Self Directed Support User Experience Survey – What people said

Findings from the Self Directed Support Scotland pilot survey of Social Care Users, June 2016

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1 Executive summary

This project was designed as a pilot survey to collect a sample of users' experiences of Self Directed Support in a few regions of Scotland and to find out whether a more extensive survey across Scotland would be useful in assessing how SDS is being implemented and is impacting users across Scotland. The project aimed to find out whether the Social Care users surveyed are getting choice and control over their support under SDS, whether support is tailored to users' needs and whether users are being provided with the information and help they need in order to make choices and feel that they have control over their support arrangements.

Overall the findings from this project indicate that most people who receive a support package are very positive about the support arrangements they have in place and feel that they have choice and control over their support and that it is tailored to their needs. 83% of respondents said they were satisfied with their support arrangements. There is however a low level of understanding among users about the SDS options and a low awareness of SDS itself. Only 44% of respondents said that they had heard that there was a new way to arrange support called Self Directed Support; 33% said that the person who they met to discuss their support needs had not discussed all four of the SDS options with them and 42% said that they had not been informed of their indicative budget. A substantial proportion of people did not know what SDS option they were on, and 34% said they did not feel they understood the options well enough to decide which one they wanted.

People who understand the SDS options and who have had them explained clearly by the person who assessed them are more likely to say that they feel they have choice and control over their support arrangements.

SDS Option 2 appears to be poorly understood by users and very few people are using this option.

49% of people who responded said they received help and advice from someone apart from the person who they met to discuss their support needs.

While the majority of people receiving support through Option 1 were very positive about the level of control and choice they had in setting up their support, a number of problems were

raised with the way Option 1 operates and the burden that the person organising it has to cope with. Several people felt that they had only managed this option because they had already worked in a related field and had previous expertise and felt it would not have been possible otherwise. Some people felt that the organisation was too complicated and stressful, but that they had been forced into taking Option 1 in order to receive the support they needed. Some people who had Personal Assistants (PAs) said that any further support was only considered by the person who assessed them if it would reduce the hours a PA was needed, and more generally several people had found that the assessment process was needs-based on a traditional medical model, rather than adopting the approach intended in SDS legislation that an outcomes approach and flexibility in achieving outcomes should be used.

The results highlight two user groups for whom understanding the options, and gaining choice and control over their support and care are likely to be problematic. These (overlapping) groups are:

1. People who do not have carers or PAs or friends and family to support them.
2. People in the 85+ age group.

Further issues of concern with arranging care under SDS that were raised by respondents are:

- Delays in assessments and in setting up support arrangements, which, sometimes in the context of great need for support can cause extreme stress and practical problems for people.
- Several carers applying for support with respite care had found that the only way they could do this was through SDS Option 1 (a direct payment). This seemed unnecessarily burdensome, complicated and stressful, and these people would have preferred a simpler option for accessing respite care.

2 The project: The research questions, who was included, how we went about it and who responded.

2.1 Project aims and research questions

The project was designed as a pilot survey to find out the experiences of users of Self Directed Support (SDS) since it became mandatory in April 2014. The research questions that the project aimed to address are taken in turn in sections 4 – 9 of this report. They are:

- Are new and re-assessed social care users being given all of the relevant information about options available to them under SDS, and is this done in a way that is supportive and accessible? (Section 4)

- Are people aware of and able to access advice and support from other agencies to help them to make an informed choice and to set up their preferred arrangements? (Section 5 and 6)
- Are people able to access care and support arrangements that are flexible and tailored to meet their own personally-defined outcomes? To what extent are people able to obtain non-conventional forms of social care? (Section 7)

The above three research questions all contribute to the over-arching research question addressed by the project, which is considered in the final section:

- Do people get choice and control under SDS? (Section 8)

Section 4 looks at the outset at the take-up of the different SDS options to set the context for the implementation of SDS. Finally, section 9 presents some further problems and issues in relation to SDS and care and support that were raised a number of times in interviews and responses to the survey.

2.2 Project methods and design

The project involved two stages. In the preliminary stage, eight informal interviews were carried out with SDS users. The interviews served both as a way of testing and developing the questionnaire wording and format, and to provide an informal context in which to discuss users' experiences and develop an understanding of the real life contexts and rationales behind possible responses to the questions in the questionnaire. Interviewees were contacted through the Lothian Centre for Inclusive Living, SDSS, VOCAL (a carers' support organisation), The Advocacy Project, and through informal contacts. Because of limitations of time and the difficulty of accessing more vulnerable people, all of the interviewees had taken up either SDS Option 1 or 4 and were accessed through local organisations. As a result, interviewees include social care users living in Edinburgh and also in East and West Lothian, which meant that users from other areas, as well as those who only receive support through Option 3, were not represented in the interviews.

In the second stage, a paper questionnaire was then sent out to users in three local authority areas: Aberdeenshire, City of Edinburgh and East Dunbartonshire. Local Authorities who participated selected all users who had completed assessments within a period of 3 months up to March 2016.[1] As East Dunbartonshire has a considerably smaller population than the other two areas, their sample encompassed the longer period of 6 months in order to allow sufficient numbers to be returned to provide useful feedback for the council itself.

The questionnaire also offered a link to an online version of the questionnaire, but this was only used by one carer.

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[1] Edinburgh and Aberdeenshire excluded a small number of users who had already been included in their own monitoring exercises, who had been randomly selected.

It is important to note that the survey did not include the following groups, whose experiences of SDS are likely to be distinct from other groups and so are important also to investigate:

1. People who had been offered a support package but not taken it up.
2. Social care users living in residential homes.
3. Children in Edinburgh and Aberdeenshire.
4. People who have applied for support and not been offered it.

Ideally, in further surveys larger numbers of people would be included, allowing for sufficient responses for statistically significant analysis to be carried out. The relatively small number of people surveyed and a fairly low response rate mean this is not possible in this project. It would also have been preferable to have included people assessed over a longer period of time, although this raises issues of memory recall for some user groups, and to weight sampling towards smaller user groups. As the survey only included people recently assessed, it is unlikely to be representative of the experiences of all social care users, but provides a picture of people's experiences of the assessment process in place at the beginning of 2016. Groups such as children and people with learning disabilities and mental health issues are not well enough represented in the results from this project for any meaningful analysis of their responses alone.

1,234 surveys were sent out divided between the three regions as follows: Aberdeenshire: 400; the City of Edinburgh: 634; and East Dunbartonshire: 200.

2.2.1 Language use

SDSS endorses the use of the phrases 'physical impairment' and 'learning difficulty' in preference to 'physical disability' and 'learning disability' respectively, 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.

2.3 Who responded

Response rates varied substantially between the areas, perhaps due to the difference between the cover letters enclosed and slight differences in the questionnaire format. The overall response rate was 18% (226 completed questionnaires returned), with area response-rates: 28% from Aberdeenshire; 18% from East Dunbartonshire and 12.5% from Edinburgh. While this is low relative to other social surveys in general, it is not much lower than comparable social care surveys. The Care Quality Commission in England and Wales for example, carried out a paper-based survey of home care services in 2012 which received a response rate of 21%. There are a number of methods that could potentially be adopted in future surveys to try to alleviate this problem in a larger scale survey with the help of participating local authorities (see methodology report).

Due to the low response and overall number of completed questionnaires, analysis is limited to descriptive statistics and findings cannot be claimed to have statistical significance. This is a problem particularly for analysis within, and comparisons between, user groups which are too small to be likely to be representative of all social care users within that group. Ideally in future surveys, working together with local authorities, minority groups could be over-sampled relative to the larger user groups, in order to allow their experiences to be explored. The small numbers, together with differences between the profiles of users from the three local authorities also mean that comparisons between regions cannot be made.

It should also be noted that with such a low response rate, it is not possible to state with confidence that responses are not biased towards particular user groups who are more likely to respond. Those with help available to fill in the form may be more likely to respond, and indeed a higher proportion of respondents than we might expect say that they had help with filling in the form (72% of respondents who answered the question said that they had some assistance with filling in the form). More generally we might anticipate that people who have a better understanding of the questions, who are familiar with SDS, and people who find completing and sending off the questionnaire easier may be more likely to respond. Findings from this questionnaire are tentative and where problems with SDS are indicated, further research to explore the experiences among the relevant groups is recommended.

It is also important to be aware in interpretation of questionnaire results that causal relationships between variables cannot be shown from this kind of data, but only relationships between variables. So, for example, while people receiving SDS Option 1 (Direct Payments) might in their responses show a greater awareness of SDS, it cannot be argued from this that awareness of SDS leads people to take-up Option 1, as this relationship could also arise if people’s membership of user groups for whom Option 1 is most appropriate leads them to be aware of SDS. Other alternative explanations of the link between these two variables could also be suggested.

Despite the relatively low response rate, the spread of user characteristics represented in the questionnaire response group reflects fairly well those of the social care user population in the 2015 Scottish Social Care Statistics (Scottish Government, 2015).

Looking at respondents’ age (chart 2.1), 39% of respondents were in the 85+ age group and 21% of working age. There were only 3 responses relating to users under 18.

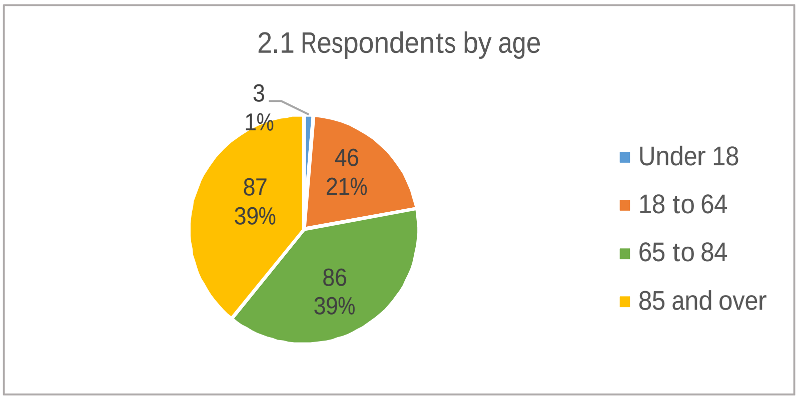
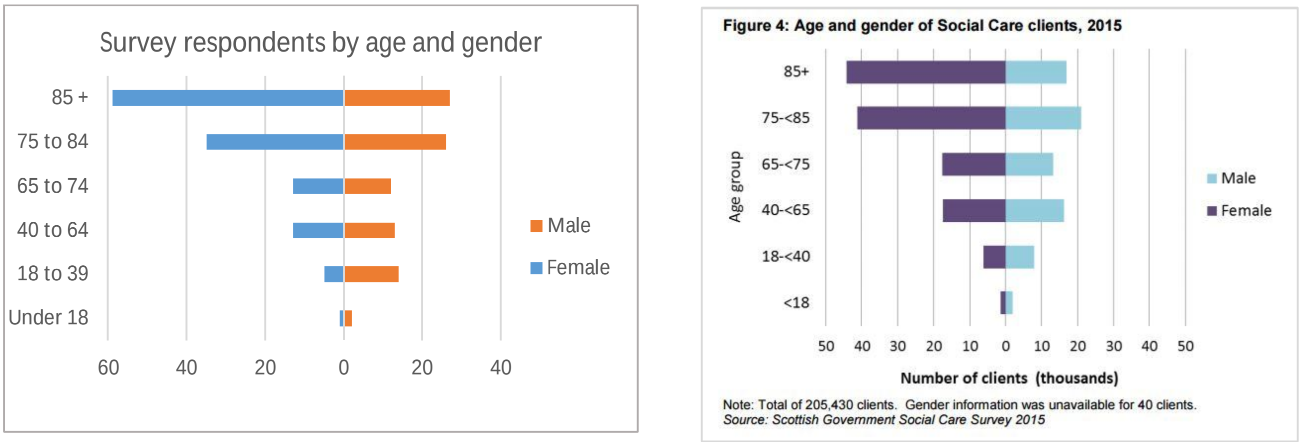


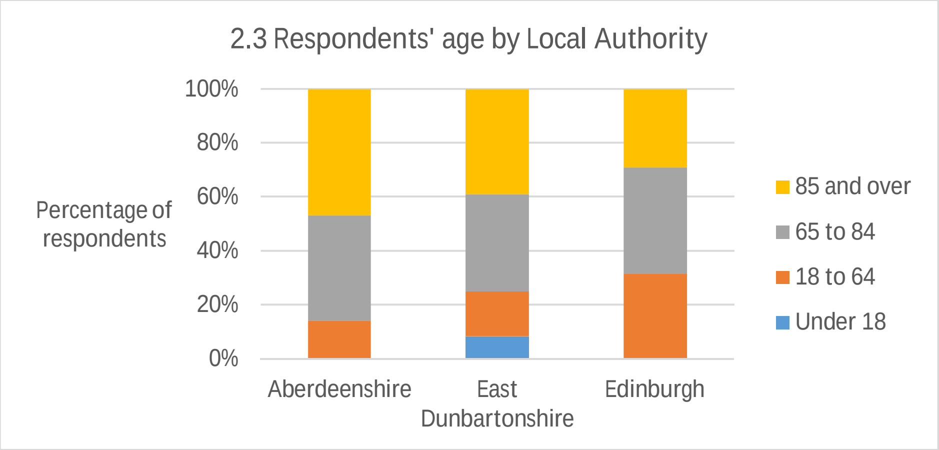
Chart 2.2 Comparison of respondents with Scottish social care data: gender and age



Respondents to this survey

Social care users in Scotland (Scottish Government, 2015)

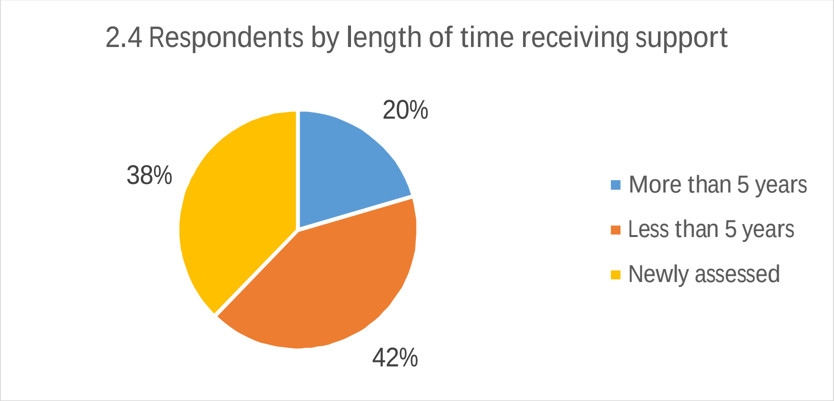
By age and gender (chart 2.2, left hand side) respondents represent a similar overall pattern to that shown for social care users in Scotland overall in the 2015 Scottish Government social care report (shown on the right hand side), but with a greater proportion of women in the 85+ category and a higher proportion of men and lower proportion of women in the 18-39 age group.



A higher proportion of responses were received from people in the 85+ category from Aberdeenshire than in the other two regions and a more substantial proportion of people aged 18-64 from Edinburgh. The 3 responses relating to people under 18 were all in East Dunbartonshire.

City of Edinburgh council supplied us with (anonymised) supplementary data relating to the users to whom they had sent questionnaires. This allowed us to compare respondents' characteristics with those in the targeted population. This comparison for Edinburgh shows that respondents were represented proportionally to the target group in terms of gender. In relation to age group, the response rate was slightly higher among the 65-84 age group than the 18-64 and 85+ groups. 63% of the target population in Edinburgh (those who were sent questionnaires, i.e. users who had completed assessments in the past 3 months) were in the 65+ age group; this is a lower proportion of users than is shown for Scotland as a whole in the Scottish Government Social Care statistics (Scottish Government, 2015) according to which, 74% of home care users are 65+. This is likely to be due, partially at least, to the lower percentage of older people in the Edinburgh population. Mid-year population estimates for 2015 (National Records of Scotland, 2015) indicate that 15% of Edinburgh's population is in the 65+ age group compared to 18% in Aberdeenshire and 22% in East Dunbartonshire. From this it seems likely that among Aberdeenshire respondents the 65+ age group is over-represented.

