Self Directed
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Self Directed Support
User Experience Survey – What people said

Survey report content

1. Acknowledgements

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This report is based on a research report written by Lucy Ramasawmy. The full version of the report can be accessed from:
www.sdsscotland.org.uk/guide-self-directed-support/self-directed-support-user-experience-survey/

2. Executive summary

This project was designed as a pilot survey to collect a sample of users' experiences of Self Directed Support (SDS) 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 people's needs and whether people 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 respondents 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, 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.

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.

3. The project: aims, design and who responded

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?
- 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
- 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?

These questions contribute to the over-arching research question:

- Do people get choice and control under SDS?

The project involved two stages. In the preliminary stage, eight informal interviews were carried out with SDS users. Interviewees included social care users living in Edinburgh and also in East and West Lothian. In the second stage, a paper questionnaire was sent out to users in three local authority areas: Aberdeenshire, City of Edinburgh and East Dunbartonshire. Local Authorities sent out questionnaires to all users who had completed assessments within a period of 3 months up to March 2016 (extended to six months for East Dunbartonshire).

It is important to note that the survey did not include the following groups:

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

It is also worth noting that as only people assessed in recent months were surveyed, the results are unlikely to be representative of all social care users, but provide a picture of people's experiences of the assessment process in place at the beginning of 2016.

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

A note on 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.

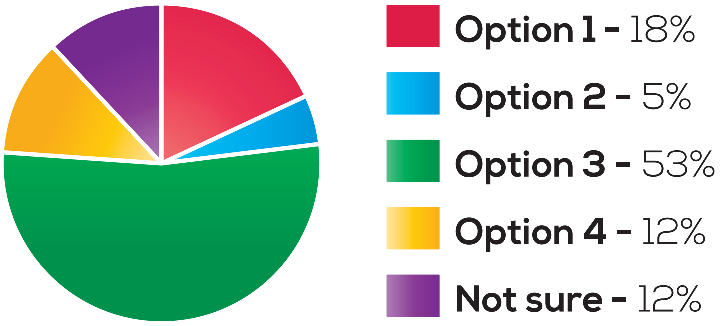
Who responded

The overall response rate was 18%, with area response-rates: 28% from Aberdeenshire; 18% from East Dunbartonshire and 12.5% from Edinburgh. Due to the low response rate and with only 226 returned questionnaire, analysis is limited to descriptive statistics and findings cannot be claimed to have statistical significance. It seems likely that people who had help available and those most able to understand and complete the questionnaire, and as a result those already familiar with SDS, may be better represented in the data collected.

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, showing similar variation in gender, age, user group and with long-term recipients of social care and newly assessed users included. Respondents in the 65+ age group in Aberdeenshire were over-represented, and respondents in the 18-64 age group slightly over-represented in Edinburgh. For Edinburgh respondents, and potentially across the respondent group, users on Options 1 and 4 appear to be slightly over-represented.

4. Take-up of SDS options

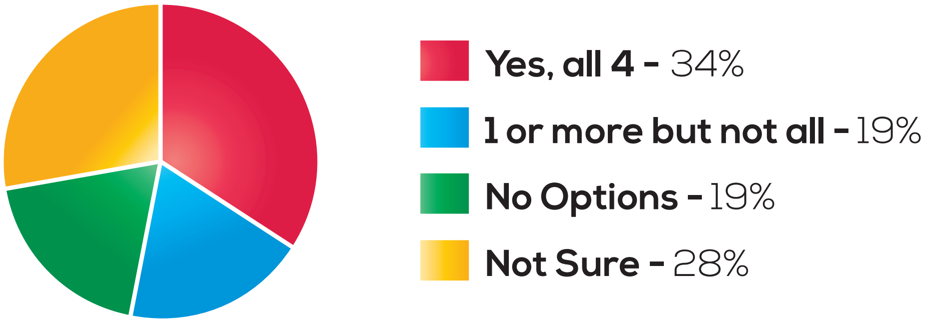
4.1 Respondents by Current SDS Option



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 are not always consistent with answers to other questions, or with council records. People with learning disabilities and mental health issues are more likely to use options other than Option 3. Those 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. There were very few responses for Option 4 users, but if this pattern held more widely it may reflect that combined options are set up in response to problems encountered over time while receiving support.

