Personal experiences of Self-directed Support
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INTRODUCTION

From October to December 2016, the Health and Social Care Alliance Scotland (the ALLIANCE) carried out a small-scale, mixed methods research project into people’s personal experiences of Self-directed Support (SDS). We want to increase awareness and understanding of these experiences in order to help improve practice at the local and national levels.

SDS is defined as “the support individuals and families have after making an informed choice on how their Individual Budget is used to meet the outcomes they have agreed.”¹ It is aimed at shifting the balance of power from people who provide social care services towards those who access them, including disabled people and people living with long term conditions. SDS is administered by local authorities, who are legally required to offer those eligible a choice of four different options over how their SDS budgets and social care services will be managed.

We carried out a rapid desk-based inquiry into existing research on SDS in Scotland, followed by an online survey and focused one-to-one interviews with people who access social care services. As far as we are aware, at the time this was one of the largest direct consultations with self-selecting respondents who access or have applied for SDS in Scotland.

The desk-based research revealed issues about how well SDS is being implemented across the country and serious gaps in national evidence.

Our online survey and focused interviews revealed a mixed picture for SDS and the different groups of people who access it, including by age, gender and social care requirements. This reinforces anecdotal evidence from ALLIANCE members and others that people’s experiences of SDS are very varied. These diverse experiences could be the result of different approaches taken by Scotland’s 32 local authorities and their social work departments, as well as by individual social workers. Certainly, from some respondents’ feedback, there would appear to be inconsistencies in messages and understanding about what SDS can, or cannot, be used for and how it can be managed.

Although there is a welcome increase in satisfaction levels among people who have moved onto SDS, there remains several key issues highlighted by our findings that must be addressed if the underlying human rights principles and values of SDS are to be fully realised.

Resources permitting, in future, the ALLIANCE will be able to share more analysis. We also aim to refine and repeat the research to get a better idea of people’s changing experiences of SDS over time. In the meantime, we welcome opportunities to discuss this report and work with others to help address the issues raised.
ABOUT THE PROJECT

Context

About Self-directed Support

Self-directed Support (SDS) is defined as “the support individuals and families have after making an informed choice on how their Individual Budget is used to meet the outcomes they have agreed. SDS means giving people choice and control.”

SDS is enshrined in the Social Care (Self-directed Support) (Scotland) Act 2013 (‘2013 Act’), which came into force on 1 April 2014. The 2013 Act sits within Scotland’s 10-year national Self-directed Support strategy. The national SDS strategy is underpinned by the fundamental principles of choice and control and the human rights principles of equality, non-discrimination, participation and inclusion.

The national SDS strategy notes that, “The process for deciding on support through SDS is through co-production ... support that is designed and delivered in equal partnership between people and professionals.” The goal is to shift the balance of power from people who provide services towards those who access them, including disabled people and people living with long term conditions. In this way, people become pro-active agents in their support instead of passive recipients of care.

People should have choice and control over how to use their SDS. For example, they could decide to use it to support independent living, such as help with personal care in the home; for equipment or temporary adaptations. People could also choose to use SDS for support outside the home, for example to attend college, go to work, enjoy leisure pursuits or take short breaks. People should also be able to choose between using SDS to buy support from a local authority, private or third sector service provider or by employing Personal Assistants (PAs), or a combination of both.

The 2013 Act places a legal duty on local authorities to offer people who are eligible for social care a range of four SDS options. These are:

**OPTION 1**
Option 1 is a direct payment to the individual, who can use it in any way they choose as long as it secures the support agreed between the person and their social worker as set out in their support plan.

**OPTION 2**
Option 2 is when an individual chooses their support and provider but the local authority or a third party maintains control of the budget. In order to make an informed choice, individuals should be made aware of all the resources that are available to achieve their support plan.

**OPTION 3**
Option 3 is when the budget and support is managed and provided by the local authority in coordination with the individual. The individual should still retain choice and control over the type of support they receive.

**OPTION 4**
Option 4 is a mix of some or all of the first three options. This is suggested in the 2013 Act Statutory Guidance to provide maximum flexibility and may be attractive to those who would like to experiment with direct payments.

The principles of choice and control are supposed to apply irrespective of which option is taken.
Aims and objectives

The ALLIANCE carried out this research to gain a better understanding of the personal experiences of SDS among people who access social care and support across Scotland. By increasing awareness and understanding of these experiences, we aim to help inform and improve SDS practice at local and national levels.

Design

From September to October 2016 the ALLIANCE carried out a rapid desk-based research exercise to establish the level of data available about SDS since it came into force in Scotland in April 2014, including people’s personal experiences (see Appendix A). We then carried out a national online survey and semi-structured one-to-one interviews.

Survey respondents were asked if they would want to take part in one-to-one interviews to discuss in more depth their experience of SDS. We carried out 19 semi-structured interviews with individuals on the phone or face-to-face. The semi-structured approach enabled participants to guide the flow of the conversation depending on the issues most pertinent to their experiences. Each interview lasted on average 40 minutes and covered the entire process of accessing and managing SDS.

The interview guide is included at Appendix C and a copy of the consent form is included at Appendix D. The data was analysed using Nvivo, which broke down the qualitative interviews into codes that matched the framework of the survey responses.
Who took part?