People who have received support for a long period as well as those who began receiving support in the past five years and newly assessed users are all well represented among respondents. In chart 2.4, 'newly assessed' users are those for whom the assessment completed in the last 6 months was their initial assessment for support.[2]



Responses were divided into user groups, using the Scottish government's categorisation of social care users. As can be seen from Chart 2.5, a much larger proportion of respondents were categorised under dementia and fewer simply as 'frail older people' than in the

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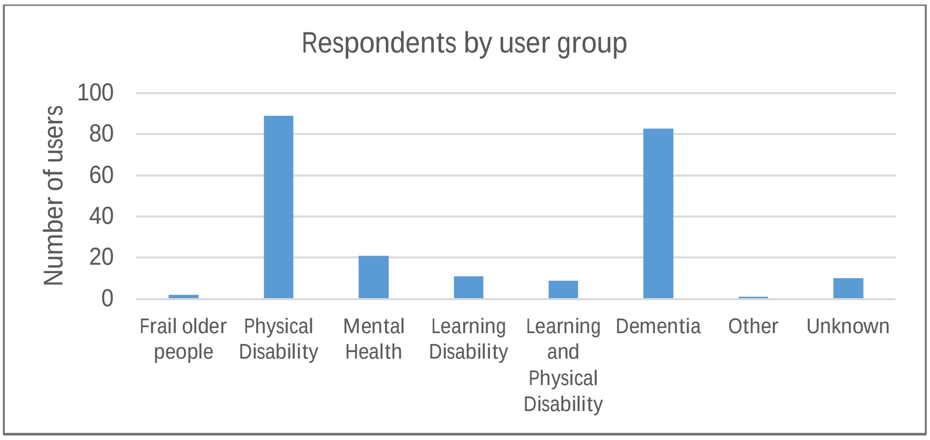
[2] Data is taken from local authority records for Edinburgh and survey responses for respondents from other regions. Survey responses are sometimes inconsistent and LA data is not comprehensive, so this chart should be seen as an indication only.

Government statistics, but the Government report notes that their figures are known to under report dementia and it seems likely that many of those recorded as frail older people in the government statistics have here reported that they have dementia. People with mental health issues appear to be slightly over-represented as a proportion of respondents, while a greater proportion of people report having both learning and physical disabilities and fewer having only learning disabilities than are recorded for social care users in Scotland as a whole (although the numbers of these respondents are small, with fewer than 25 respondents in each of these groups).

Chart 2.5 Comparison of respondents to this project and Scottish social care data: User groups


Respondents by user group

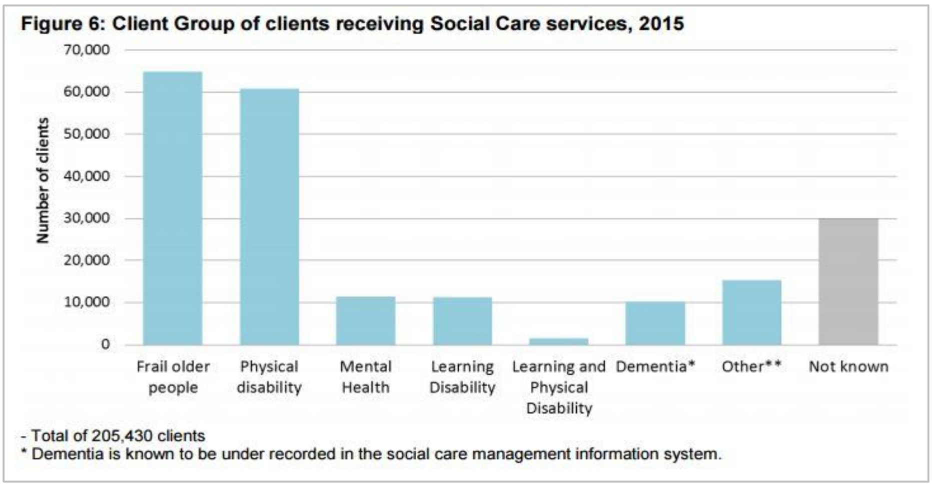


Figure 6: Client Group of clients receiving Social Care services, 2015

- Total of 205,430 clients
* Dementia is known to be under recorded in the social care management information system.

Social care users in Scotland (Scottish Government, 2015)

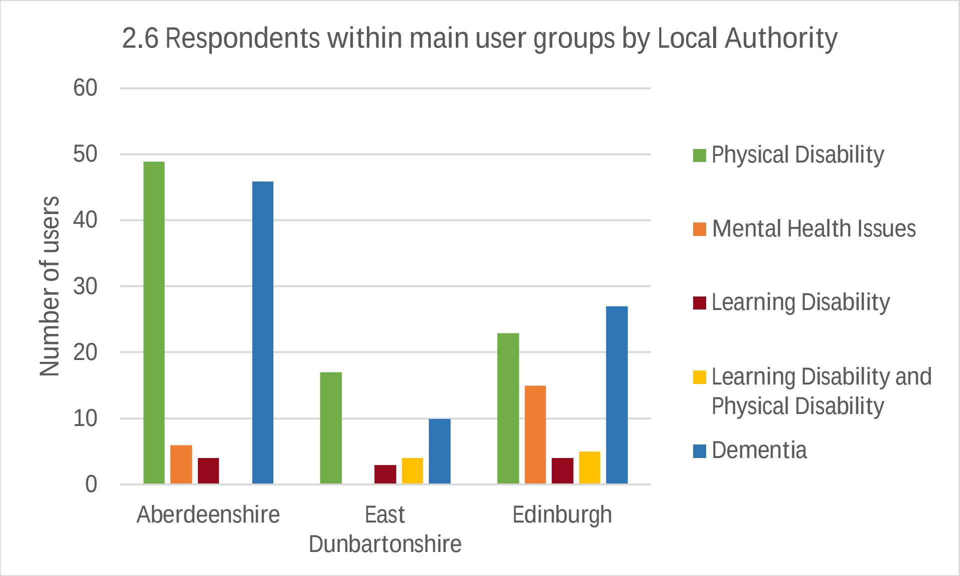


Chart 2.6 shows that people with mental health issues are better represented in Edinburgh than in the other regions. This may reflect that Edinburgh users in this group have a greater awareness of SDSS and the other organisations involved in running the pilot survey. Overall, users in Aberdeenshire are better represented than the other two regions due to the much higher response rate from that region. There were no respondents with mental health issues from East Dunbartonshire.

Respondents were asked about how much help they had with answering the questionnaire. This was intended as an indicator of how much support people have with day-to-day tasks more generally. This might include physical assistance with reading or writing, talking the questions through, translation of questions, or answering the questionnaire in its entirety on the user's behalf. Only 45, or 21%, of respondents who answered this question, said they had filled it in without any support or help of any kind. At the other extreme, 24% said that someone had answered it for them. Five respondents said that someone had translated the questionnaire for them.

Only 60, or 28%, of the people who responded to this question read and filled in the form by themselves without assistance (as well as the 45 respondents above, this includes 15 people whose only help with the form was talking the questions through with someone else). This is lower than the estimate for social care users suggested by the Picker Institute and Kings Fund feasibility study (Picker Institute Europe and The King's Fund, 2013: 83) which advises that 68% of people responding to the 2011-12 Adult social care survey in England and Wales required help with completing the questionnaire. However, given the low response rate to this survey, this may simply reflect that those who have someone available to help them fill in the form are more likely to return it. It is worth noting that the fact that responses for a quarter of users were given by someone else, without the users' involvement, presumably has implications in relation to the ability or desire on the part of these users to engage in processes such as choosing SDS options for themselves. Altogether these responses raise a concern that the views of users who live alone and don’t have someone to help them fill in the questionnaire are not represented in the data.

Comparing the data supplied by Edinburgh about the people who were sent the questionnaire with respondent data, it is apparent that people receiving support through Option 1 were over-represented in responses (constituting 23% of responses, but only 14% of people to whom questionnaire were sent), while those on Option 3 were under-represented (constituting 64% of responses, but 79% of people to whom questionnaires were sent out). People receiving support through option 4 (a small group, with only 9 responses) were also over-represented. This may reflect that users on Options 1 and 4 are those most able, or willing, to complete and return a questionnaire.

3 Take-up of SDS options

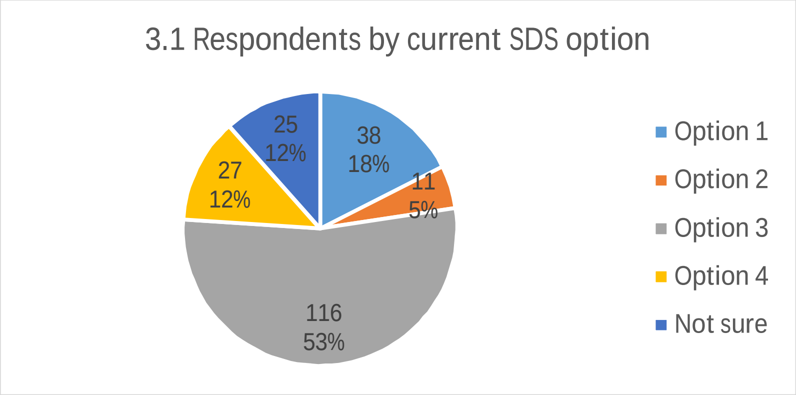
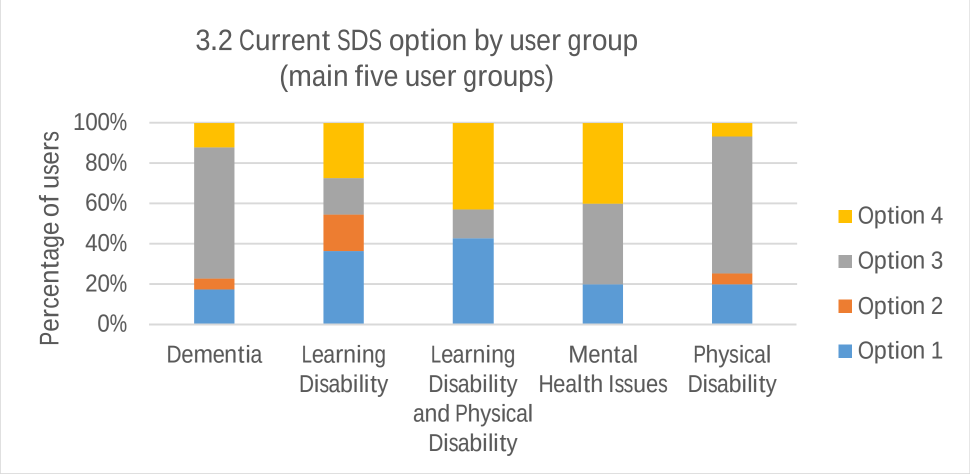
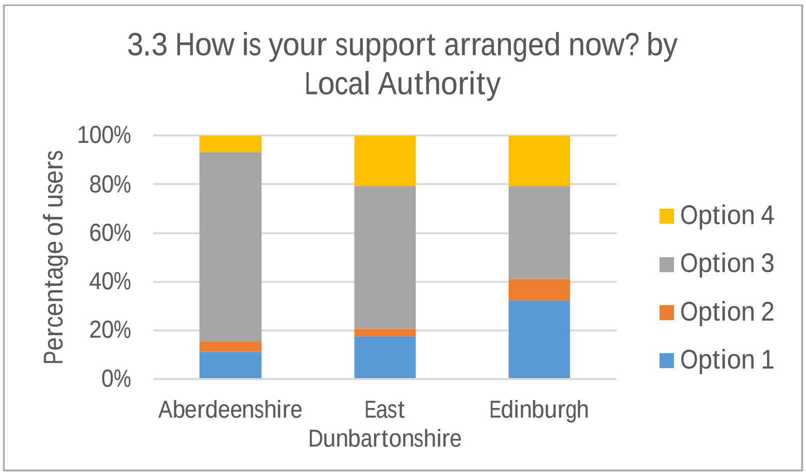


Chart 3.1 shows that 53% of respondents say they are on Option 3, while 18% say they are on Option 1. 12% are unsure of which option they are on. It should be noted however, that responses to this question cannot be assumed to be a reliable statement of the arrangements in place as they are not always consistent with answers to other questions, or with council records.

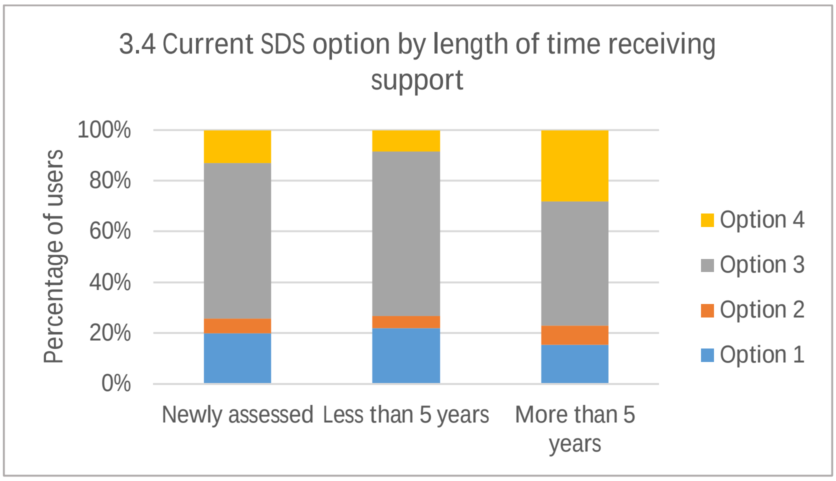


Looking at current SDS option of people in each user group (Chart 3.2), the data indicate that people with learning disabilities and mental health issues are more likely to use options other than Option 3 (although it should be noted that there are only small numbers of respondents from these groups).



A higher proportion of respondents reported being on Option 3 in Aberdeenshire than in the other areas. This is consistent with the age profiles of the respondents from the different regions (see above) which show a higher proportion of Aberdeenshire respondents in the 85+ user group. A higher proportion of Option 1 respondents is shown in the table above in Edinburgh, and we might expect this, as Scottish government data indicate that take-up of Option 1 is high in Edinburgh (Scottish Government, 2015); this result will also be affected by the higher proportion of people receiving options 1 and 4 responding to the survey in Edinburgh (although data is not available to gauge whether this also occurred in the other regions).

