – January 2018

Health and Social Care Alliance Scotland (the ALLIANCE)



This briefing follows the publication of the ALLIANCE's 'Personal Experiences of Self-directed Support' research in May 2017¹.

Introduction

From late 2016 to early 2017, the ALLIANCE carried out a small-scale, mixed methods research project into people's experiences of Self-directed Support (SDS). After a rapid, desk-based research exercise to establish the level of data available about SDS since it came into force in Scotland in April 2014, we conducted an online survey of 102 people who had applied for or accessed SDS, followed by 19 semi-structured interviews.

SDS is defined as “the support individuals and families have after making an informed choice on how their Individual Budget is used to meet the outcomes they have agreed.”² It is aimed at shifting the balance of power from people who provide social care services towards those who access them, including disabled people and people living with long term conditions. SDS is administered by local authorities, who are legally required to offer those eligible a choice of four different options over how their SDS budgets and social care services will be managed.

By looking in greater depth at the responses to our research questions from people aged over 65, we aim to gain a better understanding of how older people engage with and experience the process of SDS. We also hope it will contribute to a growing body of evidence to help improve SDS policy and practice.

Separate sections of this paper look in detail at older people's awareness and understanding of – and satisfaction with – SDS; how they manage their support; and whether it is enough to meet their requirements. The final section sets out a summary of the main findings and our recommendations.

¹ Personal Experiences of Self-directed Support, Health and Social Care Alliance Scotland, 2017
<https://www.alliance-scotland.org.uk/wp-content/uploads/2017/10/ALLIANCE-SDS-Personal-Experiences-of-SDS-Report-2017.pdf>

² Self-directed Support: A National Strategy for Scotland, Scottish Government, 2010
<http://www.gov.scot/Resource/Doc/329971/0106962.pdf>

Foreword

Dr Donald Macaskill, Chief Executive – Scottish Care

Achieving equality ...

When discussions first began in Scotland about the possibility of enabling people who use services and supports to have greater choice and control in the process of decision making around these, two of the core themes that were articulated time and again, were those of **transparency** and **equal treatment**.

These core themes were important in a context in which people who felt that the previous social care system of needs-based assessment had often led to a situation where decisions were being made without clear consistency and those who were able to articulate their wants were better able to get their outcomes met compared to those who were less confident, aware or connected. Very explicitly, Self-directed Support was about making sure that all individuals were treated in a manner that was open and transparent and that supported people in a way which was related to their need to access services and supports.

All that is fairly uncontroversial. The reality of the Social Care (Self-directed Support) Act, however, has been very different. For a manifold number of reasons there has been a process of implementation of this progressive and rights-based legislation which has resulted in some real challenges.

This new briefing report from the ALLIANCE helpfully highlights some of the positive steps which have been taken for some older persons (aged 65+) across Scotland. So, it is good to see that more older people are feeling that they are able to exercise choice and that they are ending up broadly with the sort of supports which they initially wanted. It is good to see, from the cohort studied, that there is a high use of Option 1.

But for Self-directed Support to be the person-centred legislation it seeks to be, for there to be true transparency and equity then this report helpfully suggests specific areas where there is a need for sharper focus and further development.

There is something still not working if according to Scottish Government and Local Authority data, that older people, who constitute the majority of social care clients, are much more likely to choose council arranged services (Option 3). Is this really the exercising of individual choice or is this because there is a lack of accessible information being communicated to individuals at the point of decision-making and choice? Do people really know the range of options and choices open to them? Are those ranges of choice being limited by the way in which supports and services are procured and commissioned? Are local authorities opening up the 'market' to enable people to have real choice?

More fundamentally this report states that it is extremely concerning that half of people over 65 said they did not have enough hours in a day to meet their requirements. Older age necessitates a different approach, a need to develop systems of assessment, guidance and information that are sensitive to the altered nature of decision-making which happens as we get older. But more than all that it also necessitates an appreciation that as we get older we need to be supported in different ways, that independence looks different, that risk has a different shape, and that safety and security feels different. It requires a time flexible, relationship based approach to meeting individual outcomes. We are still working in the world of time and task to meet individual needs rather than forming and paying for relationship based care/support, which is focused around preventative support and the promotion of independence. For this to be happening shines a light on the empirical failure of Self-directed Support for too many older Scots today.