Online survey

The quantitative data and quotes in this report come directly from the online survey with 102 self-selecting respondents.

Who took part in the interviews?

- 77% On someone’s behalf
- 23% Myself

We acknowledged that there could be access implications for some people wishing to complete the online survey and to maximise participation we enabled people to respond directly or with support.

Age of the person requiring SDS

- 49% 18-40yrs
- 17% 0-18yrs
- 19% 65+yrs
- 15% 40-65yrs

Gender of the person requiring SDS

- 50% Female
- 49% Male
- 1% Prefer not to say
We asked how people identify per the Scottish Government’s categories of ‘client group’. The largest groups of respondents are those who identify as having a learning and physical disability (26 per cent) and a physical disability (20 per cent). The ‘Other’ group was an open question that people used to indicate conditions like neuro-degenerative life-limiting illness, autism, and multiple conditions.
Access to social care before SDS

We asked people to indicate if they accessed social care support before they considered, applied for or acquired SDS.

Two thirds of respondents (66 per cent) were already in receipt of social care before getting or applying for SDS. One third (33 per cent) indicated that they were not already in receipt of social care before SDS.

“My son receives higher rate DLA and is 100% fully dependant on us for all care. Yet we have never received any social care or indeed SDS. The system is a joke.”

“We have never received any SDS or social care. We had a social worker who flagged up the possibility of SDS but he reassured us that some home help might be an option. As a result, we are currently on a waiting list for a care package.”

We asked people to indicate their SDS status at the time of completing the survey. As we can see, around 68 per cent of respondents were in receipt of SDS at the time they took part and 7 per cent were in the process of being assessed. 10 per cent of respondents hadn’t yet moved onto SDS, while a further 7 per cent had already been assessed and told they weren’t eligible. 8 per cent of respondents were unsure whether they were on SDS or not.
We asked people to indicate which SDS option was chosen by or for them. As we can see, the largest group is people on option 1 (50.6 per cent), followed by 16.9 per cent on option 2. A roughly similar proportion of respondents are on options 3 and 4 (10.1 per cent and 11.2 per cent respectively). Finally, 11.2 per cent of respondents indicated they were unsure which option was chosen.
Focused one-to-one interviews

Information about the 19 people who took part in focused one-to-one interviews is set out below. The personal stories in this report are from experiences shared during the interviews.

Who took part in the interviews?

- 63% On someone’s behalf
- 37% Myself

Age of the person requiring SDS

- 37% 18-40yrs
- 16% 40-65yrs
- 37% 65+yrs
- 10% 0-18yrs

Gender of the person requiring SDS

- 58% Female
- 42% Male
Current SDS status

- In receipt of SDS: 90%
- Currently being assessed for SDS: 5%
- Have social care but not on SDS yet: 5%

Category of social care requirement

- I have a physical disability: 32%
- I have a learning disability: 11%
- I have dementia: 21%
- I have a mental health issue: 5%
- I have a learning and physical disability: 5%
- I am a carer: 16%
- Other: 10%
From September to October 2016, the ALLIANCE carried out a rapid desk-based inquiry to identify and analyse the data available about SDS since the 2013 Act came into force on 1 April 2014.

Scottish Government statistics released in July 2016\(^6\) gave the first official indication of how SDS is being implemented across the country, some two years after its introduction. The analysis, which looks at data collected from each local authority\(^7\), provides a broad overview of the operational delivery of SDS for the period 2014-15.

Some of the Scottish Government’s headline findings were that:

- 35,173 people who accessed social care services used SDS, an estimated 20 per cent of all social care clients at the time.
- There are wide regional variations in the SDS implementation rate.
- The best estimate of which SDS option people chose was: 13 per cent option 1; 9 per cent option 2; 75 per cent option 3; and 3 per cent option 4.
- In total, the combined value of all recorded budgets associated with an SDS option in 2014-15 was estimated at £250m.

\(^6\) Data Under Development: Self-directed Support, ibid.

\(^7\) The report is prefaced by a caveat: “The introduction of SDS has resulted in changes to the way that Social Care information is recorded across Scotland; due to the changes required in data recording systems, the 2014-15 data on SDS for many local authorities remains incomplete. The results presented here should be interpreted with this in mind.”
The other information sources about SDS we identified are included in Appendix A. Our analysis of all sources has prompted the following concerns:

- To 2015, an estimated 20 per cent of those eligible had accessed SDS. We are concerned at this slow rate of uptake, particularly considering the figures come from what is effectively year 6 of a 10-year national SDS strategy.

- There are serious gaps in qualitative evidence for SDS across all local authority areas since implementation of the 2013 Act, and whether there has been a positive and sustainable impact on people’s lives.

- While we recognise the importance of recording statistical and expenditure data on SDS, we do not believe this fully tells us whether SDS is being implemented as the national law and strategy envisage; nor the extent to which people are enjoying their human rights to co-production, choice and control.

- We are concerned that the changes required in statistical data collection due to the introduction of SDS, as reported by the Scottish Government, should not lead to poor or incomplete evidence being gathered, or prevent the creation of a strong base level against which progress can be monitored.