Comparing new, recent and long-standing social care users:



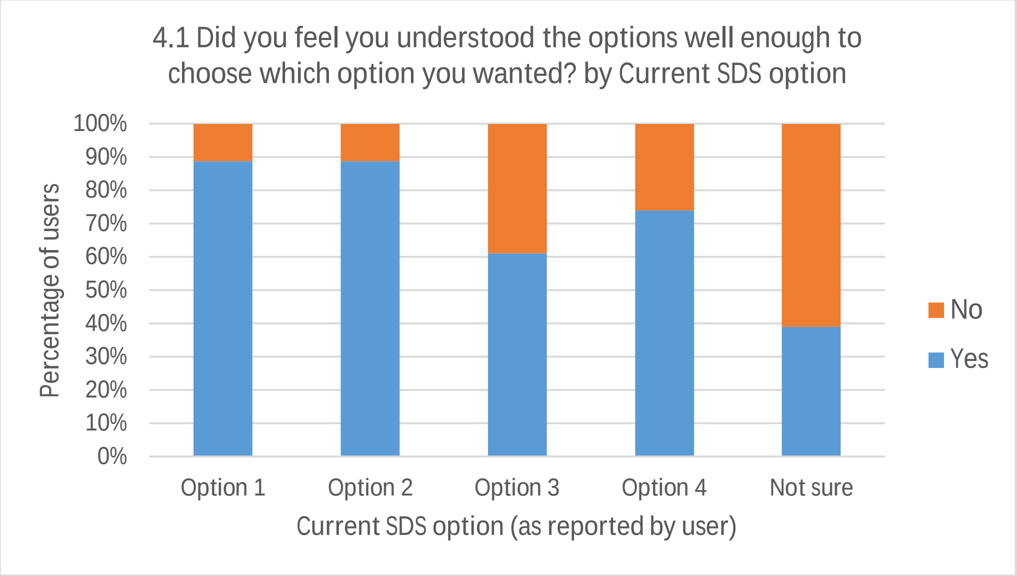
Among respondents, people who started receiving support in the last five years appear to be slightly more likely to be on Option 1, while those who have received support for more than five years are those most likely to be on Option 4 (although numbers are very small and as noted above, lengths of receipt of support are estimates, so these results should only be read as suggestive of possible patterns). If true more widely this pattern could be reflecting that combined options (being on Option 4) may occur as a response to problems encountered over time while receiving support.

4 Information and support about the SDS options in the assessment process

4.1 Understanding of the SDS options

This section looks at whether new and re-assessed social care users are being given all of the relevant information about options available to them under SDS, and whether this is being done in a way that is supportive and accessible.

In Section 3, chart 3.1 shows 12% of respondents who answered the question ‘How is your support arranged now?’ saying that they are not sure which option they are on. Data provided from client records in one of the participating local authorities, the City of Edinburgh, allows us to compare people’s responses about which option they understand they are receiving, with the Council’s record of the support package provided. Only 44 out of 77 people gave a response to this question that matched the Local Authority client record of current SDS option, while 24 user responses gave an option other than that recorded by the council, and 9 were not sure. This suggests a substantial failure of communication and understanding over SDS and the support option in place. It is worth bearing in mind that there is variation in interpretation and terminology in relation to the SDS options even among social care practitioners in different regions (see, for example, Kettle, 2015; Ridley *et al.*, 2011).

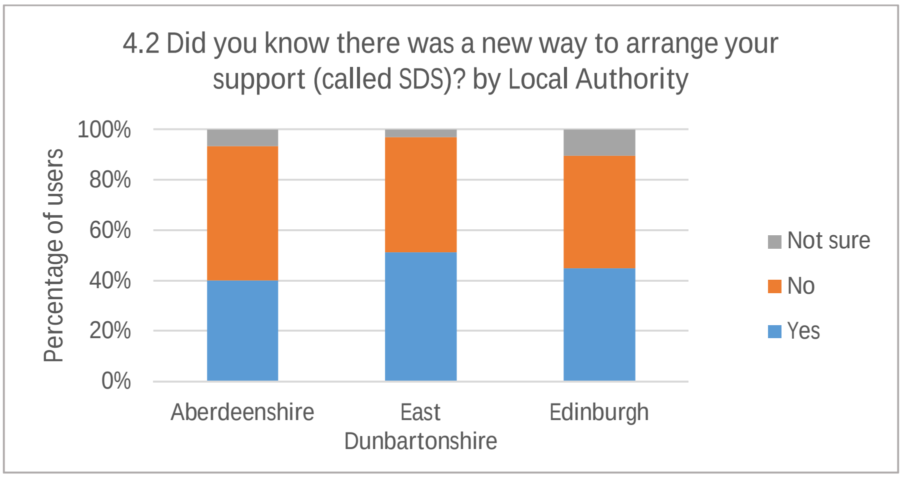


People’s own perception of whether they understood the options is captured by responses to the question: ‘Do you feel you understood the options well enough to be able to decide which one you want?’. 69 people (33.5% or 1/3 of those who answered this question) say they didn’t feel they understood the options well enough to decide which one they wanted. There were no discernible differences in responses between user groups or local authorities.

Looking at the answer to this question by current SDS option (chart 4.1), among those who reported knowing which option they were on, those on Option 1 and Option 2 were most, and those on Option 3 least, likely to feel they understood the options well enough to decide which they wanted. Those who were unsure of which option they were on, were, unsurprisingly the group least likely to feel they understood the options well enough to choose which one they wanted.

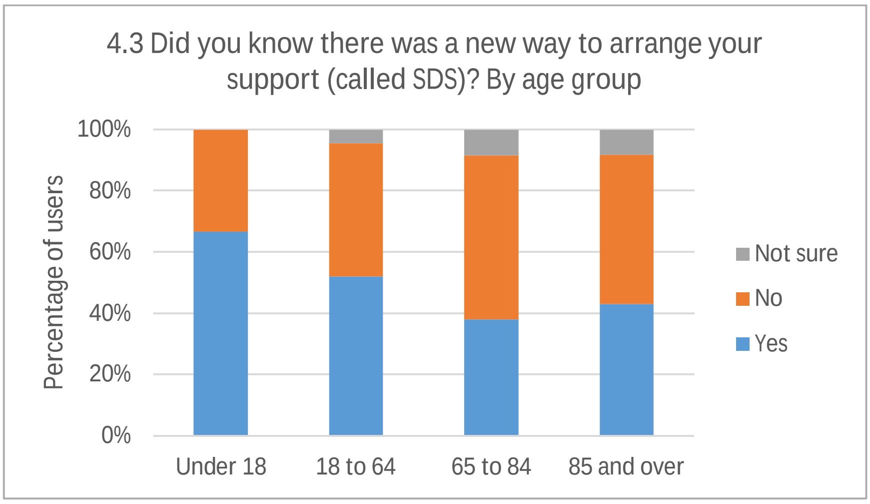
4.2 User awareness of the existence of Self Directed Support

Looking at answers to the question: Did you know that there is a new way for people to choose how their support is arranged (called Self- Directed Support or SDS)? Less than half of people who answered this question, or 44 per cent, say that they knew about SDS, while around half say that they had not heard about it.



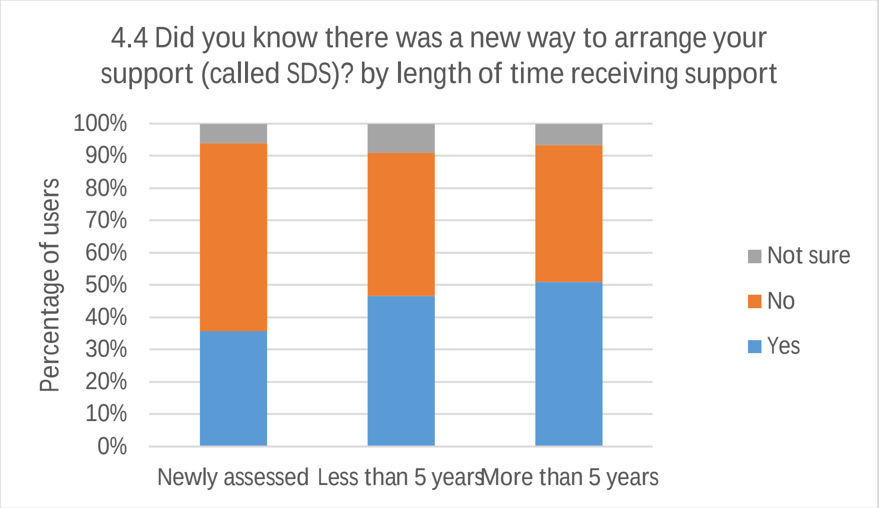
Comparing answers between Local Authorities, a rather lower proportion of users in Aberdeen knew about SDS than in the other regions. This is likely to be influenced by the different user profiles of the three areas.

Comparing age groups, 52% of respondents between 18 and 64 said that they knew about SDS, while only 43% of 85+ group, and 38% of those between 65 and 84 said they knew about it.



Awareness of SDS by new and reassessed users:

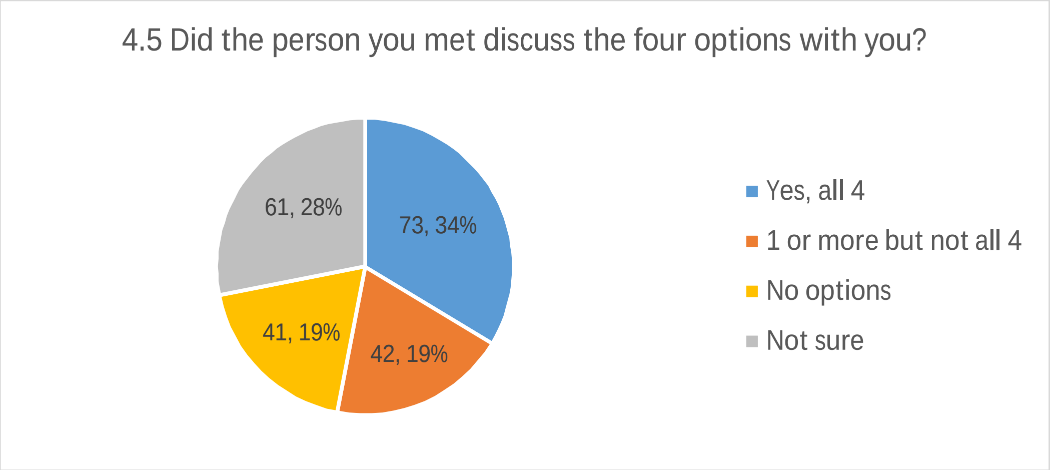
Awareness of SDS was higher among users who were being reassessed than among new users. 45% (65 of 145) of reassessed users said they knew about it, compared to 36% (30 of 84) of new users. Looking at answers to this question by the number of years people had been receiving support:



A slightly higher proportion of those who have been receiving support for over five years are aware of SDS than other groups. This may reflect the different proportions of user groups in these categories, as there are a higher proportion of people who have mental health issues and learning disabilities in the 'more than five years' group and a higher proportion of people who have dementia in the other groups.

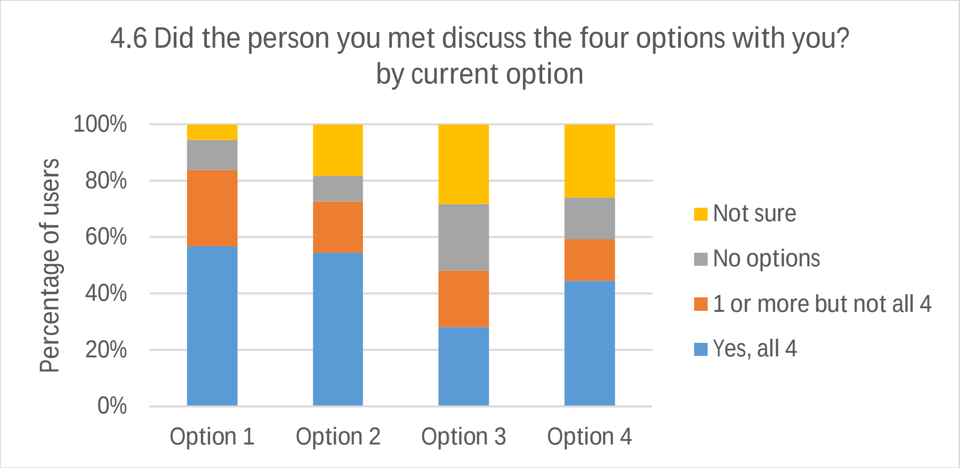
4.3 Information provided to users at the assessment

Looking next at information given by the person carrying out the assessment. People were asked whether the person they met to discuss their support needs discussed all of the SDS options with them.

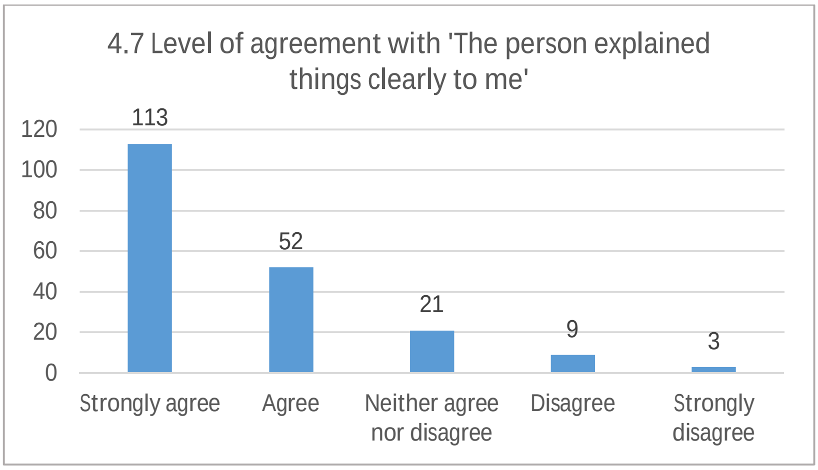


Across all respondents and responses to this question, a third of respondents (see chart 4.5) said that the person they met to discuss their support needs had discussed all four SDS options with them. If we exclude 'not sure' responses, 47% of people who answered said that all four options had been discussed.

In chart 4.6, responses to this question are shown separately for people on each of the SDS options. As might be expected those on Option 3 were the group least likely to say they had had all of the options discussed with them and those on Option 1 were most likely to have had all four discussed (note that numbers for Options 2 and 4 are too small to show reliable relationships).



Respondents were asked for their level of agreement with the statement, 'The person who I met to discuss my support needs explained things clearly to me'. 165 respondents, or 88% of those who answered the question, either agreed or strongly agreed that the person explained things clearly to them, while 12, or 6%, disagreed with this statement (chart 4.7)



The 33 individuals who don't agree with this statement are not all unhappy with their support generally. Despite their dissatisfaction with the explanation provided by the person who assessed them, 20 of these respondents say that they are happy with the support arrangement they currently have in place. One elderly user who has age-related physical disabilities, for example, adds in the comments box:

> '*I can't remember seeing a statement of my indicative budget. I have no recollection of different methods of care being discussed. I am more than happy with care provision currently being provided.*' (respondent from Aberdeenshire)

However, several respondents were unhappy that they had not been given satisfactory information and support by the person who carried out the assessment and respondents emphasised the stress and the problems and delays in accessing appropriate care and support that can result from this lack of information and support about options.