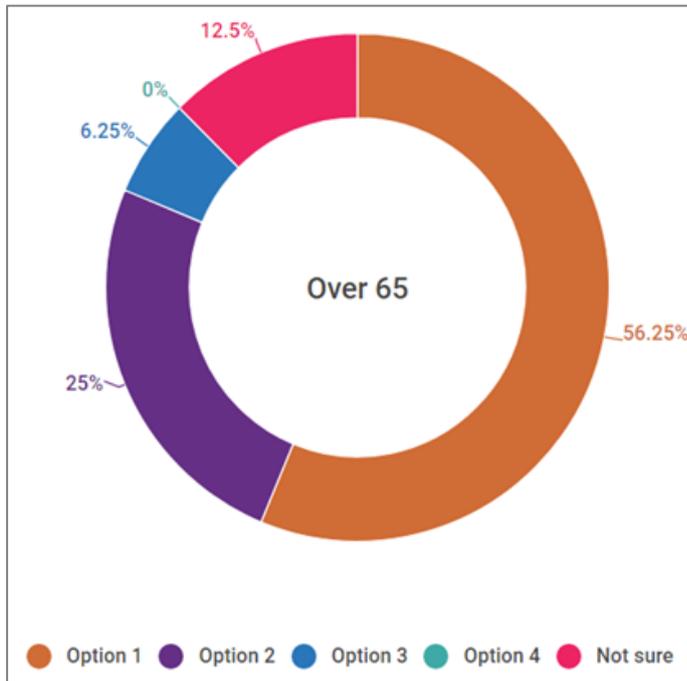
There is still a distance to go to enable a truly transparent system of assessment, information and support planning for older people. The dream of Self-directed Support has still not been achieved, but it is a dream which is still worth the struggle. The alternative is the removal of choice, the limiting of options, the restricting of independence, and a one size fits all approach which is when care and support is decided by another and not fit for 'me'.

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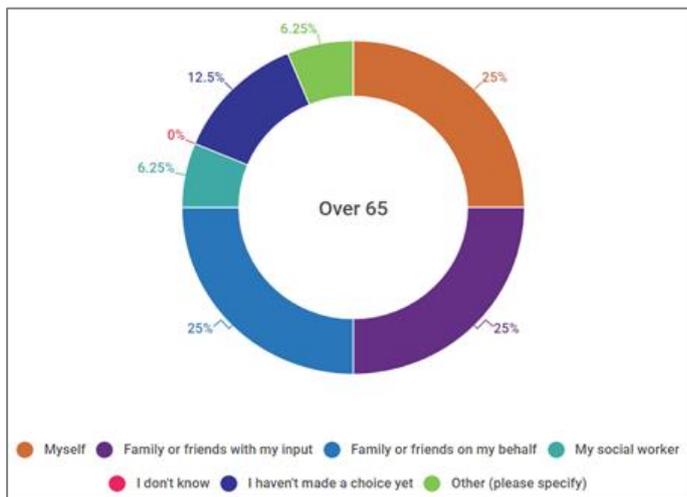
Choosing an SDS option

What SDS option was chosen by or for you?



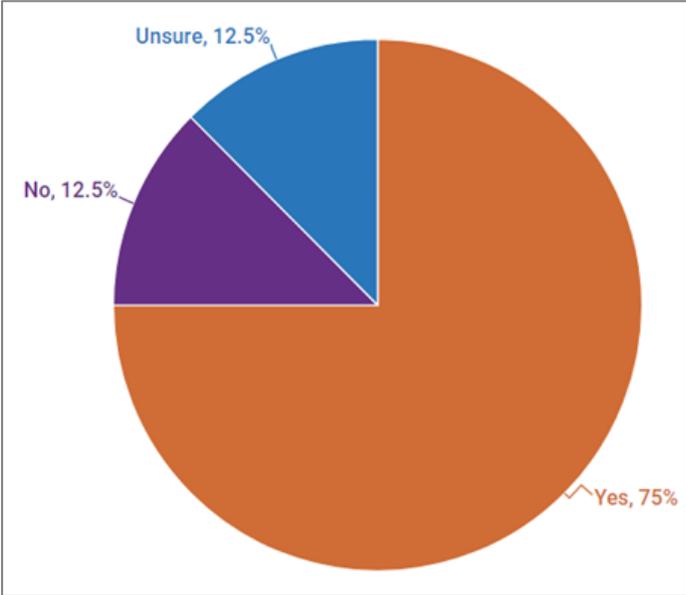
Just over half of our respondents aged over 65 (56 per cent) chose option 1, 25 per cent chose option 2, 6 per cent option 3 and no one chose option 4. 13 per cent of over 65's indicated they were unsure which option was chosen.

Who chose the SDS option?