- There are varying levels of SDS implementation across different local authority areas. The Scottish Government has identified that this may be down to difficulties in data gathering as well as phased roll outs as deemed appropriate by each authority. However, we believe that the human rights based principles underpinning SDS call for consistent implementation across the country so that people are not subject to a ‘postcode lottery’.

- Data suggests that the vast majority of people accessing SDS are on option 3, which is when both budget and support is managed and provided by the local authority. We are concerned about this for two reasons. Firstly, it indicates that less choice and control has been shifted towards people accessing services than we would like to see; and, secondly, it could signify that the move to SDS is being done in the most expedient way for local authorities, rather than those accessing services.

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8 Data Under Development: Self-directed Support, op. cit.


10 Option 3 is often perceived to be a simple continuation of the existing arrangements between local authorities and people accessing social care services and support.
This section explores people’s experiences of finding out about, and getting to know, SDS.

**How did you find out about SDS?**

<table>
<thead>
<tr>
<th>Category</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social Worker</td>
<td>22.2%</td>
</tr>
<tr>
<td>Family Member/Friend</td>
<td>12.2%</td>
</tr>
<tr>
<td>Scottish Government Info</td>
<td>5.6%</td>
</tr>
<tr>
<td>Internet</td>
<td>6.7%</td>
</tr>
<tr>
<td>Local Third Sector Org</td>
<td>13.3%</td>
</tr>
<tr>
<td>Local Authority Info</td>
<td>7.8%</td>
</tr>
<tr>
<td>Other</td>
<td>24.4%</td>
</tr>
<tr>
<td>Carer/PA/Support Provider</td>
<td>7.8%</td>
</tr>
</tbody>
</table>

As we can see, people were more likely to find out about SDS through contact with someone that is likely known to them (social worker / third sector organisation / family-member or friend), rather than information received from a more impersonal or official information source, such as the internet, the Scottish Government or local authority.

When broken down by SDS option, it appears that respondents on options 3 and 4 were twice as likely to have found out about SDS from a social worker compared to those on options 1 and 2.

Many of those who answered ‘Other’ used this open question to indicate that they found out about SDS via face-to-face contact with a third sector organisation or social work. One respondent indicated that they found out about SDS through their role as an independent advocate; another at school during transition planning; another via ‘other parents’; while another found out at day centre closure meetings. None of the respondents selected the category ‘Info at GP or hospital’, however two people referred to NHS sources in their ‘Other’ response.
How informed do you feel about SDS?

- I am not informed at all: 5.4%
- I know a little about SDS: 24.7%
- I know a fair amount about SDS: 29%
- I know a lot about SDS: 18.3%
- I am very informed about SDS: 22.6%

We asked respondents how informed they feel about SDS. The chart above indicates that the largest group know a ‘fair amount’ about SDS (29 per cent), while 23 per cent feel ‘very informed’ and 18 per cent know ‘a lot’.

Overall around 70 per cent of respondents indicate they are well informed about SDS. While this is positive, it is important to note that because the survey was disseminated predominantly via the ALLIANCE membership and third sector networks, there is a strong likelihood that respondents would already have a greater awareness of SDS than those not so engaged with the third sector. Bearing this in mind, it is somewhat concerning that around 30 per cent of respondents reported that they ‘did not feel informed at all’ or know only ‘a little’ about SDS.

Discussion(s) with social workers about SDS

- 81.7% YES
- 14% NO
- 4.3% Not Sure

We asked people if they have had any discussions with their social worker about SDS. Encouragingly, a large majority (82 per cent) have done so; however, 14 per cent have not and 4 per cent are unsure whether they have or not.
“Whilst our social worker advised us of SDS up-front she made it clear we did not want to have it & obstructed up-take.”

“Third sector organisation encouraged me to look at directing my own support in order to reduce isolation so I will be able to get out of my house - I cannot do this unaided and as yet only personal care is being discussed.”

“We didn’t know what we’re doing and it was never really explained to us in the first place but if I had known then what I know now, you would be more on the ball about what to ask for.”

As this chart indicates, around one third of respondents who identify as having a mental health issue have not had a discussion about SDS with a social worker.
Local advice centres and SDS

We asked respondents if they’d been in contact with their local advice centre.

As we can see, a fairly similar proportion of respondents either have (35.9 per cent) or have not (37 per cent). Of some concern is the fact that over a quarter of respondents (27 per cent) are not aware that they have an advice centre.
We cross-referenced people’s depth of knowledge by the SDS option they are on and our findings indicate that people’s depth of knowledge varies greatly depending on which SDS option they are in receipt of.

As we can see, people in receipt of options 1, 2 and 4 indicate far greater levels of knowledge than those on option 3. Around two thirds (66.6 per cent) of respondents on option 3 indicate that they are not informed or know only a little about SDS. None of the respondents on option 3 state that they feel very informed about SDS.
The majority of female respondents consider themselves relatively well informed about SDS, with around 74 per cent indicating they know ‘a fair amount’, ‘a lot’ or are ‘very informed’. In comparison, 65 per cent of male respondents consider themselves similarly informed.