One respondent who cares for a parent with dementia and applied for support with respite care says

> '[*The*] *Social worker gave me no information other than named nursing home. He gave no help whatever about further care or general situation, though I did ask*.' (Edinburgh)

Another user emphasises the emotional impact of a lack of information coupled with apparently disjointed provision of support:

> *We were not clear about exactly what was at stake or what we could or could not expect. The whole process has been both traumatic (our mother has become increasingly ill) and bewildering as no single person has explained to us what we could or could not expect from the systems/process. It has been a series of episodes with no joining up that we can see.* (respondent on behalf of mother who has dementia and lives in Edinburgh)

One interviewee who organises care for her teenage son who has multiple disabilities says:

> *They didn't really go through all the options, they really geared me towards Option 1.* (Edinburgh)

Some respondents say they do not understand the terminology used in relation to SDS:

> *Don't really understand the terminology on this form*. (Respondent who gets Option 3, 75-84, who has dementia and age-related physical disabilities, Aberdeenshire)

Several respondents stress that they had too little information about Option 1 (direct payments), and without it were unable to make the choice:

> *I would like to know what the amount I would have to contribute to Self Directed Support. Would I have to choose which Nursing Agency I would have? I did not have any information on Self Direct, i.e. how much it would cost. Is it quite easy to arrange?* (male user in the 85+ age group with physical disabilities and Parkinson's, Edinburgh)

> *Sounds difficult to arrange Option 1 and don't know how much a budget there is* (carer looking after a mother who has dementia, Edinburgh)

Another respondent who cares for a mother with dementia, says:

> *I [have] Power of Attorney & attended the meeting with my mum. Still feel that advice of what is available to her & for my time and support, should be more readily available & clearer.* (Edinburgh)

Several respondents commented that unless their carers had already been well informed about the support options they would not have been able to arrange what they have. For example, a user who needed support following an operation says:

> *I still have no idea how assistance can be arranged. I have had good support from [local medical practice] Physiotherapy and OT in connection with Parkinson's. No support from anyone in respect of arranging help required in connection with knee operations. My daughter is an NHS employee and arranged for whatever help we get.'* (male user, 65-84, Aberdeenshire)

Similarly, another carer who arranged a direct payment for his/her parent says,

> *If I didn't have some knowledge of direct payments, gleaned from my own work, I feel that care would possibly still not be in place.* (Male user, over 85, Aberdeenshire)

A user who has age-related physical disabilities comments

> *I only knew about direct payment through my daughter who works for CAB* (Male user, 65-84, East Dunbartonshire)

Several people pointed to long delays before they were given information, as well as delays in managing to get an assessment set up. Delays in provision of information about options meant that people could spend long periods of time in hospital waiting for care to be arranged unnecessarily:

> *Was advised about Direct Payment after we'd been waiting for 5 months. If we'd been more aware of the option we would have done this much sooner and spent less time in hospital waiting for care package.* (Carer of parent who has dementia and receives Option 1, Edinburgh)

A respondent who has organised Option 3 care for her mother who has dementia, finds the route to getting an assessment set up via NHS and independent advice organisations is disjointed and difficult to negotiate:

> *Once the Social Worker was appointed it was easier however getting to this point was never ending phone calls, being given endless leaflets to read from e.g. consultants, Alzheimer's Scotland, Carers' Link. I found this a very disjointed service that does not flow well. For example if someone is diagnosed with cancer then treatment is arranged then aftercare and eventually hospice (if needed), but with Alzheimer's you have to find every service for yourself. My mum was lucky to have me but I pity anyone facing this alone - it is a very stressful situation to be in.* (East Dunbartonshire)

It was clear in interviews and from questionnaire responses that people are often unsure why a person from the social work department has come to talk to them and whether or when an assessment actually takes place. One respondent says for example:

> *The person came to review the Guardianship and didn't say they were reviewing Support package too* (respondent with physical and learning disabilities who is on Option 1, Edinburgh)

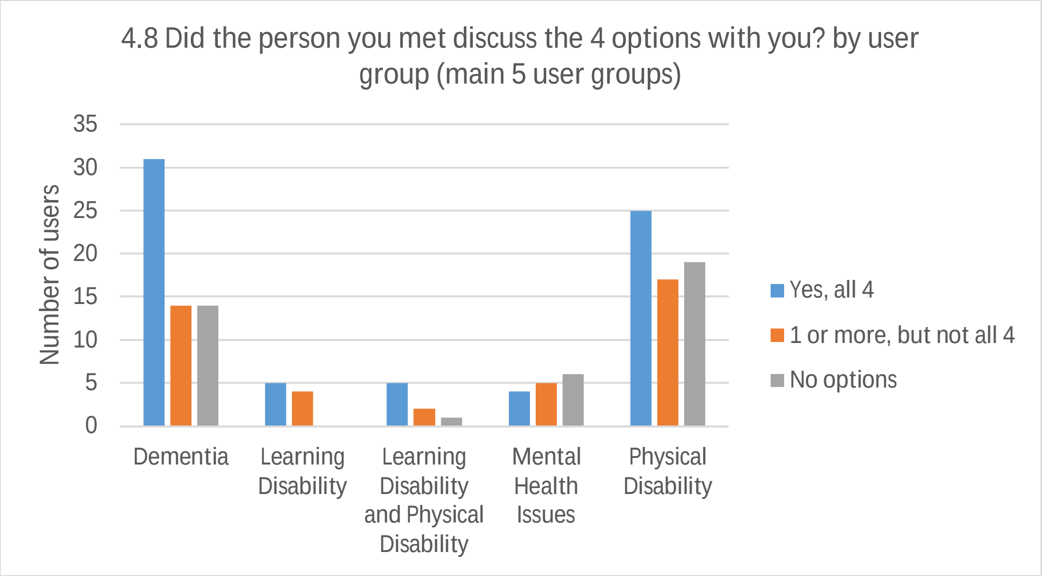
One user who was interviewed and who has been on Option 1 for many years, explained that she was the one who led the assessment. She told the Social Worker that she wanted a Direct Payment and didn't give her the chance to go through the other options. She didn't ask the person assessing her what else she might be able to claim for, even though she currently needs some new equipment to assist with mobility, because she expected that any further support beyond payment for her full time PA would be means-tested and she would not be eligible. Her experience highlights that discussing all four options may not always be what users want, and they may themselves prefer not to explore extra options if they feel they are likely to be turned down.

There were also several very positive responses about help and support from social workers, Occupational Therapists (OTs) and other health professionals, including for example:

> *I have found both the social worker and the OT excellent and very helpful. They respond very promptly to any queries I have about support.* (male user, 65-84, long term physical illness, on Option 4 - Options 1 and 3 combined - Edinburgh)
>
> *An excellent Social Worker at the Western General Hospital called Rosemary King helped us through the process.* (male user, 70-75, who has a long term illness, changed after recent assessment from Option 3 to Option 1, Edinburgh)
>
> *Each and every professional concerned was both helpful and understanding - with all discussions conducted at a level easily understood. At the outset I had more or less determined to go for Option 3 and conducted this aim in almost all the discussions.* (female user 80-85, who has dementia and is on Option 3, Edinburgh)
>
> *Lynn Milne, Social Worker, in discussion with my mum and I (daughter) organise my dad's care package not only for my dad's sake but also to help my mum the Carer! [The social worker] is very supportive and helpful.* (male user with dementia, 65-84, East Dunbartonshire)

4.4 Which users get information and which don't

Looking at responses by user group, it seems likely that some particular user groups may be more likely to lack information and be given a good understanding of the assessment and options than others. The chart below looks at answers to the question, 'Did the person you met discuss all of the options with you, by user group.



Although numbers from several of the user groups are too small to give an indication of whether this finding would hold across the population, chart 4.8 suggests that those with mental health issues may not be as likely to have the options explained to them as other groups. People with dementia – or the carer or family member who organises their care for them – appear from this to be those most likely to have had all of the options discussed with them.

A later question in the questionnaire asks about how much help respondents had with filling in the questionnaire. This question could perhaps be used as an indicator of the amount of help and assistance the user usually has and needs with daily tasks. We might expect that if someone has help with filling in a questionnaire, they are also likely, for example, to have help with the assessment and with making the decision over SDS options.

Looking at answers to the question, 'Did the person you met to discuss your support needs discuss the four options with you?' and dividing responses into three general categories using the answers to the question about assistance with filling in the form:

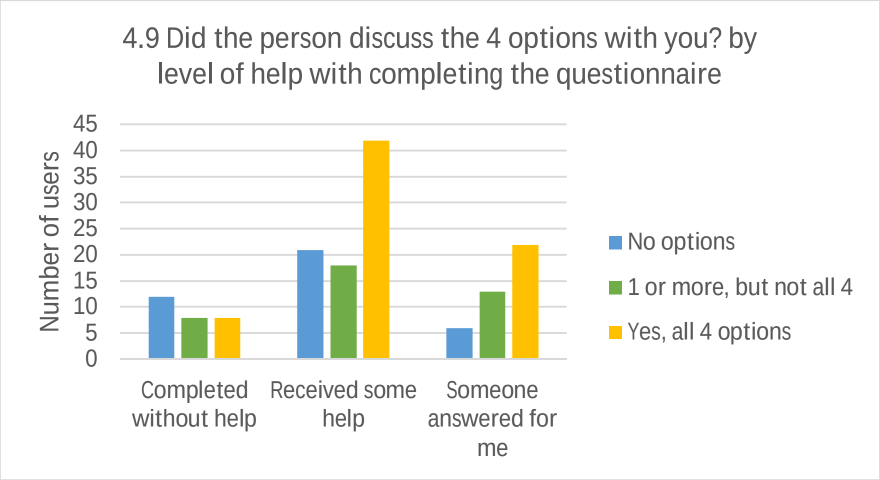
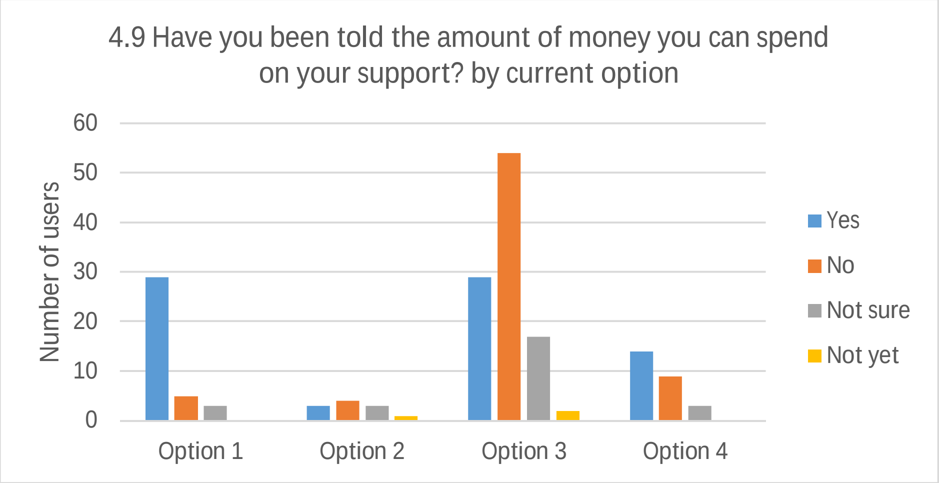


Chart 4.9 shows that a higher proportion of those who had help with filling in the questionnaire say that the four SDS options were discussed with them. If this question does actually represent the general amount of informal support that a user has from day-to-day then this result would indicate that those without a family member, carer or PA, available to talk for them and explain things to them may be less likely to have the options explained to them, or to remember having had them explained after a period of time. An alternative reading of this result might however be that when someone assists a user in filling in the questionnaire their influence may lead to more positive responses irrespective of the user's experience (see Section 8.5 for further discussion of responses to this question).

4.5 Information about users' indicative budgets

People were also asked, 'Have you been told the amount of money (sometimes called an estimated or indicative budget) you can spend on your support?'. 41% of people who answered this question said that they had been told their indicative budget, while 42% said they had not. Comparing answers across Local Authorities, a slightly higher proportion of respondents from Edinburgh and East Dunbartonshire said that they had been told their indicative budget than users from Aberdeenshire. This may reflect the different demographics represented in each of the regions, as there were a higher proportion of elderly respondents in Aberdeenshire and a higher proportion of working age respondents from Edinburgh.

Looking at responses to this question by current (reported) SDS option (chart 4.9), as we might expect, people receiving support through Options 1 and 4 are more likely to say they have been told the amount of money they can spend than those on the other options.



One of the interviewees, arranging care for his wife through Option 1, pointed out that even knowing the indicative budget, as users are not told how the budget has been calculated, it is hard for them to understand the rationale behind the decision and what is supposed to be covered under Option 1:

> *I don't know what the assessment is. They don't actually tell you. They don't break it down financially. They don't explain. I've had a carer's assessment. I don't know how they calculate respite, because East Lothian have said it's different for every client.*

4.6 Summary

A substantial proportion of Social Care users are not well informed about SDS and the options available to them. Less than half know about the existence of Self Directed Support. A third say that they did not have all four of the SDS options discussed with them and a third say they do not feel they understand the SDS options well enough to make the choice of which option to receive. Less than half of respondents are aware of having been told about their indicative budget. People are sometimes unclear about the purpose of the assessment visit and unaware that an assessment is being carried out. Option 3 users, people who do not have someone to assist them with daily tasks, and new users, seem to be less well informed than other groups.

Lack of information about the options can result in people being limited to Option 3 when they might prefer Option 1, in delays to support provision, in restrictions to the support provided, as well as in a high level of uncertainty and stress about whether support will be provided. Some people feel that they are left on their own to find out what they are entitled to and to seek out the relevant departments and organisations to assist them in getting an assessment that meets their needs and defined outcomes.

5 Help with setting up the support arrangement

This section explores whether people are able to access help with setting up their support arrangement, once the option has been agreed. It focuses primarily on responses from people receiving Option 1, for whom this kind of support is most relevant.

People who receive Option 1, or Option 4 including Option 1, were asked whether they felt they got enough help with arranging their support. 77% (37 out of 48) of people who replied to this question said that they did, and 19% (9 people) said they did not.

Several users and carers however described problems they had encountered with organising Option 1 both in questionnaire responses and in the interviews. Recurring issues highlighted include: delays in providing information about direct payments and in setting up payments, lack of information about care providers, and a sense that the assessment process is still based around a narrow needs-based conception of support, rather than an outcome-focused approach in line with the SDS ethos. Several people commented that if a family member had not already had knowledge of direct payments or social care arrangements, or experience of managing staff, this option would not have been possible for them.

One respondent who has arranged support through Option 1 for his father who has dementia and is over 85 describes, in setting up a direct payment for his father's support, how much was left to him to organise and find out on his own, and the lengthy process and delays that he had to navigate:

> *I have Power of Attorney for my father and organised his support package for him. I received minimal support from his care manager. I was left to source the company who now provide his live-in care. In addition, I was asked by care manager to provide costings of this support. Once the support was in place, it took 3 months for payments to commence as I was not sent the necessary forms to complete. I eventually by-passed care manager and spoke directly with local authority finance department who sent me the forms. If I didn't have some knowledge of direct payments, gleaned from my own work, I feel that care would possibly still not be in place. As it was, it took four months to organise and then a further 3 to receive payments.* (user in Aberdeenshire)

Those who received help with setting up Option 1 arrangements nevertheless also report struggling with managing all the organisation required within Option 1:

> *It has been hard to find the right independent PAs due to original carer's exhaustion and lack of internet at mums home. Many carers said 'yes', but then their business stopped them taking on PA work. It's been completely exhausting. I got great visits from LCIL early on and excellent info on agencies and interview questions. When I phoned agencies recently to get a new service, several said they had no availability or only 2 hour slots which is 1 1/2 hours more than we need. It's too exhausting to have staff in for 2 hours and too expensive.* (user in Edinburgh)

Several respondents said that they would not have been able to organise direct payments if they had been on their own, as they relied on a family member to do this; this put an extra burden on family members, some of whom had their own health problems:

> *Took far too long to get the extra funding in place. Not nice having to fight to get what I am entitled to. I would not have been able to do this on my own. My wife did it all for me which took a lot out of her as she is still recovering from breast cancer.* (user in Edinburgh)

Three of the carers interviewed described how they were told at the assessment that they would be able to claim under Option 1 for expenses that they were subsequently told were ineligible by the social work department. One carer described how she felt:

> *You're constantly going, 'Can I claim for that?' and someone tells you one thing - you know, where you get your money from - and then if you get another person they're completely different, so it's all up in the air, what you can claim, what you can't claim, what you can spend it on, what you can't. I mean, it's so frustrating.* (respondent who organises care for her adult daughter who is on the autistic spectrum, in relation to support with respite care under Option 1)

This interviewee said she felt strongly that anyone taking Option 1 should be given a clear information pack telling them what could be claimed and what couldn't and exactly how to fill in the paperwork.