In general, older people are slightly more likely to have made the choice themselves – either alone or supported – than overall research respondents. 25 per cent of people over 65 chose themselves or with input from family or friends. 31 per cent had the choice made on their behalf by family or friends or a social worker. Older people were more likely than overall respondents to be included in the decision-making process by family and friends (25 vs. 16.5 per cent) and a far smaller proportion had the choice made for them by a social worker (6 vs 15 per cent).

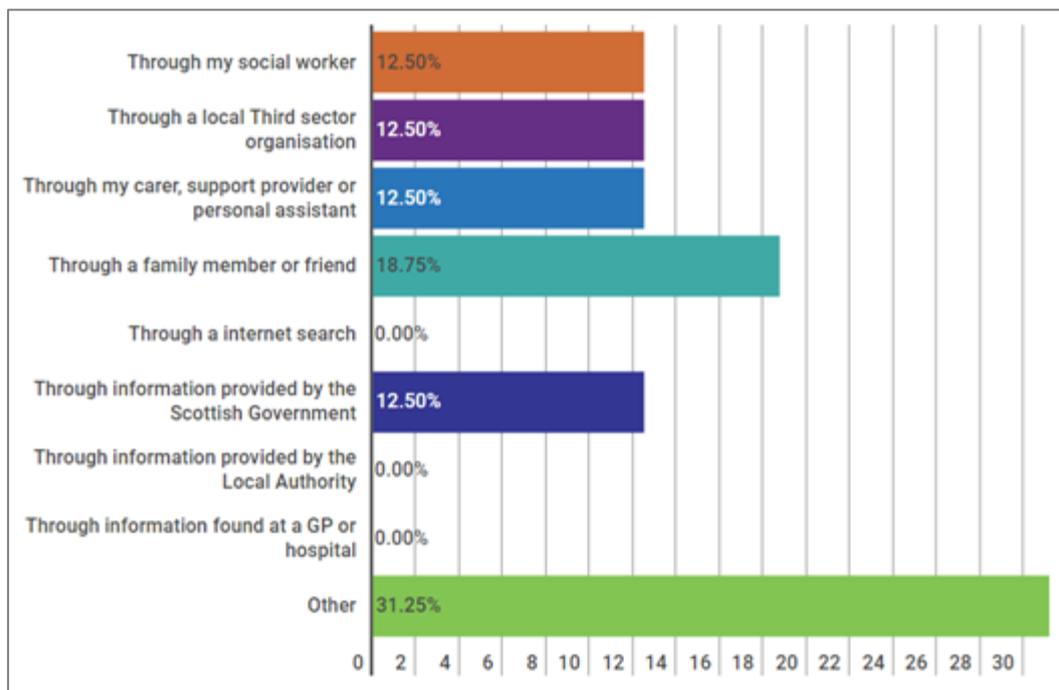
Did you get your preferred SDS option?



A large majority (75 per cent) of older people did receive their preferred choice. This is slightly higher than the 70 per cent of research respondents overall who received their preferred SDS option. Whilst this is an encouraging proportion, a quarter of participants over 65 either didn't receive their preferred choice, or were unsure whether they had or not.

Older people's awareness and understanding of SDS

How did you find out about SDS?



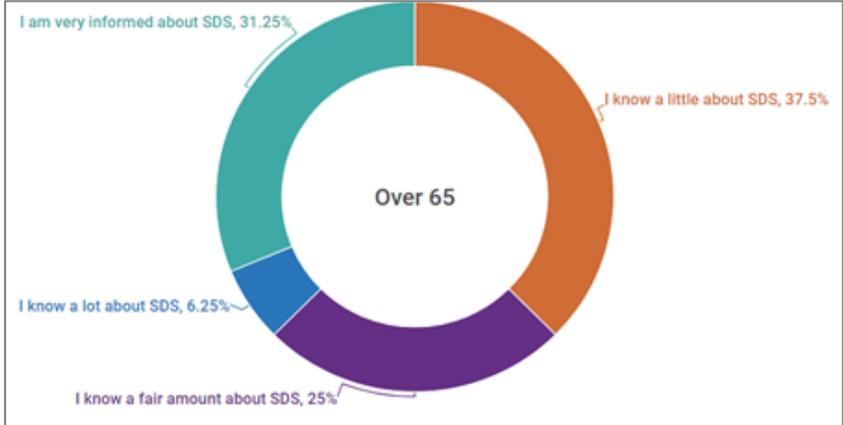
Over 65's predominantly found out about SDS from family members or friends (19 per cent). Meanwhile, an even split found out about SDS from their social worker (13 per cent), local third sector organisations (13 per cent) or carer, support provider or personal assistant. While the 'Other' category accounts for 31 per cent of responses, this only pertains to 5 people's experiences. Of the answers given, 2 people stated that they had been made aware of SDS through Alzheimer Scotland, while the other 3 had personal experience either through work or from caring responsibilities.