5. Information about the SDS options provided during the assessment

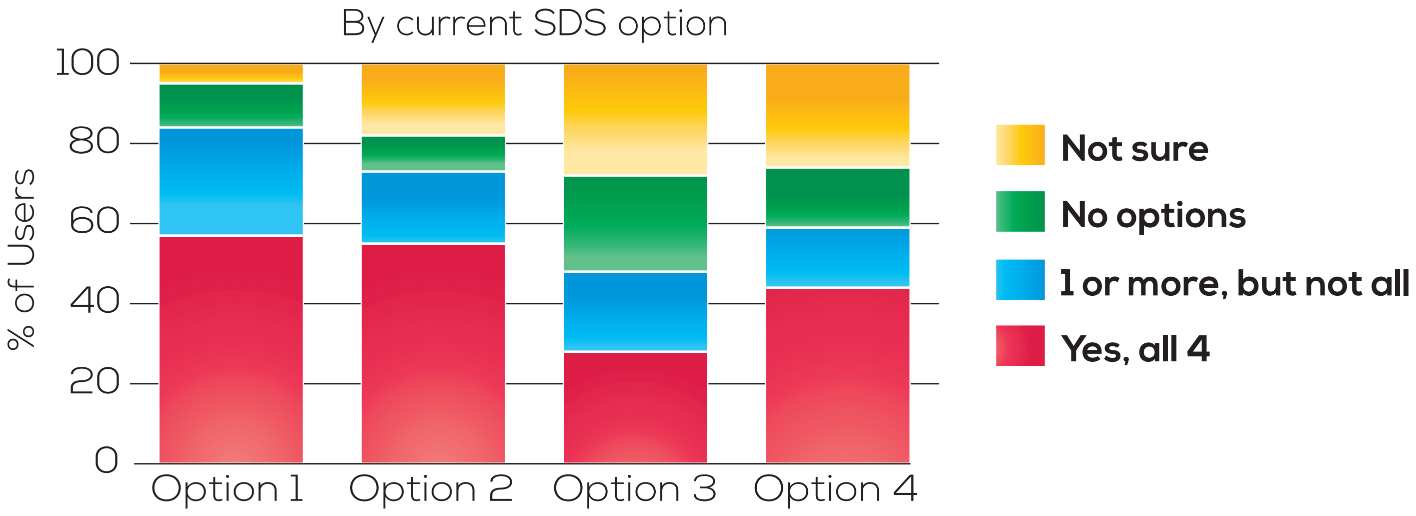
5.1 Did the person you met discuss the four options with you?



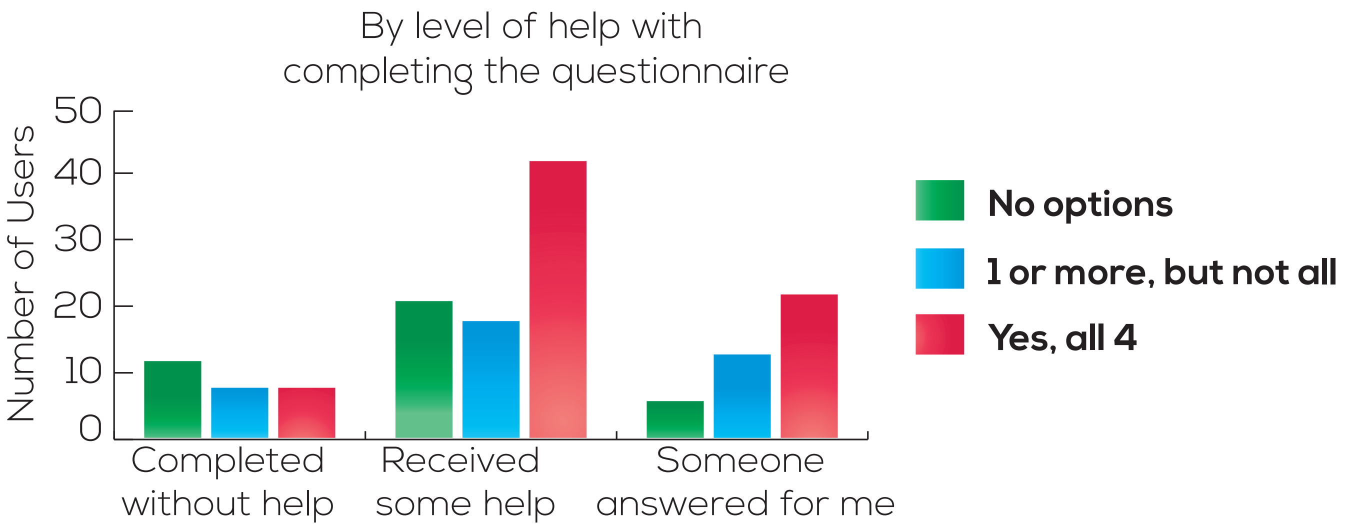
The findings show a substantial proportion of Social Care users to lack information about SDS and the options available to them. Less than half of respondents know about the existence of Self Directed Support.