> *Anyone taking out a direct payment should be given an instruction pack of what you can spend it on and what you can't spend it on and how to record your receipts. I have said that you really need for a carer to have that package to see what it entails.*

Another mother who was in general enthusiastic about Option 1, describes a similar experience, having been initially promised more than could be delivered under Option 1:

> *When we re-did the process with my social worker - I think he was very inexperienced, he didn't know how the system worked and he basically told me to go away, and just, 'The sky's the limit! What would you like for your son? What do you need for your son?' And I said, 'Well, it would be great if instead of me taking him to swimming every week, he goes to a music club that I found, on a Saturday – if someone could take him to his bike club.. So I listed everything that would mean that I could then not do all these things I do, which of course gave me a figure – an exorbitant figure – so then when we did the Section 23 and we got allocated - the nominal budget, I think they call it. They were really far apart, which I think for me.. That set my expectations all wrong. If they'd said 'This is the maximum budget you could have. Go away and think about what you could do with it, how it could help your son'. But to me, they started the wrong way round, they gave me this 'Wow! I can get all these things for him. How wonderful!' They kind of set us up to fail. To me, it should really be a partnership. Social services and me, we should be partners together, 'How can we best get my son a better life?' It's an experience I've seen across other parents, they've been disappointed. They thought the process was going to be different.*

This interviewee also described the lack of assistance from social service in setting up the required support using Option 1, and emphasised the importance of independent support agencies such as the Lothian Centre for Independent living (LCIL), as well as personal contacts in accessing a good PA:

> *There's no support from social services. They just give it to you and 'bye, bye!'. I knew about an organisation call LCIL. I mainly use them to do the payroll. They give you all the documents you need, for you know, contracts. I've been able to recruit people through people that I know, so who've worked with my son either at play-schemes or at school.*

Finding appropriate carers was highlighted as a problem by several people and a respondent who has arranged Option 1 for a father with dementia similarly commented in relation to support in setting up the care arrangements that there was '*not much help given in identifying care agencies to approach.'*

5.1 Summary

Several respondents felt that they had not received sufficient support with finding care provision and setting up their support. Some people said they had been left on their own to find independent advice and support agencies and care provision. Some Option 1 users said they felt that there had been insufficient and contradictory information supplied by the council about what they could claim for and how to go about claiming it, and this sometimes resulted in them failing to spend their allocated budget and having it taken back. Some people who took on Option 1 support said that they had only been able to do this because they had support from relatives who had previous knowledge or experience in this area, highlighting that many people who do not have help of this kind would be unable to organise support through Option 1.

6 Information and support from independent agencies

One section in the questionnaire was dedicated to questions about help and information provided by someone or somewhere other than the person the user met to discuss their support needs.

In response to the question 'Did you get help or information about choosing how to arrange your support from someone or somewhere apart from the professional you met to discuss your support needs?' nearly half (48%) of respondents replied that they had. It is worth noting however that organisations that people listed in this section included organisations providing advice on setting up direct payments and on other issues relating to care and support as well as those advising on choice over SDS option, and also included departments and individuals within NHS and social care departments. 44 people gave details of an independent agency from whom they received help or information.

The proportion of people saying they had received help or information differed between regions: 70% of respondents in East Dunbartonshire, 46% in Aberdeenshire, and 41% in Edinburgh.

Sources of help or information are categorised as:

Family member, friend, PA or carer	75
An Organisation (face to face or on the phone)	41
A website	7
A leaflet	10

Respondents listed health and social care employees from the Social Work department and NHS, as well as the following types of organisation, as having provided help and support:

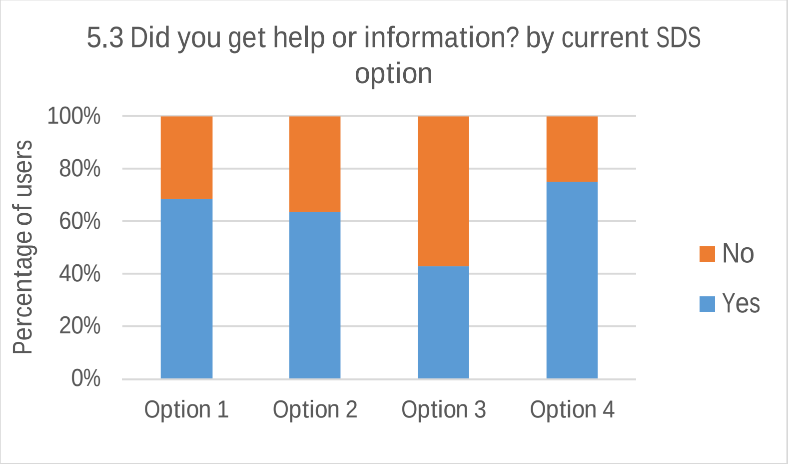
Type of organisation	
Care Agency	5
Government website	1
Housing	2
Independent support and advice and Care Agency	14
Independent support and advice organisation	22
Internet (website not specified)	1
Residential Care Home	2
Total	**72**

Independent organisations listed as having provided support are shown in the table below:

Care Agencies	**Independent support and advice and Care Agencies**	**Independent Support and Advice organisations**	**Housing and Residential Care Homes**
The Action Group Eildon Carers Lifecare Places for People Scotland, Care and Support	Alzheimer's Scotland Cornerstone Crossroads Thistle Foundation VSA	Age Scotland BEAT Boyndie Trust Carers' link Citizens Advice East Dunbartonshire Direct Payments Support Service Health in Mind Inclusion Scotland LCIL PASDA Scottish Huntington's Take Control Upward Mobility Vocal	Abbotsford Care Carers from the Inchmarlo Care Home Warden at Blackhills Court, Westhill (signposting)

Almost all respondents said they had found the help and information useful or very useful, with responses particularly positive about independent support and advice (and care) agencies. Independent Organisations that were rated as very useful by more than one respondent were: Alzheimer's Scotland, Cornerstone in Aberdeenshire, Take Control in East Dunbartonshire and LCiL in Edinburgh.

Websites that were named as having been used to access information were Government website, 'SDS', Deaf Action and Threshold.



Looking at which user groups received help and information outside of the assessment, chart 5.2 shows that a smaller proportion of people on Option 3 received help and information about choosing which option to take than people on the other options. This may mainly reflect that the help and information people are thinking of is that received in setting up direct payments, rather than in choosing which SDS option to receive.

Some respondents described how help from independent organisations had enabled them to manage Option 1 successfully:

> *Things were quite straightforward especially with help from Cornerstone* (male user, 18-64 with learning disabilities in Aberdeenshire)
>
> *Take Control supported me with the recruitment process, the choice of staff down to myself* (user of working age with learning and physical disabilities in East Dunbartonshire)

While some others had found it difficult to navigate between the different organisations to get to relevant information and support, or had approached organisations which were unable to supply the information and support needed:

> *I've actually approached organisations, unsuccessfully, for advice* (mother organising respite care for daughter who has autism, Edinburgh)
>
> *The support organisation did not deliver all they promised meaning PA went unpaid for a significant length of time - support contract subsequently cancelled - little support from L.A. thought this difficult time and process.* (user on Option 1, physical disability, age 55-64, Edinburgh)

6.1 Summary

Nearly half of respondents had received help or information by someone other than the person who assessed them. This included information from independent advice and support agencies as well as from social service departments and the NHS. Independent agencies were rated particularly highly for the advice and help they offered, with LCiL in Edinburgh, Cornerstone in Aberdeenshire, Take Control in East Dunbartonshire and Alzheimer's Scotland highlighted as very helpful. Signposting was provided by a variety of kinds of contact, including family and friends, day centres, residential care homes and housing wardens.

Some people had found negotiating between the various different support agencies difficult, and people had not always managed to find an appropriate agency to provide the information needed. Even with support from independent agencies, some people found managing Option 1 problematic.

7 Flexible support tailored to meet user-defined outcomes?

This section looks at whether people are able to access care and support arrangements that are flexible and tailored to their meet their own personally-defined outcomes, and at the extent to which people are able to obtain non-conventional forms of social care.

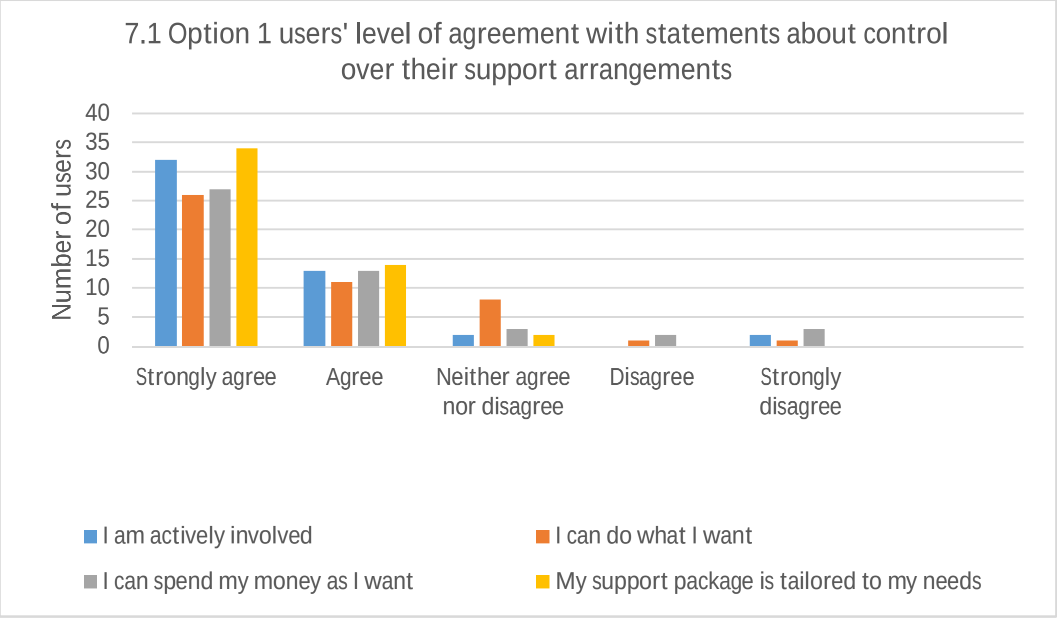
It was recognised during the design stage of the project that these are questions of a kind that would be more appropriately addressed through informal interviews and discussion than through a questionnaire. ‘Tick box’ answers cannot provide detail about the individual kinds of support that people receive, but only a general picture of perceptions of flexibility and user satisfaction as a whole. While different kinds of support users might receive could have been listed on the questionnaire, this would have necessarily limited replies to preconceived types of support, whereas the ethos of SDS is that original and creative ways of meeting individuals’ defined user-outcomes should be encouraged, rather than that support should be restricted to a pre-defined list of types.

The section first looks at people receiving support through Option 1 and their levels of agreement with statements designed to address whether they feel they are able to define their own outcomes, whether the assessment is seen as a co-production, whether the support people receive allows them achieve their outcomes, and whether in meeting their outcomes, the support arranged was creative and flexible. It then looks at answers from Option 2 users relating to whether they were able to choose how their budget was managed and at whether they felt their support was tailored to their needs, and finally at one response which relates to flexibility within Option 3.

7.1 Within Option 1

To gauge the success of Option 1 in enabling people receiving direct payments to be able to define their own outcomes and arrange support which allowed them to meet these outcomes, people receiving support through Option 1 were asked to indicate how much they agreed with the following four statements,

- ‘I am actively involved in deciding what I want to achieve with my support’
- ‘I can do what I want to do when I want to do it’
- ‘I can spend my money as I want in order to meet my support needs’ and
- ‘My support package is tailored to suit my needs’.



The percentage of Option 1 users who answered the questions and agreed or strongly agreed with the statements was as follows:
92% of people agreed that ‘I am actively involved in deciding what I want to achieve with my support’
79% of people agreed that ‘I can do what I want to do when I want to do it’
83% of people ‘I can spend my money as I want in order to meet my support needs’ and
96% of people agreed that ‘My support package is tailored to suit my needs’.

People were most likely to agree that they were actively involved in deciding what they wanted to achieve and that their support is tailored to their support needs, and they are least likely to agree with the statement ‘I can do what I want to do when I want to do it’. However, this statement may be problematic, given that people may have impairments that prevent them from doing what they want, whatever the support. From interviews it appeared that this statement could be seen as too general to agree with unconditionally. If there had been space to add a clause ‘in relation to meeting my support needs’ agreement might have been at a higher level.

Several respondents described specific support they had asked for to meet their outcomes that they had not been allowed to claim for within Option 1:

> *I would have liked my bathroom to be adapted to a shower or wet room but because I live in a 2nd floor flat I did not meet adaptation criteria.* (male user who is 65-84 and has a physical disability, Edinburgh)

One respondent says she doesn’t understand the restrictions placed on use of a taxi service arranged through the OT:

> *Can’t understand why I can't use it to visit chiropodist. Only for social visiting.* (user from Aberdeenshire receiving support for physical disabilities through Option 4).

A man organising support for his wife who has dementia and needs full-time care, explained that available therapies were potentially as effective for her health as formal medical services and that the categorisation of these services as non-critical didn't make sense. LCIL had helped him to claim for some of these services, despite initially being told that they could not be included in Option 1:

> *The Social Worker and Care Broker did their best to assist me and meet my needs, but I was puzzled as to why I was told not to pay for Music Therapy and Art Therapy and Cornerstone care through the Direct Payment. I was happy to top up the DP account and it seemed to me that Social Care is divided into Personal Care and Personal Support – e.g. taking a course or going to counsellors. .. I feel that Art and Music Therapy, the 'Sitter service' and Aquarobics can [all] be seen as 'critical'.*
>
> *I could have asked for money for [my wife] going to Aquarobics, but again they said 'that's kind of frivolous' but I got a letter from the specialist saying that the Aquarobics was very important for [my wife] for her arthritis, and it's also got a social aspect. And that was sent to my GP. They haven't challenged - I began to assemble the evidence, if they wanted to have a fight about it, but they didn't [..] they gave me the benefit of the doubt. I think they're stuck in their ways but if you push them politely they do come round.*

This user feels that the implementation of Option 1 categorises support in a way that fails to reflect the reality of the usefulness of different kinds of support to the user:

> *I phoned up the council and I spoke to a man who said 'we work from the top level "critical"'. And things like music and art therapy don't come into that, they come in the second. But you could argue that they do, because they have a direct impact on the disease as much as taking medicines. Music therapy, art therapy and taking [medicine] for your memory. I think it's demeaning to call Crossroads 'a sitter service'* (respondent organising support for his wife, 65-84, who has dementia)

On the practical organisation of support, he explains that the care agency hours are not flexible, and are unable to adapt when support needs vary:

> *'One of the problems [is that] at Christmas, when I tried to change the pattern of care, they told me you can't. You can only get what you're getting.*

A mother organising care for her teenage son, who has multiple disabilities, in contrast, finds that her PAs, who she found through personal contacts and interviewed and employed with the help of Lothian Centre for Inclusive Living (LCIL), are prepared to be flexible and work more hours when she needs them. She sees it as a strength of Option 1 that she can vary the hours from week to week as needed:

> *There is flexibility in there, so for me.. like I find Christmas and New Year a really difficult time, because there's no play scheme, there's no nothing, everything stops, and for me, since I lost my mum it's a really difficult time personally, so what I tend to do is I kind of save hours throughout the year so that over Xmas and New Year I can*

> *use a PA more, to give me help when it's a really difficult time for me emotionally, so that's one of the things I really like about Self Directed Support, I have a budget for the year, so there's some flexibility in that.. It means when I find things really difficult, like school holidays when there's no cover, I can play with my hours a bit, so I can use the hours when I need it most.*