While no one over 65 stated that they had heard about SDS through their GP or other health service setting, internet search and information provided by the Local Authority, the descriptions given in the other category suggest that people get information about SDS through health services, find information for themselves through the internet or the Local Authority.

Discussions about SDS with social workers and advice centres

Encouragingly, a large majority (88 per cent) of people over 65 had discussed SDS with their social worker and 50 per cent had been in touch with their local advice centre, while 38 per cent had not. Only 2 people suggested that they did not know if they had a local advice centre.

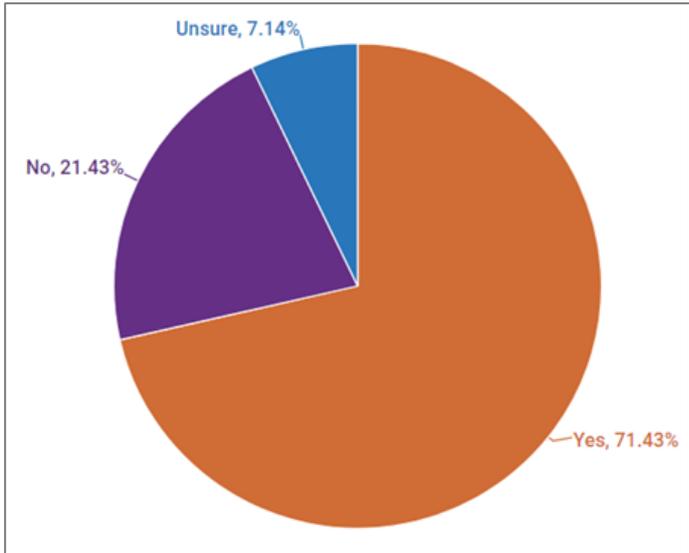
How informed do older people feel about SDS?



Around two thirds of people over 65 (62 per cent) consider themselves well informed. Although this high figure is welcome, it is concerning that there is a substantial minority who do not feel well informed about SDS (38 per cent).

Also of concern is that the proportion of people over 65 who say that they know a lot about SDS is substantially smaller than that of the average research participant (7 vs 21 per cent).

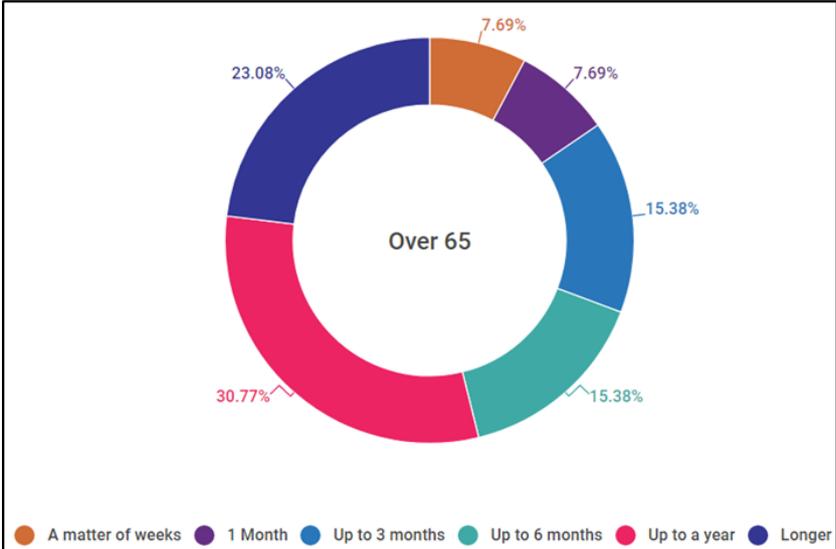
Did the information received help older people choose an option?



Nearly three quarters of people over 65 (71 per cent) felt that the information they received about SDS helped them to choose which option would enable them to meet their requirements. This is a noticeably higher proportion than the average (56 per cent). However, it is concerning that one fifth of people over 65 (21 per cent) said that the information had not helped and 7 per cent were unsure.

Waiting for support

How long did you wait for your SDS package?



It is clear from these findings that people over 65 have waited unacceptably long for support. 53 per cent of people over 65 waited up to a year or more. However, a slightly higher proportion of people over 65 received their support within 3 to 6 months compared to the average (31 vs 20 per cent).