While female respondents were much more likely than men to indicate that they know ‘a fair amount’ about SDS (40.4 per cent vs. 17.4 per cent), a higher proportion of male respondents feel that they are ‘very informed’ compared to female respondents (28.3 per cent vs. 17 per cent).
This chart indicates that as you move through the age groups the more informed respondents consider themselves to be about SDS. While a higher proportion of those aged over 65 were more likely to answer that they are ‘very informed’ about SDS (31.3 per cent), an almost equal amount said that they only know ‘a little’ about SDS (37.5 per cent). A fairly similar proportion of younger people (aged 18 or under) indicate they only know a little about SDS (35.3 per cent).
As the chart demonstrates, people’s depth of knowledge varies according to how they define their characteristics. A far greater proportion of people who identify as having a mental health issue indicate they know only a ‘little’ about SDS compared to the other groups. No-one with a mental health issue indicated they know a lot or feel very informed about SDS, compared to 35 per cent of those with a physical disability, 64 per cent of those with a learning disability and 39 per cent of those with both a learning and physical disability.

The high level of awareness amongst those who identify as having a learning disability could be explained by the fact that the survey is being completed on the person’s behalf by an informal carer (family member / friend). This could suggest that there is more availability of information and advice for families with members with a learning disability, or greater informal support networks.
This chart indicates the relationship between people’s depth of knowledge and whether they’ve discussed SDS with their social worker or not. Overall, those who have spoken with their social worker indicate greater knowledge about SDS than those who have not. 25 per cent of respondents who have had a discussion with their social worker report being either completely uninformed or only knowing a little about SDS compared to over 45 per cent of those who had not had such a discussion. These findings indicate not only how important it is for social workers to discuss SDS with people but also that there is some way to go to ensure that even when those discussions occur there are checks to ensure that people come away feeling fully informed.

“I think for cons, maybe because we weren’t given enough advice about how we could use it and what we could use it for, we weren’t given enough information.”

“I find social work department very resistant in coming forward with SDS. Unless someone tells the client about it. We are lucky we found out but other people are not.”
Role of information in SDS option choice

We asked respondents if the information they received about SDS helped them in choosing their SDS option.

The findings indicate that the majority of respondents (58.4 per cent) felt that the information they received about SDS helped them to choose which option of SDS would enable them to meet their requirements. However, a significant proportion (around 40 per cent) feel that the information they received had not, or were unsure if the information had assisted them in making a decision. Given the underpinning principles of choice and control, it is concerning to note that such a large proportion of people in receipt of SDS in Scotland may not feel that the information provided to them supports their decision-making process.
As we can see, the largest group is people on option 1 (50.6 per cent), followed by 16.9 per cent on option 2. Roughly similar proportions of respondents are on options 3 and 4 (10.1 per cent and 11.2 per cent respectively). Finally, 11.2 per cent of respondents indicated they were unsure which option was chosen.

“I thought people could have choice, either they wanted to attend a day centre or if they wanted, as it suited my son better, an outreach, so I thought self-directed support was a fantastic thing. What you read in legislation and the ethos of it is completely different from what you kind of find out.”
This chart indicates that a greater proportion of female respondents are on option 1 compared to male respondents (56.8 per cent vs. 44.4 per cent). We can also see that more than twice as many male respondents than female respondents are unsure which option has been chosen for them (15.6 per cent vs. 6.8 per cent).
This chart indicates that there are also variations of SDS option choice depending on the person’s age. A higher proportion of people aged 40-65 are on option 1 compared to all other age groups (66.7 per cent). More respondents in the highest age group (65+) are also on option 1 (56.3 per cent), and a high proportion of respondents aged 18-40 are also on option 1 (47.6 per cent).

At the other end of the age range, a quarter of those aged 18 or under have a mix of support, which is the highest proportion of those on option 4 amongst all age groups.
This chart demonstrates that those respondents who identify as having a physical disability or both a physical and learning disability are far more likely to be on option 1. No-one with a mental health issue indicates being on option 1 or 3.
We asked respondents to indicate who chose their SDS option. As we can see, 44 per cent of respondents either chose themselves or with family or friends. Just over one fifth (22 per cent) had their option chosen for them by a family member or friend. Around 15 per cent of respondents had their SDS option chosen for them by a social worker. Two respondents in the ‘Other’ group indicated they chose with the support of their parents or partner; two indicated they were not offered a choice; and another two indicated that social work made the choice.

From these findings it would appear that there is still some way to go for people to be fully in charge of choosing their SDS option, using, where required, supported decision-making rather than substitute decision-making approaches, and thereby putting into practice the principles of choice and control that underpin SDS law and strategy.
This chart shows that male respondents are more likely to report having made the choice of SDS option themselves than female respondents (30.4 per cent vs. 24.4 per cent). However, more female respondents made the choice with support from family or friends (20 per cent vs. 13 per cent). Female respondents are also more likely to have had the choice made for them either by family or friends or by a social worker.
This chart shows that those aged 40-65 were far more likely than any other age group to state that they made the decision themselves (53.3 per cent). Respondents aged 18-40 and 65+ were more likely to have the choice made on their behalf by family or friends. Respondents in the youngest age group were far more likely to indicate that a social worker made the choice compared to other groups.
"At the time I thought it was good, but now I’m kinda swaying to and forth with it because that was about a year and a half ago and since then a lot of things changed, so I was thinking that maybe if I had that money now, I could maybe use it to pay people to come in and help at bedtime or bath time"