Another mother organising respite care for her adult daughter who has autism, explained that she ends up paying for some items that should be covered, because it isn't possible to separate them from other expenses in order to claim for them:

> *It's so, so complicated. And if [daughter] goes away for a weekend away, where it's buying in food, which we want to do. What do we do there? So I ended up just buying the whole lot myself. And I'm just fed up with it. .. The 1st time.. I had money taken back – this will be the 3rd time.*

This user's sister would be happy to go away with her for respite care, but would have to take time off work, but payment to cover this has not been allowed under Option 1:

> *They have said 'oh yes, [user's sister] can go away with her, but [user's sister] can't get paid even though she has to take time off her work to go away overnight.*

Similarly, a respondent organising support for her father who has dementia was not allowed to employ a family member under Option 1:

> *I wanted to employ a family member in order to minimise the confusion for my Dad with multiple people coming to the house and I was not allowed to do this.*

A user of working age who has a physical disabilities and a PA to assist him with mobility explains that the person carrying out the assessment was only prepared to consider including payment for mobility aids under Option 1 if using these would reduce the hours he had a PA. From his perspective, the PA enabled his independence and control, and this would be reduced if mobility aids were arranged only in order to replace the PA:

> *They tried to get me mobility aids along with my support package, so it was always going to be an SDS package, but they were trying to cut down the amount of support you would get in terms of a PA, so for example, "If you need the toilet, could you use a bottle or a commode?"- instead of someone take me to the shower room, which we'd just forked out money for. So it was using the aids and things to cut corners with support, whereas my argument was, 'No, I want the support, because it will give me the freedom I want and allow me to use the limited mobility that I already have.' So it actually gives me more independence having someone there than not having someone there.*

He felt that the assessment was based around needs rather than outcomes, again pointing to an approach that is not sufficiently flexible to encompass people's priorities in defining their outcomes:

> *It was based on need rather than outcome unfortunately: 'What do you need? When do you need it? How long can you go without support?' It was needs-based, rather than what I wanted. When I did say what I wanted, the council wrote to me and said - for example, I put in that I wanted to be able to attend the mosque every a Friday - 'We can't do that, we'd be treating you more favourably than anyone else.' They didn't get into specifics, it was basically, 'How many hours of support do you need?', and it was almost as if they're trying to fit SDS into their existing procedures and processes and they've not taken account to change the processes and procedures to take account of SDS. They're trying to fit SDS into what's already there and therefore the culture's still the same.'*

7.2 Within Options 2 and 3

People who appear to be on Option 2 were identified from the available data.[3] Further research would be required to identify the kind of arrangements that people receive and describe as Option 2. Answers to questions about choice over management of their budget were as follows:

Who manages your budget?	
The council	6
Another organisation	3
An individual	2
Don't know/blank	5
Total	**15**

Were you able to choose who manages your budget?	
Yes, I was free to choose	9
I could choose from a list	2
No, I wasn't given a choice	2
Not sure/blank	3
Total	**15**

All of these people (who answered the relevant questions) agree or strongly agree that they have control over who provides their support, that their package is tailored to their needs and (in relation to the support they receive under Option 2) that they can choose the support they want to live as they want to.

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[3] The description of Option 2 on the questionnaire, 'I choose who I want to provide my support and someone else arranges it (Option 2, also called an Individual Service Fund)' seems to have been misunderstood by many respondents so that it is not possible to be certain from questionnaire responses which users are on Option 2. Comparing questionnaire responses with the council's records for Edinburgh respondents, only one of the 6 users stating that they are on Option 2 is recorded as being on Option 2 on Edinburgh's client records.

One of the interviewees, a mother with an adult daughter who is on the autistic spectrum who receives care 27 hours a week, receives extra funding from the Independent Living Fund to top up the fees for autism-specific care. She stresses how important specialist care is for her daughter, although it could not be arranged through Option 2 or 3 alone.

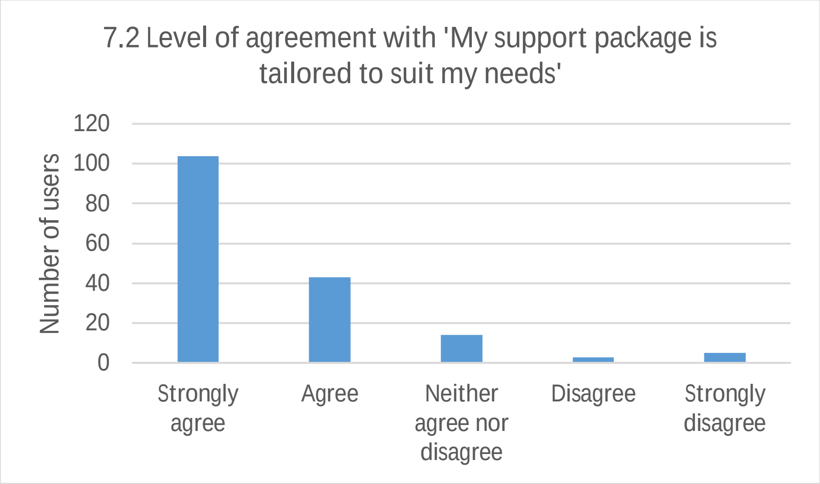
> *I have to fight to keep an autism-specific [care service]. They don't want to keep Scottish Autism. They say it's a very expensive service, and I've had to fight all the way. And I worry about them forcing me to go down the direct payment [route].*

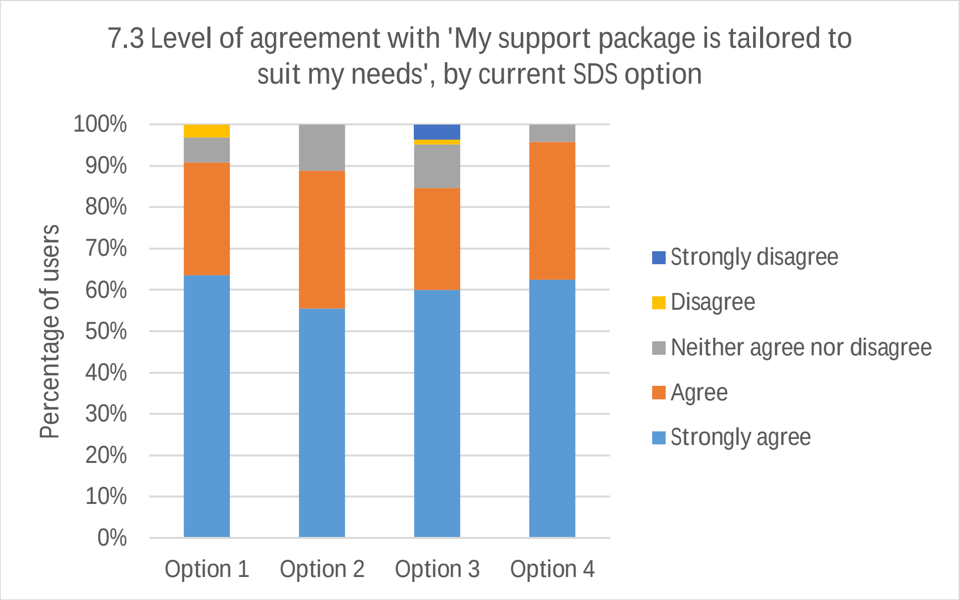
Flexibility in service provision is also relevant to people on Option 3. In user comments it is the flexibility and reliability of care agencies that provide the main focus of concern.

As an example of the kinds of flexibility that matters to users, an interviewee who receives daily support through Option 3 (in combination with Option 1), described her frustration that her carers are not prepared to take her out in her garden, following an occasion when she fell and injured herself there. She also describes how they sometimes fail to arrive at the time they've said, or even don't come at all. On the positive side she pointed out however that they have responded to her stated preference not to have male carers to help her getting up and going to bed.

7.3 Tailored support across the whole respondent group

Across all respondents, level of agreement with the statement 'My support package is tailored to suit my needs' is shown in chart 7.2. 87% of respondents (147 out of 169 who answered the question) agreed or strongly agreed with the statement.





While the highest level of agreement among Option 4 and Option 1 respondents, over 90% of whom agree with the statement, the level of agreement is only slightly lower among Option 3 users. Four Option 3 users disagree, but the lower level of agreement among Option 3 users is mainly accounted for by the fact that a more substantial proportion give a ‘neither agree nor disagree’ response (note that numbers within users receiving Options 2 and 4 answering this question are too small for any definitive conclusions).

7.4 Summary

87% of respondents said that their support is tailored to suit their needs. Several Option 1 users however highlighted that assessments are often restricted to meeting critical needs using conventional methods and fail to encompass more creative potential ways of meeting people’s defined outcomes. Mobility aids, alternative therapies and social engagement choices that people felt to be as useful as conventional support options were refused under Option 1. A focus on reducing PAs’ hours to a minimum was prioritised over other options that would improve users’ health or quality of life. In some cases, refusal to allow family members who could provide care to be paid under Option 1 ignored the potential benefits to the user of care provision by a familiar person.

Responses make it clear that availability of care provision is varied and depends on the user’s locality as well as their personal needs and networks. As a result appropriate solutions need to be personalised and the application of generalised rules or approaches is not appropriate.

Option 2 was only available to a very few people in the survey and data was insufficient to identify how it is being implemented, although people who say they receive this option are positive about the level of control they have over their support. It is worth highlighting that flexibility and personalised provision of support are important for all users, including those on Option 3.

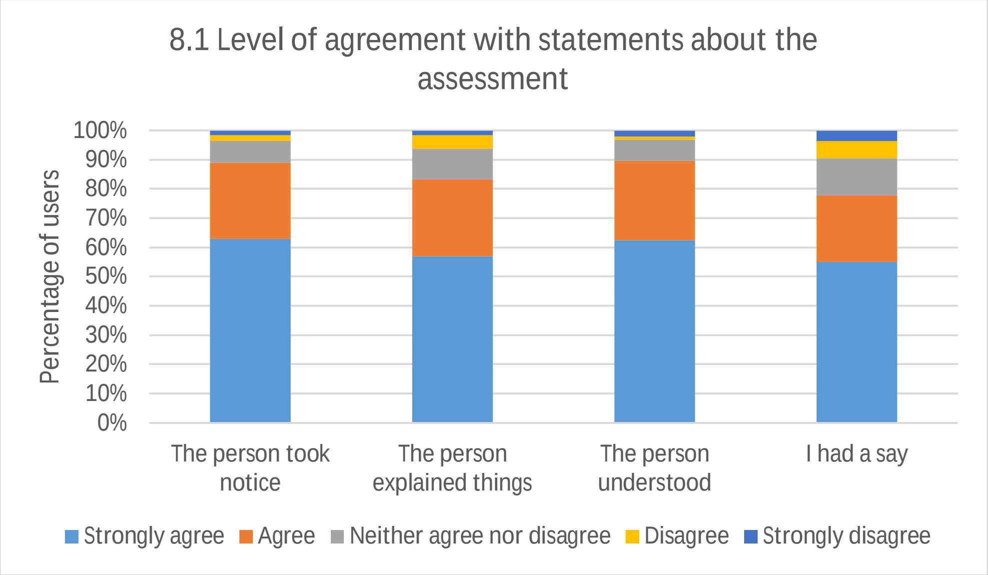
8 Do people get choice and control under SDS?

This section brings together the various elements involved in assessment and setting up support in addressing the key research question 'Do people get choice and control under SDS?'. In the first part it looks at responses about choice and control in relation to the assessment itself and at the relevance of information and assistance provided by independent support agencies in the SDS process. The second subsection looks at perceptions of choice and control over the support arrangements that have been put in place and overall satisfaction with the support arrangement. The third and fourth sections use relevant comments from respondents to highlight the restrictions that people encounter in achieving choice and control and then further factors that are highlighted as impacting on whether they have choice and control. Finally, 8.5 explores which user groups may from the questionnaire responses have more control and which less.

8.1 Choice and control in the assessment process

Respondents were asked to what extent they agreed with the following statements about the care assessment:

- The person took notice of the things that matter to me
- The person explained things clearly to me
- The person understood what I wanted
- I had a say in how my help, care or support was arranged



In Questionnaire responses:

89% of people agreed that the person who they met to discuss their support needs with them understood what they wanted.

89% agreed with statement, ‘The person took notice of the things that mattered to me’.

83% agreed that ‘The person explained things clearly to me’.

78% agreed with the statement ‘I had a say in how my help, care or support was arranged’.

When we look at the current SDS options the people who disagree with this statement are receiving, as we might expect, a slightly higher proportion of those on Option 3 disagreed with the statement that they had a say in how their support was arranged than people receiving support through Options 1 and 2.

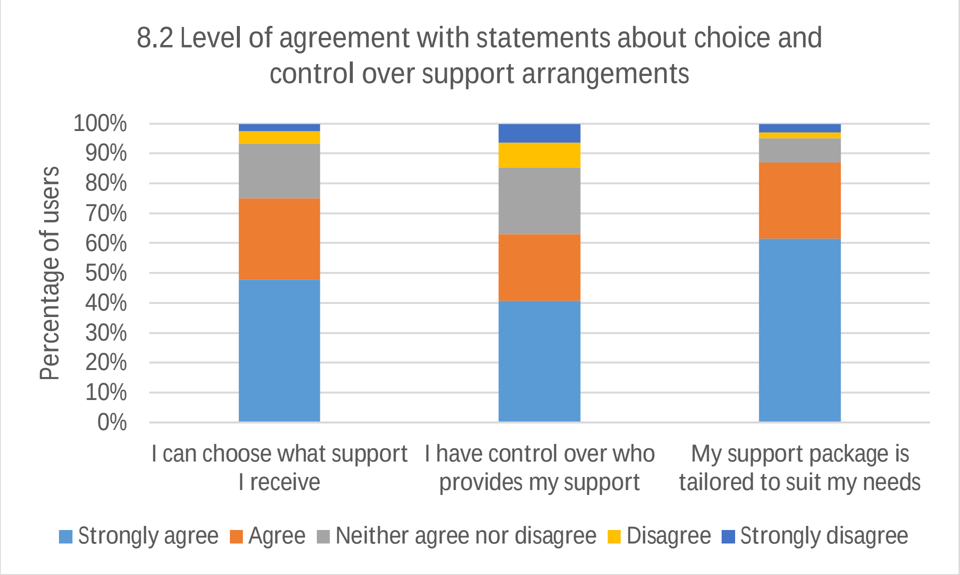
8.2 Choice and control over support arrangements

In response to the survey, reponses to the general questions about choice and control were as follows:

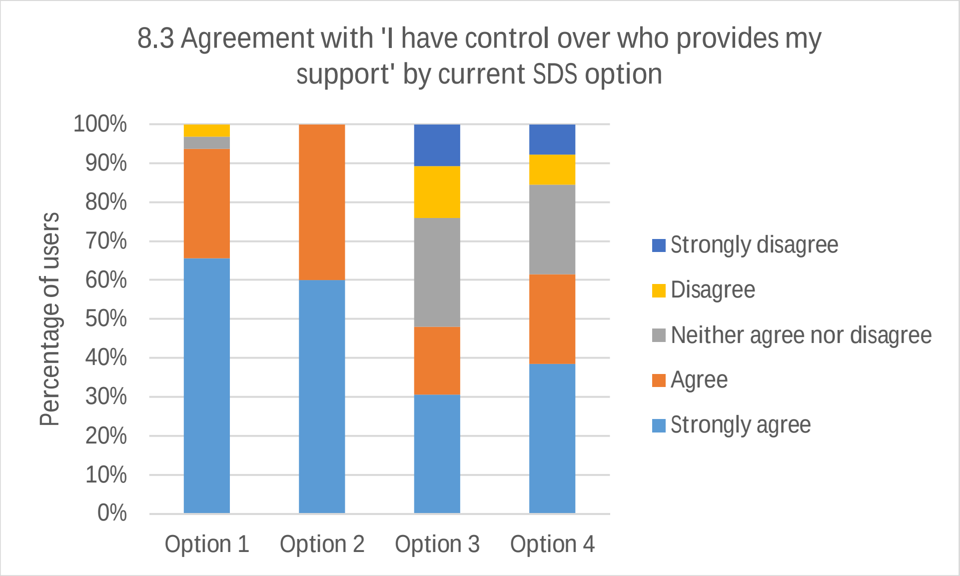
87% of respondents agreed with the statement ‘My support package is tailored to suit my needs’ and 5% disagreed.