Using and managing SDS

What services older people use SDS for

Type of service	Over 65 (%)
Personal Care	56
Social, Educational, Recreational	38
Other (please specify)	31
Respite	25
Meals	25
Domestic Care	19
Equipment and Adaptations	6
Housing Support	6
Unsure	6
Health Care	0

People over 65 mainly use SDS to support personal care and social / educational / recreational activities. They are less likely to use it for respite (25 per cent), meals (25 per cent) and domestic support (19 per cent). Very few people over 65 used their SDS for equipment, adaptations or housing support. No one over 65 stated that they used their SDS for health care.

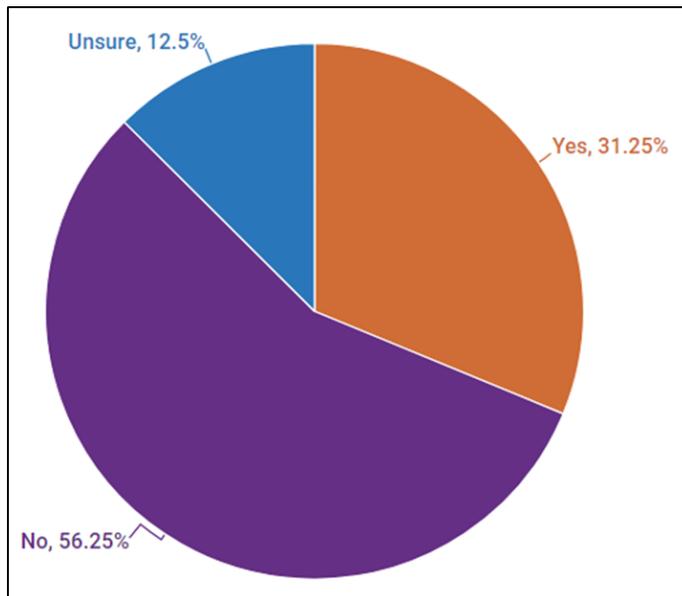
How older people manage their SDS

How SDS is managed	Over 65 (%)
I purchase services from a local private provider	33%
I employ my own PA who I recruited through advertising	25%
My family recruited a PA on my behalf through advertising	17%
I purchase services from a local third sector provider	17%
I employ a family member or friend as a PA	8%
I receive services that I chose from the local authority	8%
I receive services from the local authority that I had before I chose SDS	8%
I use SDS for short breaks	8%
I use SDS to give my family a short break	8%

One third of people over 65 use SDS to purchase services from a local private provider. The second most likely type of support was a PA either employed by themselves or recruited on their behalf. People over 65 are less likely to have continued to receive local authority services and short breaks for themselves or family members after moving onto SDS.

Does SDS meet older people's requirements?

Do older people have enough support to meet their requirements?



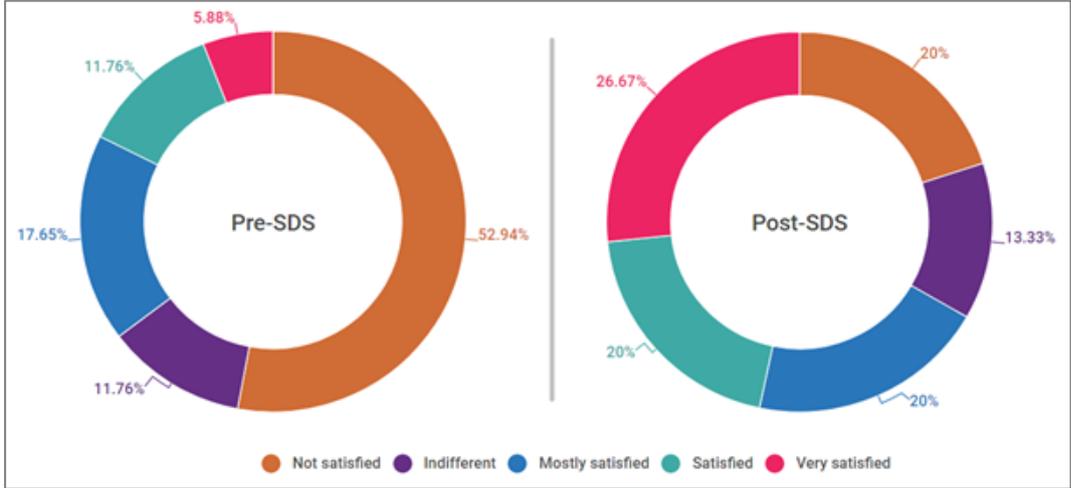
We asked people over 65 to tell us if they felt like they have enough hours to meet their support needs for each day.