"I wasn’t offered 4 options I had to ask, at first I asked for a mixed package way back and I was told I couldn’t get a mixed package [...] They just said that they didn’t do that."
As we can see, the majority of people on options 1 or 2 either chose themselves or with ‘family or friends’, whereas the majority of people on options 3 or 4 had the decision made on their behalf. It would appear that the more autonomy people have over their choice, the more likely they are to take more direct control of their SDS. Some respondents who used the ‘Other’ box to give additional information indicated that they were on option 3 and were not given any choice. It is also significant that it is only respondents on option 3 who indicate they do not know who made the choice. Around half of those on option 4 stated that they had the choice made for them by their social worker, which is the highest proportion across all four options.
Was the option you got your preferred choice?

71.3% YES
12.6% NO
16.1% Not sure

The majority of respondents (71 per cent) indicate that they received their preferred SDS option. While this is encouraging, we are concerned that 29 per cent of respondents indicate they did not get their preferred choice or are unsure.

“I was not offered any choice at all. Only personal care is being discussed and they didn’t ask me about choosing anything other than local authority workers.”

“Social Work gave us no option for SDS”

“Decided by social work chief officer”
The vast majority of those on options 1 and 2 indicate they are in receipt of their preferred SDS option. Over 40 per cent of respondents on option 3 state that they did not get their preferred choice. Those on options 3 and 4 are more likely to indicate that they are unsure as to whether they had received their preferred choice or not.

**Personal story**

My mum started showing signs of dementia. My mum fell down the stairs and broke her collarbone. [...] We were forced to put my mum in a care home against our wishes. They made the decision that we could not look after our mum because of it.

I became aware of [SDS] when I wanted to get money for my mum [and] my two sisters and I decided that we would keep her in the house instead of a care home. I was talking to a social worker. He told me about SDS and that was it. I had never heard of it. I was very happy. [...] When we brought her back home, we looked after her.

That is what Self-directed Support did for my mum. It gave us the opportunity to hire the best people that we could take. The carers that we got for my mum seemed like they were part of the family. One of them had a daughter and she named her daughter after my mum. She loves my mum. That is what SDS does it gives you the choice.
WAITING FOR SUPPORT

We asked people how long it took for their SDS package to be put into place after having been assessed. The question offered respondents a choice of six timeframes, ranging from a matter of weeks through to over a year.

As we can see, 12.5 per cent of respondents had their SDS package put into place within a few weeks of being assessed, while 6.25 per cent of respondents waited up to one month. 16.25 per cent have waited up to three months and 13.75 per cent have waited up to six months. 22.5 per cent have had to wait up to a year, while the largest group of respondents (28.75 per cent) have had to wait longer than a year for their SDS package to be put into place.
We analysed the length of time people waited for their package to be put in place by their SDS option. Traditionally, people on option 3 are most likely to have continued with their existing local authority services. This can explain why the majority of these respondents have waited a matter of weeks for their SDS package to be put in place.

Evidence suggests\textsuperscript{11} that those on option 2 may be offered services from a pre-prepared list of providers supplied by social work. It is therefore concerning that such a high proportion have had to wait more than a year for their package to be put in place. As we know, around 50 per cent of survey respondents are on SDS option 1 and the answers to this question demonstrate that people on this option have experienced a wide variation in the amount of time it has taken to get a support package in place.

\textsuperscript{11} Kettle, M., Self-directed Support - an exploration of Option 2 in practice, Caledonian University. 2015
In 2010 me and [my son’s] dad, we took ill health, we had always cared for my son and [he] wasn’t really known to Social Work, so in 2010 we went for help and it’s been a bit of an eye opener to me… He got assessed and I had asked for Self-directed Support because I had been Googling things and came across Self-directed Support and thought it was great… I just thought that you went to social work for help and it was available, so it took months and months and months and months for my son to get assessed… It’s just been a complete and utter nightmare.

My son liked going to ten pin bowling and it’s not free entry for the carer you’ve got to pay, so that was explained to me that their staff would need to be subsidised from the budget. I said that’s fine. The social worker said as long as it’s meeting his needs [it’s ok].

So I started getting the receipts off the staff and every monitoring return, three months, I was putting the receipts into the [Local Authority] Finance Section and everything was going fine. A whole year passed and I was whipped with a payback for all the money [and] they are still demanding all the money. [It] went into a few thousand pounds [and] I’m not the only carer that’s had a payback.

So I’ve had this hanging over me which is very stressful and a lot of carers are very stressed with it, … You feel very threatened, you go to meetings and you can be shouted and bawled at, I’ve seen carers in tears.
This section looks at how people use their SDS in order to meet their personal outcomes.