75% agreed with the statement ‘I can choose what support I receive’ and 7% disagreed.

63% agreed with the statement ‘I have control over who provides my support’, while 15% disagreed.



There is less agreement with the statement ‘I have control over who provides my support’ than to the other two statements. Looking at responses to this question by user’s current SDS option gives:



As we might expect, people currently on Options 1 and 2 are those most likely to agree that they they have control over who provides their support.

36 respondents indicated that they felt they did not have choice or control, through indicating disagreement with at least one of the above three statements, or by indicating their agreement with the statement ‘I didn’t get any choice about my support’ (answers to this question that contradicted responses to the other three statements about choice and control were excluded).

Of these 36 people:

- Less than half (14) said that they felt they understood the options well enough to be able to decide which one they wanted.
- Only 3 said that all four SDS options had been discussed with them, while 14 said that no options had been discussed.
- 24 are on Option 3, 3 on Option 1, 1 on option 2 and 4 on Option 4.

However

- 22 agreed that the person who met them to discuss their support explained things clearly to them.
- 28 say that they are satisfied with their current support arrangement.
- Only three say that they would prefer to be on a different option than they are currently on. These three people are all on Option 3. Two say they would prefer to be on Option 2 and one would prefer to be on Option 1.

8.2.1 Satisfaction with current support arrangement

88% of respondents (191 out of 216 who responded to the question) say they are satisfied with the arrangement they have in place. Of the 15 respondents who say they are not satisfied and know which option they are on, eight are on Option 3 and three are on Option 4. All respondents who say they are on Options 1 and 2 and whose support has been arranged also say that they are satisfied with the arrangement they have.

Respondents were asked, ‘If you are not satisfied with your current support arrangement what would you prefer?’. In response, 16 respondents say that they would prefer to be on a different SDS option from the one they are currently on. Eight respondents who are on Option 3 say they would prefer to be on a different option and five of them would prefer to be on Option 1. Six people on Option 4 say they would prefer to be on one of the other Options.

8.3 Restrictions on choice and control

This section describes and presents comments from respondents to illustrate in turn a number of restrictions that recurred in people’s comments about accessing choice and control over their support.

8.3.1 Lack of Information about SDS and Option 1 prevents some people taking up direct payments.

Comments from the five people who are on Option 3 but say they would prefer to be on Option 1 (see previous section) indicate that a lack information about direct payments and what kind of budget would be available, and sometimes lack of confidence about how difficult it would be to arrange, prevent some people from taking up Option 1, even when they would be interested in doing this. Four of these five people say that they were not aware of SDS. These five people all live in Edinburgh.

One user writes on the questionnaire the questions he would like answering about Option 1:

> *I did not have any information on Self Direct, i.e. how much it would cost. Is it quite easy to arrange? I would like to know what the amount I would have to contribute to Self Directed Support. Would I have to choose which Nursing Agency I would have?’* (male user of over 85 who has Parkinson’s Disease)

Another user organising support for a parent with dementia says:

> ‘*Sounds difficult to arrange Option 1 and don't know how much of a budget there is*’

As described in Section 4, other people on Option 3 said they had not been offered a choice, or had been told that direct payments were not available for what they wanted:

> *The care plan was arranged by the hospital on my behalf. I only found out afterwards what was planned. I have always had to ask what services available.* (male user, 65-84 with physical disabilities, Edinburgh)
>
> *This form refers to "direct payment" - We were told by the social worker that this option was not available.* (male user, 65-74 with mental health issues, receiving Option 3, Edinburgh)

However, the majority of Option 3 users reported that they are satisfied with their support arrangements, and there were positive as well as negative comments about Option 3. For example, a respondent answering for a female user with dementia and physical disabilities, who didn't know about SDS but said all 4 options had been explained at the assessment, says:

> *I am more than happy with the cover I get from the council.* (Edinburgh)

8.3.2 Some users felt that they were 'directed towards' or even forced into taking Option 1.

As described in Section 9 below, several users who needed support with respite care said that they were told Option 1 was the only way they could access this.

> *Was not given info about SDS. Told I had to have SDS to arrange respite [care]. Not in the spirit of the Act.* (female user, over 85 with physical disabilities, Aberdeenshire)
>
> *I do worry about people being forced to take a direct payment. I don't know if I'm an isolated case. The Social Worker ticked the box. I was tricked in one way of doing it. So I had to just go along with it.* (Mother arranging support for adult daughter with autism)

One user who feels Option 1 is best for organising support for her son who has multiple disabilities, nevertheless expresses concern about its appropriateness for other parents:

> *Some parents have learning disabilities themselves, and for them my worry is, in the same way as I was sold Option 1, they might be sold an option that isn't necessarily the right option for them.* (Mother who has a disabled son, has Option 1)

8.3.3 Under Option 1 care can be more expensive, so fewer hours can be covered.

An interviewee in Edinburgh who arranged care for his mother, who is 85+ and is blind, took Option 1 so that they would have choice and control. He later found out that the care agency would charge higher rates to a user on Option 1 than they would have charge for the same care through Option 3, reducing the total hours of care available:

> *Using SDS 1, by its nature promotes inequalities, because as an SDS user, [my mother]'s assessed hours were 20 hours a week and [the council says] 'here's a budget to pay for that'. If I use a care provider chosen using Option 1, the number of hours I can get for my money are less because the charge rate is different. [..] So by using SDS 1 this highlighted for me, the difference is that you, for this right to say, you pay a higher rate, and that's as much as £2.50 an hour. But my mum wasn't assessed for money, she was assessed for needs, as needing 20 hours at £15 an hour, however with my £300 I do not get the 20 hours by approaching care providers in Option 1.*

8.3.4 If people employ carers from care agencies using Option 1, agencies draw up contracts that take away users' control over care provision.

The same respondent expressed concern that the care provider had asked them to sign a contract which was worded to take control of the care provided away from the user:

> *It's not the same contract that would be signed if it was between the care provider and the council or any other combination. The contract I was asked to sign, in my opinion, goes in the face of choice, the main reason being that there's a clause which says you give up the right to them not having the final say.. There's a section that says they have final say in everything. Ultimately they can decide what they want to give me.*

8.4 Other issues in relation to choice and control

8.4.1 People highlighted the importance of the individual social worker – whether they listened and were 'on the side' of the user:

One of the interviewees, herself an ex-social worker, pointed out that asking people about which options were explained to them may not get to the heart of what's important in users' choice and control in the assessment. She says:

> *They might say, 'Yes she was really nice. Yes, she told me everything she could' but in fact, how do they know that? It's not so much explanation [of the options] as - I'm just thinking of one of my friends who receives Direct Payments and has been through two or three different social workers in the few recent years. She knows when someone's like a breath of fresh air and totally is on the ball, totally understands, totally gives the right information and then with hindsight she can see that the person she maybe most recently experienced - a social worker for example - was a lot different. It's about ethos and whether.. When I was a social worker I was never a friend of the council. I was a friend of the client.*

This account also highlights that a 'new' user, someone who has recently had their first assessment and who didn't previously know about SDS and the options, may not be in a position to judge whether they had the options explained (correctly) or not.

The brief comment of a respondent who had a bad experience of assessment, demonstrates that a bad outcome and a bad relationship with the social worker may be closely linked:

> *Social Worker very aggressive, unsympathetic and tried to reduce support package.* (user in East Dunbartonshire)

It is also worth bearing in mind in relation to this comment that a negative outcome may affect the way a user feels about the assessment process and about SDS itself even if these are not the reason why support has been refused (see also Ridley *et al.*, 2011).

8.4.2 The relevance of the available care and support in the local area.

People in different areas had access to different kinds of care providers and availability impacted on the Options that could be offered as well as the way in which Options could be implemented.

Two people in Aberdeenshire, for example, gave local care provider availability as their reason for choosing Options 3 and 1 respectively:

> *Living in a rural area, [Option 3] is still the best option.* (carer of female user, over 85 who has dementia)
>
> *Self Directed [Option 1] was the only option available to me as social services had no carers employed to give an alternative* (Male user, 75-84, who has dementia and physical disabilities)

Users in Edinburgh also comment on the impact of limits on available appropriate care:

> *In looking for 24/7 care for [user], City of Edinburgh couldn't give a lot of choice - so this form is tricky to fill out. Ark Housing provides most of [user's] care and because care is in crisis in Edinburgh, not a lot of choice over who is hired* (respondent arranging care for male user 18-64 who has autism and dyslexia)

An interviewee who has been trying to organise respite care for her adult daughter who has autism, explained that lack of continuity of carers in care agencies is a contributory factor in her failure to arrange respite care and as a result having her Option 1 money taken back by the council:

> *Staffing at the provider has, has been in such turmoil for the last two years, when they finally get up and running and there's someone [my daughter] trusts to go away with, then they up and leave. So hence all this money lying around. It's because of the care at the moment - that people don't stay. And they're going to take money [back] because I haven't been able to spend all my money.*

8.4.3 People need to be confident and competent to choose Option 1.

To choose Option 1, people need to be competent and confident, first in order to assess what is involved, and subsequently to organise payments and employing and perhaps dismissing staff and arranging the relevant documentation. Even when they have support from an independent support organisation this can cause ongoing worry and stress. If Option 2 is not offered, this means that those who do not feel able to take on this responsibility have less choice and control over their care and support. Several respondents clearly felt that Option 1 was too complicated for them to want to take on:

> *I felt that Self Directed Support would be too stressful and complicated to go down that road and we would be abandoned. I have no idea how all the care packages / companies work. The whole business is so complicated and too many choices. We just want somebody to tell us what we can have and organise it. There are so many care*

> *companies we don't know who is good and who isn't and what areas they cover. We are over 65 and have enough to deal with without all this extra complications.* (Man, 65-84, who has dementia and physical disabilities, on Option 3, Edinburgh)

> *It's very complicated to understand quickly and I have a high level of capability in that area* (Man, 18-64, who has mental health issues, Aberdeenshire)

> *My mother is my father's main carer. I am their daughter and I am a carer for both. I deal with all the support arrangements, meetings, paperwork etc. They would not manage to do this without me and would have ended up with council support for ease as opposed to this being a conscious decision. It was made clear that if I chose this option I would have to do it all.* (Respondent whose father has dementia and is over 85, Edinburgh).

> *The new system seems very daunting. I am glad council support is still available. This has worked very well so far.* (Carer of female user, over 85 who had dementia, living in Aberdeenshire)

> *I would not have been able to do this on my own. My wife did it all for me which took a lot out of her as she is still recovering from breast cancer.* (male user, 18-64 who has a long term illness, and is housebound, Edinburgh)

An interviewee organising respite care for her adult daughter who has autism describes the effect of the stress she has felt in trying to manage Option 1:

> *I have very much related health problems with stress.. even my mental health through this.. so that's the impact it has on me and the family of a direct payment. And I wish to God I'd never heard of it. In theory it should work, but it doesn't. .. I think it's just the way the care is. The people who work in care come and go and you're not getting continuity. .. When I first looked at direct payments I thought it would be a really, really good thing.*

Another mother interviewed who has a teenage son with multiple disabilities explains that she managed Option 1 OK because of her past experience as a manager in HR, but that even for her, employing someone to look after your own child poses challenges:

> *before I had to give up work, I was a project manager, I managed a big team, and I did recruitment, so I would do the interviews and I would choose who was going to work in the team, and I managed them, but obviously we had a whole HR team who managed all that, but it's difficult when you've not got someone who's working with you and it's difficult to withdraw the emotional side of it, because you're so worried about the impact of someone on your son, and I think a lot of families would find that really difficult.*

A user who organises support for his wife who has dementia, describes the difficulties involved with complicated arrangements with different agencies. On receiving advice from a local authority advice organisation, he reduced the care to one agency, but then found that with one single carer for 8 hour stretches, his wife was bored and unhappy. His account highlights the complications and stresses in managing Option 1, and negotiating and reconciling the variety of issues: the need for flexibility over holiday periods, the availability and reliability of care staff, the difficulties in assessing how much care is going to cost to match the allocated budget, and the demands and stress of becoming an employer and having to negotiate with carers over pay:

> *I went to PAs because it was put to me that they were cheaper, you could tailor them better. But there is one PA, with a back-up, and she disappeared at Christmas time. 'I'm sorry, I've got kids I can't work. So Xmas time was very, very complicated, and I was going crazy trying to work it all out, plan it all in advance, so it was a terrible. I can show you - I had a piece of paper with columns with all the companies, trying to work it what's happening, but you only get the service you've already got, you can't change it for Christmas. Well, that's what [the care agency] said. I think they're short of staff. Well they're all short of staff, which caused [my wife's] problem with the council, because I saw that since there were no extra staff, I could get no extra care, so I'd be left with a big surplus, which they'd then claw back. It hasn't happened, but it might happen. And it's very difficult to know from week to week, month to month, whether you're underspending or overspending. The overspending is OK because we have medical insurance which allows me to get 75% of any top-up back, so I'm quite happy to top-up, so I'm trying to over-spend if anything. … So I'm happier now that LCIL have taken over the payroll, because not only does it take work away from me, but I feel it distances, it makes it more credible, because I'm having a credibility problem I think. Because I don't like managing two PAs – I don't like managing anybody to be honest, it's not me. I always feel that they in some way doubt me. And one of the [PAs] came to me and said 'You're only giving us £8 an hour. I always charge £12 an hour, and I'm self-employed'. They don't really understand the package, so I keep on referring them to LCIL, which I don't think they like very much because they prefer me to do it, but I'm a novice and I don't really know, and they don't have faith in me, because they know that I don't know. The council kept asking me, 'Do you not want us to do it for you?' - to take it all back and do it themselves - and I kept saying 'No'. I'm happier to be with LCIL, but the PAs was a step too far possibly, because they're playing with my head you know. One of them emailed me today and said 'Do you want me to come on Monday?' and I said 'Yes, of course I do!' and one day last week, early in the morning, like 5.00, she emailed me to say, 'My little daughter is ill, I can't come', so the other one should have stepped in, but she didn't. [The PA] is like a shop steward. She's coming in: 'I'm self-employed, I'm £12.' I don't want to get into industrial relations. You know, it's boring - I don't need the hassle!*

8.4.4 The question of who wants to have choice and control

For some people there is a question over who it is who wants to make the choices. Couples may want to decide together, parents may prefer to rely on their children to sort things out.

> *[My husband] has very poor mobility, so we make choices as a couple.* (wife of user, 65-84, who has physical disabilities)

> *Care support was arranged against some opposition initially of [user] as the family realised she needed support they persuaded her to accept it. She now accepts it because she understands she needs it.* (Family member responding for a woman of over 85 who has dementia)

The experiences of these users who have someone to assist them in making the choice and organising their support arrangements also draw attention to the different (and here perhaps under-represented) experiences and vulnerability of users who are without family and friends to offer help and assistance.