We phrased the question like this because although the move to SDS is intended to shift the language from one focused on 'hours of support needed' to a personal outcomes approach, in practice, people still use SDS – as an individual budget – to meet their day-to-day support needs (in order to achieve their outcomes). We wanted to understand whether the support people over 65 receive enables them to meet their requirements, and thus outcomes, with the SDS package they have.

It is extremely concerning that half of people over 65 said they did not have enough hours a day to meet their requirements. This slightly higher than the average (56 vs 49 per cent).

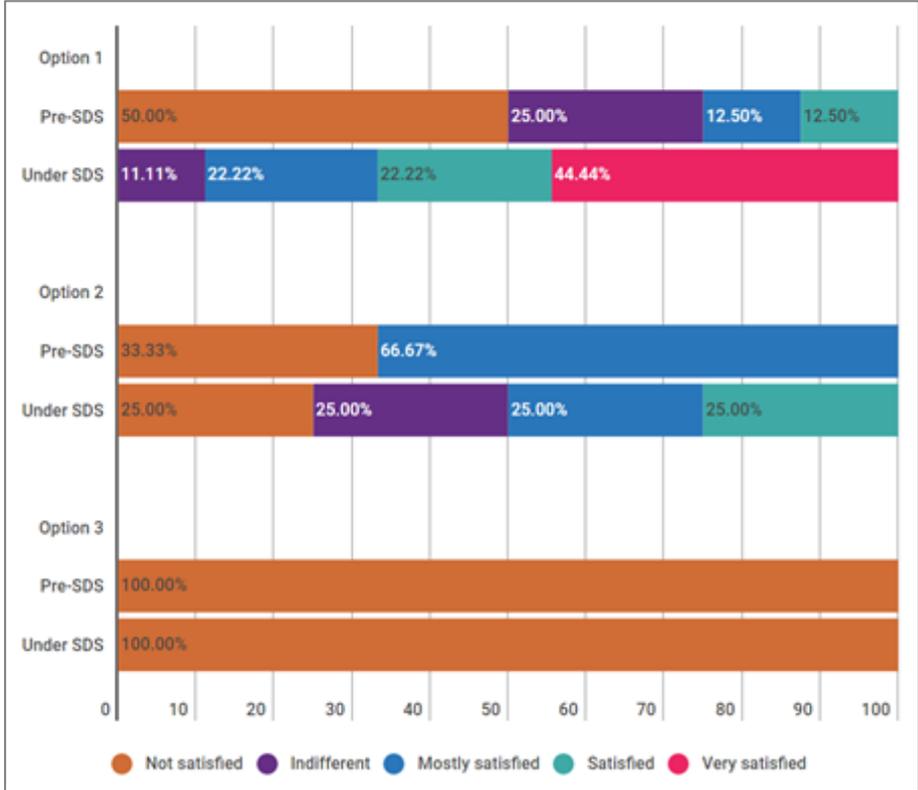
Satisfaction with SDS

Older people's satisfaction with support pre- and under SDS



It is encouraging that people over 65 are more satisfied with their social care support after the introduction of SDS: as the chart shows, dissatisfaction fell from 53 per cent to 20 per cent and rates of indifference remain approximately unchanged. The proportion of people over 65 who felt very satisfied after moving onto SDS increased from 6 to 27 per cent. Overall, people over 65's satisfaction increased from 36 per cent to 67 per cent.

Older people’s satisfaction with support (by SDS option)



Recalling the earlier chart, 56 per cent of respondents chose option 1, 25 per cent chose option 2, 6 per cent option 3 and no one chose option 4. Although the response rate is small, the chart above shows that there is a swing from people over 65 becoming more satisfied with their support after having moved onto SDS options 1 and 2.

Summary of main findings

Uptake of SDS and national evidence

- According to Scottish Government and Local Authority data, older people (aged 65+), who constitute the majority of social care clients, are much more likely to choose council arranged SDS services (Option 3).

Choosing an SDS option

- In the ALLIANCE's research just over half of over 65's (57 per cent) chose option 1, 25 per cent chose option 2, 6 per cent option 3 and no one chose option 4. 13 per cent of over 65's indicated they were unsure which option was chosen.
- 75 per cent stated that they received their preferred choice.

SDS information and knowledge

- Over 65's predominantly found out about SDS from family members or friends (19 per cent). Meanwhile, an even split found out about SDS from their social worker (13 per cent), local third sector organisations (13 per cent) or carer, support provider or personal assistant.
- Encouragingly, a large majority (88 per cent) of people over 65 had had a discussion with their social worker; however, 13 per cent had not.
- Around two thirds of people over 65 (62 per cent) consider themselves well informed.
- Nearly three quarters of people over 65 (71 per cent) felt that the information they received about SDS helped them to choose which option of SDS would enable them to meet their requirements.