**What services do you use SDS for?**

<table>
<thead>
<tr>
<th>Service</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal Care</td>
<td>48.3%</td>
</tr>
<tr>
<td>Equipment and Adaptions</td>
<td>10.3%</td>
</tr>
<tr>
<td>Domestic Care</td>
<td>18.4%</td>
</tr>
<tr>
<td>Respite</td>
<td>47.1%</td>
</tr>
<tr>
<td>Social, Educational, Recreational</td>
<td>55.2%</td>
</tr>
<tr>
<td>Health Care</td>
<td>10.3%</td>
</tr>
<tr>
<td>Housing Support</td>
<td>5.7%</td>
</tr>
<tr>
<td>Meals</td>
<td>16.1%</td>
</tr>
<tr>
<td>Not sure</td>
<td>2.3%</td>
</tr>
<tr>
<td>Other</td>
<td>25.3%</td>
</tr>
</tbody>
</table>

This was a multiple choice question and respondents could choose as many options as they wished. The chart shows that social/educational/recreational, personal care and respite services feature most prominently as part of people’s SDS packages. Domestic support and meals were less likely but still feature as part of around 16 to 18 per cent of people’s support packages. Equipment and adaptations, health care and housing support feature between 5 to 10 per cent of some people’s packages.

Respondents who answered ‘Other’ used this to indicate that they had been refused SDS or are in the process of being assessed; or use it for one of the services listed.
We cross-referenced what respondents use their SDS support for by the type of package they are on. As we can see, respite and social, educational and recreational support are commonly used across all of the four SDS options. This may coincide with the high proportion of respondents who report using local authority and third sector services (respite and short break services) as these are the main supports offered either directly by local authorities or sub-contracted to the third/independent sector.

Respondents on option 1 indicate they use SDS across the range of multiple choice options available – the only group to do so. The largest group, around 70 per cent, of those on option 1 use their budget for personal care, which is much higher than those on options 2 and 3. These findings could suggest that the more control people have over who and how their support is provided, the wider a range of options they will select and the more likely they are to use it to meet their personal care needs. Over 70 per cent of those on option 2 use SDS for social, educational and recreational purposes.
Looking at the type of support respondents use SDS for, broken down by gender, the chart demonstrates that men are around twice as likely to have respite, equipment and adaptations through SDS than women.
Broken down by age, this chart suggests that people who are over 40 are more likely to use SDS for personal care than those under 40. People aged 40-65 are almost twice as likely to use SDS for domestic care than any of the other age groups.
As the chart shows, those with a physical disability are far more likely to use SDS for personal care than any other group. Meanwhile people with a learning disability, a mental health issue, or a learning and physical disability indicate that they are most likely to use SDS to access social, educational and recreational support.
We asked people to indicate how they use their SDS to meet their support requirements and responses spanned a range of options. Almost two thirds of respondents (60 per cent) stated that they use or purchase a service from a local private or third sector provider as part of their package. Around 20 per cent of respondents indicated they receive local authority services. Over 40 per cent of respondents use SDS to employ a PA who they either recruited themselves, was recruited for them by their family, or is a family member/friend acting as a PA. This high proportion is perhaps due to the high number of survey respondents who use option 1. Meanwhile, as the next chart demonstrates those on options 2 and 3 are more likely to choose local and third sector providers.
“Do not get any money - have been told just because you were awarded a budget does not mean you are entitled to any money”

“Recruited PAs through word of mouth (council stated recruitment costs not allowed).”

“I believe you are not allowed to employ a family member as a PA”

“Y’know if you dinnae eat, you die but that didn’t count. That did not come under personal care. So, providing food was not deemed necessary so really. So yeah, I’m very sceptical about this whole Self Directed Support thing.”
In breaking down this question to explore how people use their SDS options to meet their needs and outcomes, this chart shows that, overall, those on option 1 are more likely to choose to have a PA or family member support them (around 70 per cent), those on option 2 choose a local third sector provider (60 per cent), and those on option 3 manage SDS across a mix of PA, local third sector and private providers. In fact, no respondents on option 2 use a PA. Meanwhile, as is the intention, those on option 4 have a spread of support arrangements.
“We wanted to use our SDS to help with Physio, specialist pieces of equipment required, hydrotherapy etc and was told NO by our local authority it was only to be used for a personal assistant.”

“Not allowed to use for anything other than for a PA”

“[A local authority] refused its use for anything other than personal care & restricted this e.g. would not cover costs for e.g. NI taxes & many other costs of using personal assistants.”
Personal story

I have had a direct payment for over 10 years now. And initially we only had like, sort of 8 hours a week through direct payment. Then when my son left College, we had, erm, it kind of changed a wee bit. So we then went on to the Self-directed Support so we still chose the direct payment. I employ staff for him and what he does is he has his wee business, we set up a wee business for him and he manages his wee business... He does a wee business and I employ the personal assistants to come and help him to do his job and to go and out and do his different wee things that he does. He’s away to a wee drama group today, so it just depends what he wants to do, but I find it is good because we can choose where he wants to go and what happens.

[The assessment] was quite straightforward. [But] initially it did take about a year and it was because, I don’t know why that was, I think that was just how long it was taking at the time but that initial, when we first got it, we applied for it in 2004, we didn’t actually get direct payment until 2005 and it was only the eight hours a week as I say.

However, now I have had a review and this year I have been told that my budget next year is going to be £3,000 less... I don’t have a clue how they came to that decision. What I have done is I have put a letter back to them to say that I don’t agree with that decision.

I think it will have a big difference for him because he will have to cut back on where he goes and you know and with his clubs and things, he will just have to miss out some of them. He will not be able to do as much as he does.