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 were aware of having been told about their indicative budget.

5.2 Did the person you met discuss the four options with you?



5.3 Did the person you met discuss the four options with you?



Responses highlight that 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.

"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."
Respondent on behalf of mother who has dementia and lives in Edinburgh

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 (see Charts 4.2 and 4.3)

People are sometimes unclear about the purpose of the assessment visit and unaware that an assessment is being carried out.

"The person came to review the Guardianship and didn't say they were reviewing Support package too."
User with physical and learning disabilities who is on Option 1, Edinburgh

"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

5. Information about the SDS options provided during the assessment (contd)

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.

"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... 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."
Respondent from East Dunbartonshire

However, despite lack of information, the majority of respondents felt positively about their support arrangements.

"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

"Each and every professional concerned was both helpful and understanding – with all discussions conducted at a level easily understood."
User who has dementia receiving Option 3, Edinburgh

6. Help with setting up support

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.

"I organised [my father's] 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."
Respondent in Aberdeenshire

"There's no support from social services. They just give it to you and 'bye, bye!'"
Mother organising Option 1 support for her son who has multiple disabilities

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, making arranging support particularly difficult:

"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."
Respondent organising respite care for adult daughter who is on the autistic spectrum

"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."
Mother organising Option 1 care for her son who has learning and physical disabilities

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 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. Most Option 1 users however were positive about their experience and particularly about the support they received from Independent agencies.

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.

Respondents described how mobility aids, alternative therapies and social engagement choices that people felt to be as useful as conventional support options had been refused under 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

"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 feel that Art and Music Therapy, the 'Sitter service' and Aquarobics can [all] be seen as 'critical'... 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."
Respondent organising care for his wife who has dementia, East Lothian

A focus on reducing PAs' hours to a minimum was pr ioritised over other options that would improve people's health or quality of life.

"They tried to get me mobility aids along with my support package... but they were trying to cut down the amount of support you would get in terms of a PA... So it was using the aids and things to cut corners with support, whereas... 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."
User with physical disabilities in Edinburgh

Refusals 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.

"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."
Respondent organising support for her father who has dementia

Responses make it clear that availability of care provision is varied and depends on the users' 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. While some respondents found it possible to access highly flexible care under Option 1, others described care agencies who were unable to offer flexibility.

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 receiving support through Option 3.

A carer who does not want to take on Direct Payments, for example, emphasises the importance of specialised services:

"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]."
Respondent

8. Do people get choice and control under SDS?

Overall, respondents 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 respondents as preventing them from considering taking up Option 1.

Some people, however felt that they were guided or forced into taking Option 1.

"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 respite care for adult daughter with autism

Several respondents felt that Option 1 was too complicated or burdensome for them to be able to manage it. Some said they just wanted their care arranged for them. 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 complication.

"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

Several of those who had Option 1 said that they had only been able to choose it because a family member was already experienced or informed about direct payments.

"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

Even with relevant experience and help from independent agencies, Option 1 raises personal challenges for carers.

"Before I had to give up work, I was a project manager, I managed a big team and I did recruitment .. 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."
Mother who arranges care for her son who has multiple disabilities

One 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 users sign contracts which reduced their control over who provided their support.

"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."
Respondent

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.

"Living in a rural area, [Option 3] is still the best option."
Carer of female user, over 85 who has dementia, Aberdeenshire

"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, Aberdeenshire

"In looking for 24/7 care for [user], City of Edinburgh couldn't give a lot of choice… 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

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.

Those who received help filling in the questionnaire were more likely to say that they understood the SDS options and felt they had control over their support. This result raises a concern that users who do not have someone to support them may 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

- **Respite care:**

  One of the interviewees and several respondents to the questionnaire were unhappy that having applied for support with respite care, they had been told the only way they could get this was through Option 1. This was seen by some users as unnecessarily complicated and stressful, and they would have preferred to have respite care arranged for them.

- **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 extensions to a stay in hospital.

- **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.

10. Recommendations

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 people 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 users 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 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. Users 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 people's 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 people 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 users 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.

Recommendations for future research

Insufficient data was collected in this pilot project for statistically significant conclusions about the experiences of social care users across Scotland. A larger scale survey across Scotland could address this. Several Local Authorities have offered to take part in a future survey. 80 respondents to the current survey also gave their contact details and volunteered to take part in further research in relation to SDS, generating possibilities for qualitative research to explore findings in greater depth. Issues that might also be usefully explored through further research 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 users to be better engaged in the SDS process and to achieve greater 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 people all four SDS options, some users 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 users who already receive it, reasons why people 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 surveyed people 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.

HAPPY TO **TRANSLATE**

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