Waiting for support

- 53 per cent of people over 65 waited up to a year or more to have their support in place.
- A slightly higher proportion of people over 65 received their support within 3 to 6 months compared to the average (31 vs 20 per cent).

Managing SDS

- People over 65 mainly use SDS to support personal care and social / educational / recreational activities.

Meeting people over 65's requirements

- Half of people over 65 (56 per cent) said they did not have enough hours a day to meet their requirements.

Satisfaction with SDS

- People over 65's satisfaction with social care support increased after the introduction of SDS.

Recommendations

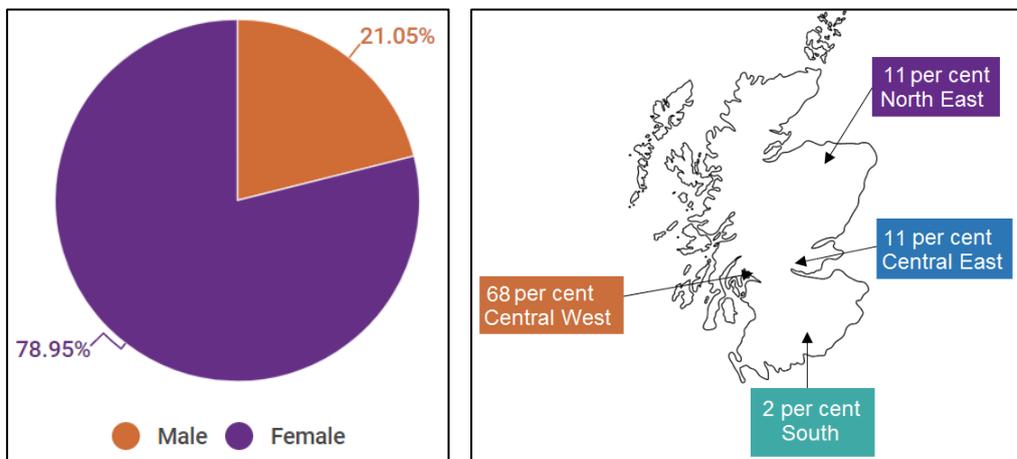
1. We are troubled by reports that half of people aged over 65 do not think their SDS package is sufficient to meet their daily requirements, or are unsure. We encourage the Scottish Government and local authorities to acknowledge the issues with SDS funding and service delivery and work with other relevant stakeholders, including older people who access services and the third sector, to develop solutions.
2. Local authorities must make greater efforts to increase older people's awareness and understanding of – and access to – SDS through their social workers.
3. Despite a rise in satisfaction levels, our findings suggest worrying dissatisfaction amongst some people aged over 65. Further national and regional investigation is needed, and social work departments should be mindful of this when engaging with people aged over 65 about SDS.
4. Social work departments should introduce regular review processes for everyone in receipt of SDS, designed to encourage older people to fully explore all four options to best establish the most appropriate arrangement that meets their outcomes.
5. Social workers should be mindful of the impact people's gender and social care requirements – as well as their age – may have on their opportunities to make autonomous or supported decisions around SDS.
6. Substantial investment in and promotion of local advice and independent advocacy provision should be made to support older people during the SDS assessment process.
7. To gain a fuller picture of SDS, local authorities and the Scottish Government must ensure robust qualitative research is regularly shared on people's personal experiences and their perceptions of the impact SDS is having on their lives, to complement current statistical and financial data.