One user points out for many people, having choice over the support arrangement isn't their main priority; instead, it is just getting support set up:

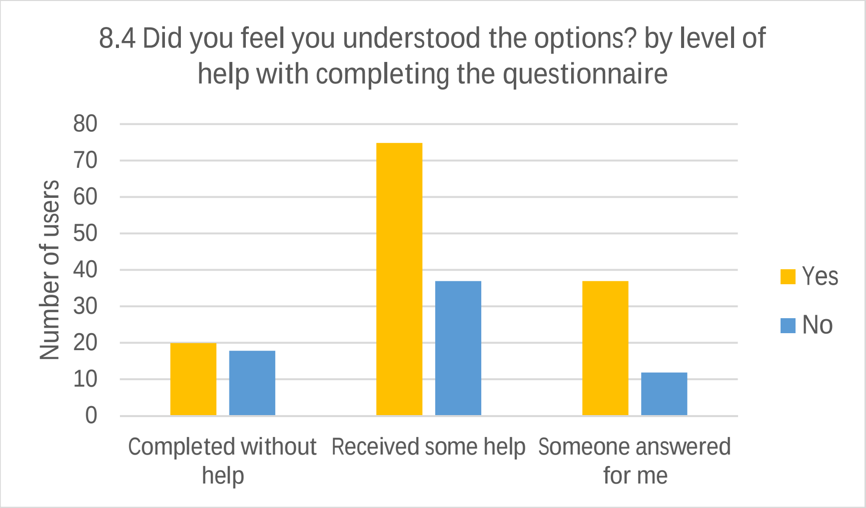
> *I'm not sure people are really that bothered how it's arranged - certainly my parents and I just wanted it arranged!* (Man, 18-64, who has mental health issues)

Many people applying for support are in crisis or in desperate need of support, and getting it put in place quickly is their main priority (see also section 9.2: Delays in setting up support)

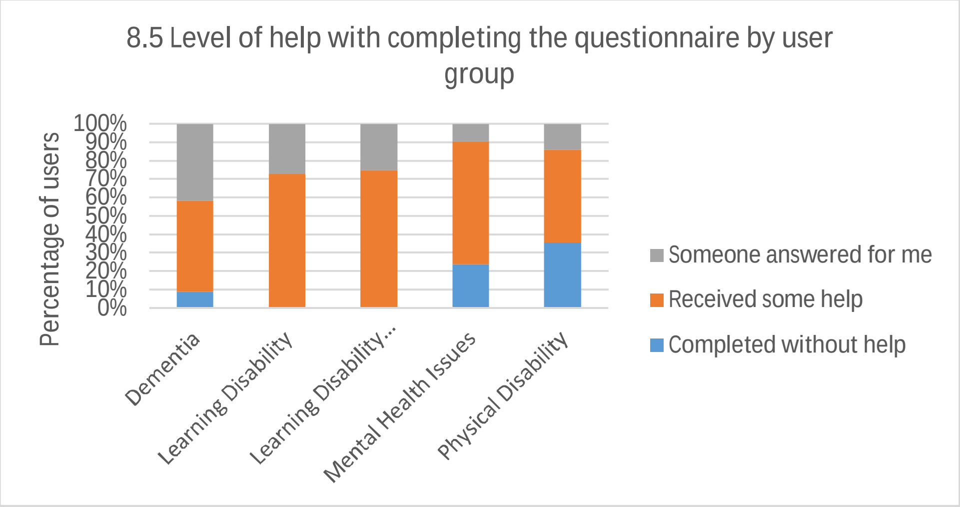
8.5 Exploring which user groups have choice and control and which don't

Respondents to the questionnaire were asked whether they received help in filling in the questionnaire and what kind of help they received. Answers to this question appear to be related to responses in relation to the assessment process and to perception of choice and control over support. This could be interpreted in more than one way. The level of help received in answering the questionnaire may perhaps be used as an indicator of the support that the user has and needs more generally with daily living - and so with choosing and managing their support arrangements, i.e. if a user received help in answering the questionnaire, this might be taken to mean that they are more likely to have a carer, PA, or family member who helps them with paperwork and decision-making and who may have been involved in explaining the SDS options to them. Alternatively, it could be that having someone else helping a person to fill in the questionnaire or filling it in for them means that the user had less input to responses and that it is the helper's view that is being represented, or that having someone else present inhibits the user from giving a negative response.

Chart 8.4 below, presents answers to the question, 'Did you feel you understood the options well enough to decide which option you wanted' according to the level of help the user received in filling in the questionnaire.



This suggests that those who do not have someone to provide informal help are less likely to say they feel they understood the options well enough to make a choice between SDS options. If help with filling in the questionnaire is taken as an indicator that the user has informal support generally, this result raises concerns about those who live alone without carer, PA, family members and friends to provide informal help, who may need more assistance and support in understanding and making the choice about arrangement of their support than they are currently received in order to have a meaningful choice over which SDS option to have.



While those who completed the questionnaire without help answer similarly to other groups to, ‘Did the person explain things clearly?’ and they are divided proportionately between different SDS options, their responses also differ from people who received help on in answer to the question, ‘Did the person discuss the four options with you?’ and in their level of agreement with, ‘I have control over who provides my support’, as well whether they say they are satisfied with the current support arrangement.

Chart 8.5 shows that people with physical disabilities were the user group most likely not to have anyone helping them fill in the questionnaire followed by those with mental health issues.

8.6 Summary

Respondents overall were very positive about the choice and control they have over their support. 89% of respondents agreeing that the person who assessed them understood what they wanted and took notice of the things that mattered to them and 87% agreeing that their support package is tailored to suit their needs.

78% of respondents agreed that they had a say in how their help, care or support was arranged' and 75% that they can choose what support they receive. A lower proportion, 63%, agreed that they have control over who provides their support, and Option 3 users are, unsurprisingly, those most likely to disagree with this.

88% of respondents say they are satisfied with the arrangement they have in place, however a minority are not satisfied, and some Option 3 users said they would prefer to be on Option 1 or 2. Lack of information provided by the council is highlighted by some people as preventing them from considering taking up Option 1.

Some people, however felt that they were guided or forced into taking Option 1 and told this was the only way of accessing the support they needed. Several respondents felt that Option 1 was too complicated or burdensome for them to be able to manage it and others said that they were only able to receive support through Option 1 because a family member was already experienced or informed about direct payments. Some respondents said that they just wanted someone else to organise support for them and they were happy with Option 3 and glad that it was available.

An interviewee pointed out that under Option 1, care agencies could charge the user higher rates, so that the assessed hours were not attainable, and that care agencies could insist people sign contracts which reduced their control over who provided their support.

The relevance of variation in available support been local areas was highlighted as impacting on which Option was most appropriate, or was feasible in individual situations. Also at the individual level, the quality of personal interactions with the social worker, and in particular whether they adopted an approach in which they were 'on the side' of the user was emphasised as of at least as much importance as whether all four options were discussed with the user.

Among respondents it was apparent that those who received help filling in the form were more likely to feel that they understood the options and had control over their support. This result is open to interpretation, but raises a concern that people who do not have someone to support them may be likely to be less able to engage with the social care process and take advantage of the options available under SDS.

9 Further issues highlighted in questionnaire responses

Issues that recurred across responses are described in this section in turn. These are: concern that respite care can only be arranged using Option 1, lengthy delays to support, and the overall level of support provided.

9.1 Respite care

One of the interviewees and several respondents to the questionnaire were unhappy that in applying for support with respite care, the only option they had been offered was a direct payment or Option 1. This was seen by some people as unnecessarily complicated and stressful, when they would have preferred to have respite care arranged for them. For example:

> *'I didn't want a direct payment, but I was given no choice, because that was the only way I could get respite care'* (Mother of adult user who has autism, Edinburgh)
>
> *Was not given info about SDS. Told I had to have SDS to arrange respite [care]. Not in the spirit of the Act* (user over 85 with physical disabilities, Aberdeenshire)

9.2 Delays in setting up support.

Delays in providing information and setting up support had a major impact on the lives of several respondents, resulting in major problems and stress and sometimes lengthy extensions to a stay in hospital:

> *I asked for respite care, giving 3 months' notice of date of my holiday. 1 month before holiday due there was still no assessment carried out. I had to chase this up again and only 3 days before respite care the assessment finally carried out. Social worker gave me no information other than named nursing home. He gave no help whatever about further care or general situation though I did ask.* (carer of a man of over 85 who has dementia and physical impairments, Edinburgh)
>
> *After a very protracted wait for a support package (still waiting) to care for my mother I had to give up working and the only option to give me respite was to take direct payments and employ an independent agency for part of her daily care needs. We have been waiting (9-10 months) for her case to be service matched.* (child of user with dementia, over 85, Edinburgh)
>
> *Chose to arrange care through private care company. Then applied to council for assistance/re-imbursement of some of the costs. This is now in place but it took 6 months to set up contract, so I had to fund this care for myself for 6 months before some of the costs were refunded by the council via the care company.* (man, over 85, with physical impairments, East Dunbartonshire, Option 2)

> *Took far too long to get the extra funding in place. Not nice having to fight to get what I am entitled to.* (Man, 40-64, with physical impairments, who is housebound, Edinburgh)
>
> *Was advised about Direct Payment after we'd been waiting for 5 months. If we'd been more aware of the option we would have done this much sooner and spent less time in hospital waiting for care package.* (Carer of parent who has dementia and receives Option 1, Edinburgh)

One interviewee in West Lothian, who had become blind 18 months previously, apparently as a result of a combination of lack of information about Option 1 and delays to setting up support, had only received minimal support in her home up to the time of the interview. When we spoke she was at last on the way to getting support with going out.

9.3 Insufficient support offered

While the care provided was not the subject of the questionnaire, and unsurprisingly in the current climate of cuts to funding, it should be noted that several people commented that the care and support they have been provided with is not sufficient to meet their needs or to achieve their defined outcomes. For example two respondents, both of whom are women over 85 who have both physical impairments and dementia and live in Edinburgh, say:

> *I feel I could do with more hours for caring as I was not given many hours for my PA.*
>
> *The direct payment scheme works well but monetary sum does not provide for the total amount of care she requires.*

10 Recommendations

This section summarises the issues raised by respondents to the survey and those interviewed, first by bringing together some of the issues raised that might be addressed through policy and implementation changes and then by highlighting areas that would benefit from further research, either to identify what lies behind unexplained findings or to explore areas that this pilot project was unable to address.

10.1 Recommendations for policy and practice

Issues with SDS that the survey findings suggest might be addressed through changes in Local Authority practice, through policy change, or through extra support from Independent agencies, include:

- **Increasing user understanding of the SDS options:** The project identified a low level of understanding of the options and awareness of SDS. Local Authorities need to explore ways of increasing understanding of the options, as well as access to all of the options, across all users.

- **Reducing Delays:** Responses to the survey highlight that delays are occurring in the arrangement of assessments and the setting up of support arrangements that have a huge impact on users who are in urgent need of support. Addressing the reasons for delays and working to minimise them should be a high priority for Local Authorities.

- **Extra support for vulnerable users who are alone:** People who are on their own without a family member or carer, and particularly elderly people with physical illness and disabilities, and people with mental health issues, may be failing to access the same level of information and support as people who have informal help. It would be worth exploring ways of improving communication and support during the assessment process for these user groups, to ensure that they understand the options and can have control, and a sense of control, over their support.

- **Developing easier routes to arrange respite care:** Users and their carers would benefit from the development of new ways of organising respite care which do not require people to go through Option 1, so that carers can access respite care more quickly and easily and it is also made accessible to people who feel unable to manage Option 1.

- **Increased flexibility over use of Option 1 budgets and a more outcome-focused approach:** In order to engage with the ethos of the SDS legislation, the assessment and budget-setting within Option 1 needs to encompass a wider range of types of support. These might include extra equipment, alternative or non-medical therapies, or care provided by a family member. People would be able to achieve their outcomes more effectively if particular kinds of support were not rigidly categorised as ‘critical’ or not critical, but the person carrying out the assessment could work with users or carers to identify ways in which the individual user might best achieve their outcomes through the different kinds of support that may be available to them.

  Applications for alternative kinds of support within Option 1 should not be considered only when they can be seen as a way of reducing the hours that a PA is required, but also as a better way of achieving users’ defined outcomes.

- **Information and assistance for Option 1 users in organising their support:** The survey data points to the need for greater support for people managing Option 1. Respondents suggest that it would be helpful if they were provided with comprehensive and consistent written advice, as well as better signposting to independent advice agencies, about how to reclaim expenses and manage the various required administrative tasks. Users would benefit from support that is coherent and easy to navigate, so that they do not feel they are left alone to hunt for help from numerous unrelated agencies.

- **Ensuring equality of access to support across the Options and with care providers:** Councils need to ensure that users are able to access an equal level of support whichever option they choose, and whoever they prefer to provide their care. In particular Option 1 users should not find themselves unable to access the level of support they have been assessed as needing, as a result of their choice of option or specialist care provider.

- **Developing Option 2:** This project highlights the lack of availability of Option 2. Developing Option 2, in conjunction with care providers and independent support agencies, so that it can be more widely available, would potentially provide a way to deliver more personalised care for people who do not want, or are unable to cope with, the responsibility of managing a direct payment.

- **Maintaining Option 3:** Many people still very much appreciate and are happy with Option 3 support. It is important to maintain this option for those who don't want or feel able to make a choice between support arrangements, or to take on responsibility for organising them.

10.2 Future research

The current survey was designed to be a pilot to test out the usefulness of a survey of social care users of this kind. Its timescale and cost-limitations, and the low response rates associated with this kind of research, meant that insufficient quantitative data was collected to allow statistically significant conclusions about the experiences of social care users across Scotland to be reached. A large scale survey across Scotland could address this, and this survey has helped to identify the issues that need to be addressed in carrying out such a survey. Several Local Authorities have offered to be involved in a future larger-scale survey. 80 respondents to the current survey gave their contact details and volunteered to take part in further research in relation to SDS.

The current project identified some issues that might also be usefully explored through further research in the near future. These include:

- **Social care users who are alone:** The responses suggest that people who don't have a family member or carer to help them may lack information and understanding of the choices, as well as lacking a sense of control over their support. Further exploration of the issues with understanding and making choices within SDS faced by those who don't have informal assistance from a family member or carer could potentially enable these people to be better engaged in the SDS process and to gain better control over their support.

- **Exploring good practice in achieving user understanding of SDS options:** While those carrying out assessments are required by legislation to offer users all four SDS options, some people find the options and the choices difficult to understand. Many people apply for support in situations of crisis in their lives and urgently require support to be set up. It would be useful to explore and identify best practice over how assessments can be carried out to provide the greatest control and personalised service to users, while reducing stressful decisions and lengthy processes of organisation.

- **Option 2:** It would be very useful to explore with individuals, councils, care providers and independent support organisations the different ways in which Option 2 might be developed. This could include looking at the experiences of people who already receive it, reasons why users might choose it, what people's preferences are for how it is organised, and problems that have been encountered in its introduction in different regions.
- **Accessing advice and support:** The current project identified that users can find it difficult to navigate among the various organisations who can provide support in the assessment and arrangement process, and that those who access independent advice and support organisations find them very useful. Further research could usefully explore the ways in which people can be supported most effectively, both in accessing the best sources of advice and support, and in setting up and arranging their support package.
- **People who apply but do not receive a support package:** This project was unable to include people who applied for support but, for whatever reason, did not receive a care package. Exploring the experiences of these people would provide a fuller picture of the provision of care and support in Scotland.
- **Experiences of support once it is in place:** This project included users who had completed assessments for support in the last 3-6 months. This captures users' experience of the assessment process and the initial support arrangement. Following users up after a longer period of time, after 6-12 months, would allow the inclusion in the data of users' experiences of established support delivered through the different SDS options.

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