I think the positives definitely outweigh the negatives and I think it is good to have it because you have got choice, flexibility and control over how it is worked. And I think for [him], it gives him what he wants, you know his wee job I don’t think anybody would be able to do... he has been put forward as an example of the kind of good practice of how it is being done.
MEETING PEOPLE’S REQUIREMENTS

In this section we explore whether people feel the SDS package they receive enables them to meet their requirements.

Although the move to SDS has shifted the language somewhat from one focused on hours of support delivered to a more personal outcomes approach, in practical terms people still use their SDS (individual budget) to meet their day-to-day support needs in order to achieve their outcomes. As such, we couched the language of this question accordingly, in order to better understand whether the support people receive enables them to meet their requirements, and thus outcomes, within the SDS package they have.

As we can see from the chart, around 51 per cent of respondents state that they do not feel the budget, translated to hours of support, was sufficient to meet their needs. 14 per cent were unsure, which means that around one third (35 per cent) of respondents stated that they feel they have enough hours of support to meet their daily requirements.
“There are 7 days in the week my son gets 4 days support and [the local authority] say I’m lucky to have this. I watch the clock constantly as I take my son to his services and pick him up again. The stress is unbearable.”

“As a carer I have stipulated I do not wish to care more than 18 hours a day, this has been ignored by social work services. I am therefore being forced to provide the additional care my daughter needs as she cannot be left on her own. If the budget is reduced further which is the proposal from social work this will force additional hours on to me as a carer. This battle has been going on for the last 5-6 years since the SDS pilot.”

“The hours only cover an assistant 8 hours of the day. I require 2 people for moving and handling at all times. Mum and dad always have to be on call during the day and always have to do night cover.”
Personal story

[Before SDS] my daughter had social care for a long time. For about 15 years I would think. [She] got 72 hours per week. That was all done by a care company. We had a few over the years. Some were better than others. The main problem with all of them was the lack of consistency of staff. There was always a huge shortage of staff. That was upsetting for my daughter. At the beginning of this year, the care company that we were with increased the prices by 70%. We were unable to get enough money to pay for the care that we needed.

[With SDS] the situation is just the same. The hours are still the same. [Social work] really concentrate on the care and number of hours. [...] There is very little left over for anything. They are just funding 72 hours of care and that is it. The basic care needs are being met indeed. However, there are not extra for visits and transport. She can only get out for one afternoon per week. That is what we can manage at the moment.

[However,] I think the direct payment means that we employ three carers directly. It has given you the ability to choose the people that you want. At the moment we are lucky, it is always the same people who do it. I do not know how we will keep all of them around. Three of them are already talking about moving away. It is very difficult to try and keep people. That is a big problem. [...] It is actually difficult to get people to do this work.
### SATISFACTION WITH SDS

#### People in receipt of social care services pre-SDS

**Satisfaction prior to receiving SDS**

<table>
<thead>
<tr>
<th>Satisfaction Level</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mostly Satisfied</td>
<td>38.71%</td>
</tr>
<tr>
<td>Not Satisfied</td>
<td>33.87%</td>
</tr>
<tr>
<td>Satisfied</td>
<td>14.52%</td>
</tr>
<tr>
<td>Very Satisfied</td>
<td>8.06%</td>
</tr>
<tr>
<td>Indifferent</td>
<td>4.84%</td>
</tr>
</tbody>
</table>

**Satisfaction after having SDS**

<table>
<thead>
<tr>
<th>Satisfaction Level</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mostly Satisfied</td>
<td>27.45%</td>
</tr>
<tr>
<td>Very Satisfied</td>
<td>25.49%</td>
</tr>
<tr>
<td>Satisfied</td>
<td>19.61%</td>
</tr>
<tr>
<td>Not Satisfied</td>
<td>21.57%</td>
</tr>
<tr>
<td>Indifferent</td>
<td>5.88%</td>
</tr>
</tbody>
</table>
### Comparison of satisfaction with support before and after SDS introduced

<table>
<thead>
<tr>
<th>Satisfaction level</th>
<th>Before SDS</th>
<th>After SDS</th>
<th>Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very Satisfied</td>
<td>14.52%</td>
<td>25.49%</td>
<td>+10.97%</td>
</tr>
<tr>
<td>Satisfied</td>
<td>8.06%</td>
<td>19.61%</td>
<td>+11.55%</td>
</tr>
<tr>
<td>Mostly Satisfied</td>
<td>38.71%</td>
<td>27.45%</td>
<td>-11.26%</td>
</tr>
<tr>
<td>Indifferent</td>
<td>4.84%</td>
<td>5.88%</td>
<td>+1.04%</td>
</tr>
<tr>
<td>Not Satisfied</td>
<td>33.87%</td>
<td>21.57%</td>
<td>-12.30%</td>
</tr>
</tbody>
</table>

As we can see, satisfaction levels among respondents after having been transferred onto SDS have shifted, with around 22 per cent indicating that they are more ‘satisfied’ or ‘very satisfied’. The number of respondents who are mostly satisfied or not satisfied have correspondingly reduced.
Satisfaction level before and after receiving SDS by option

We cross-referenced people’s satisfaction before and after SDS was introduced by the type of option they are on.