Appendix 1: ALLIANCE research participants

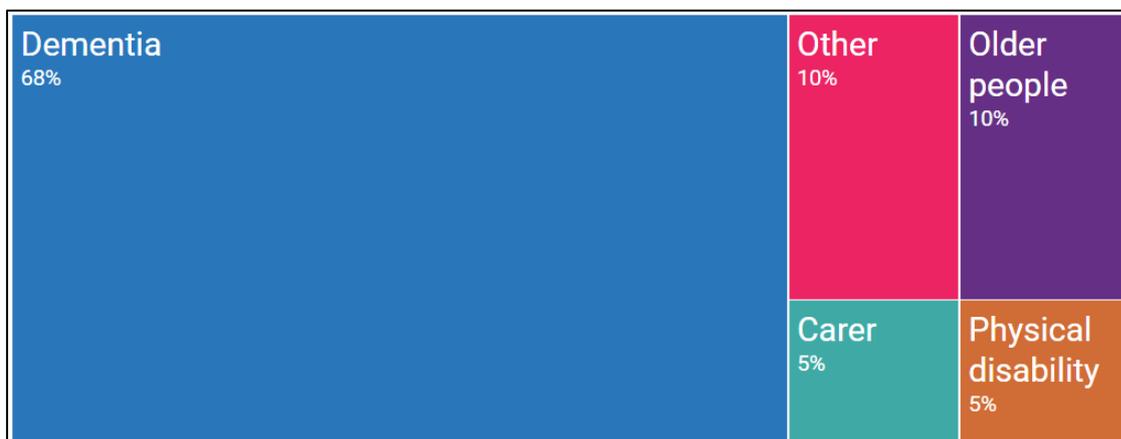
102 people took part in the full ALLIANCE SDS research survey. This briefing relates to the 19 participants who indicated they were aged 65 or over. Given the low number of older participants, the data in this briefing is an overview of the main themes affecting people aged over 65. Resources permitting, the ALLIANCE intends to refine and repeat this research over time; one of our aims is to increase the number of older people who choose to share their personal experiences of SDS with us.

To maximise participation, we enabled people to respond directly or with support: 11 per cent answered the survey themselves and 89 per cent participated with support.

Gender and geographic location of the people over 65 accessing SDS



Category of social care requirement



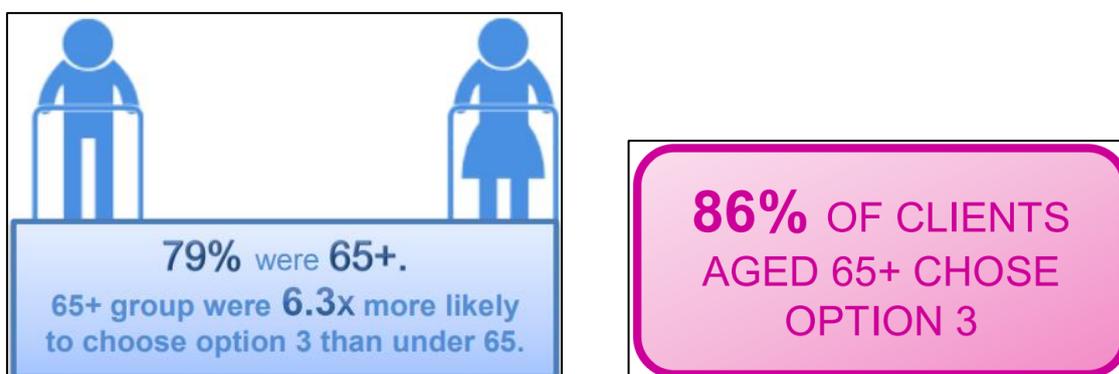
Access to social care before SDS and current SDS status

50 per cent of older participants were already in receipt of social care before accessing or applying for SDS and 50 per cent were not.

Appendix 2: Desk-based research

The Scottish Government's release of the 'Data under Development: Self-directed Support, Scotland, 2015-16'³ looks at the figures of SDS uptake by age. It shows that:

- Of the social care clients, identified as older people, who made a choice regarding their services and support in 2015-16, 6 per cent chose Self-directed Support Option 1, 4 per cent chose Option 2, 86 per cent chose Option 3 and 4 per cent chose Option 4.
- The majority of clients, therefore, opted to retain council arranged services (Option 3) when assessed under Self-directed Support.
- Older people (aged 65+), who constitute the majority of social care clients at 79 per cent, are much more likely to choose council arranged services (Option 3).



Support for older people

Earlier this year, Scottish Care produced the report 'A Human Rights Based Approach to Self-directed Support for Older People'⁴, considering applications of Self-directed Support for older people and its impact on their Human Rights.

In brief, this piece of work evidenced a disturbingly low level of allocation of personal budgets to older people; a lack of awareness on the part of providers as to whether their clients have personal budgets and the complete absence of individual budget allocation for those being supported in residential care.

³ Data under Development: Self Directed Support, Scotland (2015-16), Scottish Government, 2017. <http://www.gov.scot/Resource/0052/00522283.pdf>

⁴ A Human Rights Based Approach to Self-directed Support, Scottish Care, 2017. <http://www.scottishcare.org/wp-content/uploads/2017/08/A-Human-Rights-Based-Approach-to-SDS-for-Older-People-1.pdf>

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. The ALLIANCE has over 2,200 members including large, national support providers as well as small, local volunteer-led groups and people who are disabled, living with long term conditions or providing unpaid care. Many NHS Boards and Health and Social Care Partnerships are associate members and many health and social care professionals are Professional Associates. Commercial organisations may also become Corporate Associates.

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.

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