**OPTION 1**

<table>
<thead>
<tr>
<th>BEFORE</th>
<th>AFTER</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not satisfied: 37.04%</td>
<td>Not satisfied: 19.23%</td>
</tr>
<tr>
<td>Indifferent: 7.41%</td>
<td>Indifferent: 34.62%</td>
</tr>
<tr>
<td>Mostly satisfied: 29.63%</td>
<td>Mostly satisfied: 7.69%</td>
</tr>
<tr>
<td>Satisfied: 7.41%</td>
<td>Satisfied: 38.46%</td>
</tr>
<tr>
<td>Very Satisfied: 18.52%</td>
<td></td>
</tr>
</tbody>
</table>

Option 1 has a very significant shift of respondents who were ‘not satisfied’ or ‘indifferent’ before SDS to being ‘very satisfied’ after its introduction. Those who were ‘very satisfied’ have increased by around 20 per cent. There is also a small increase (around 5 per cent) in those who are ‘mostly satisfied’.

**OPTION 2**

<table>
<thead>
<tr>
<th>BEFORE</th>
<th>AFTER</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not satisfied: 25%</td>
<td>Not satisfied: 25%</td>
</tr>
<tr>
<td>Indifferent: 62.50%</td>
<td>Indifferent: 25%</td>
</tr>
<tr>
<td>Mostly satisfied: 12.50%</td>
<td>Mostly satisfied: 37.50%</td>
</tr>
<tr>
<td>Satisfied: 12.50%</td>
<td>Satisfied: 12.50%</td>
</tr>
</tbody>
</table>

There are a few changes in the satisfaction levels of respondents on option 2. Firstly, 25 per cent of respondents are not satisfied with support prior to SDS but there are no respondents dissatisfied with support after SDS is introduced. 62.5 per cent of respondents are ‘mostly satisfied’ pre-SDS, however this drops to 25 per cent after SDS is introduced. Prior to SDS none of the respondents on option 2 claim to be ‘satisfied’ with the support they receive, however after SDS is introduced 37.5 per cent of respondents indicate that they are ‘satisfied’.
Before the introduction of SDS, three quarters (75 per cent) of respondents on option 4 were ‘mostly satisfied’ and the rest were ‘satisfied’ or ‘very satisfied’. After the introduction of SDS there is a 16 per cent increase in those who are ‘satisfied’, however there are also more respondents who are now either ‘not satisfied’ (14 per cent) or ‘indifferent’ (14 per cent).
In the charts above we can see marked differences between the pre- and post-SDS satisfaction across all four options. Those who are ‘very satisfied’ include 39 per cent on option 1, 12.5 per cent on option 2, 14 per cent on option 3, and 14 per cent on option 4. Those who are dissatisfied post-SDS include 19 per cent on option 1, 0 per cent on option 2, 43 per cent on option 3, and 14 per cent on option 4.
People not in receipt of social care services pre-SDS

Satisfaction before and after receiving SDS

One third of respondents to our survey indicated that they did not access social care services before taking up an SDS option. These respondents show a substantial increase in their satisfaction levels after moving onto SDS. Prior to SDS, around 20 per cent of people who didn’t receive social care support were ‘mostly satisfied’ or ‘satisfied’ with support, which increases to around 56 per cent after SDS is introduced – including 21 per cent who are now ‘very’ satisfied. As the chart shows, prior to having social care around 80 per cent of respondents stated they were unsatisfied or indifferent towards their situation. This reduces by nearly half after respondents receive SDS.

While the increase in satisfaction levels with the introduction of SDS is encouraging, it is concerning that there is still a substantial proportion of those who are not satisfied (28 per cent) or indifferent (17 per cent) with the support they receive once an SDS package is in place.
Prior to getting SDS around 41 per cent of women report being “not satisfied” with their support compared to 27 per cent of men. Just under 70 per cent of men meanwhile reported being “mostly” to “very” satisfied with their social care prior to having SDS, compared to around 56 per cent of women.

For women, satisfaction levels overall have increased with the introduction of SDS, from around 56 per cent to around 74 per cent. However, although the proportion of women who are not satisfied has fallen from around 41 per cent to 15 per cent, there is now a greater proportion of women who are indifferent about the support they receive (about 12 per cent). Meanwhile, men’s satisfaction levels have evened out across the spectrum. Although there is virtually no change in the proportion of men who are not satisfied with their support and fewer are ‘mostly satisfied’ (37 per cent vs. 24 per cent), none are indifferent, and the numbers of those who are satisfied or very satisfied have grown.
This chart shows that prior to SDS over half of respondents aged over 65 were ‘not satisfied’ with their social care. This is greater than the other three age groups, although for these there is still a relatively high proportion of those ‘not satisfied’. All age groups report roughly the same levels of being ‘very satisfied’. Overall, the youngest age group (aged 18 and under) report the highest satisfaction level, with around one third ‘satisfied’ or ‘very satisfied’. This is followed by those aged 18-40, with around one fifth ‘satisfied’ or ‘very satisfied’.
The introduction of SDS has changed satisfaction levels across all age groups. Respondents aged 18 and under now report nearly double the rate of being ‘not satisfied’ with a shift from 33 per cent to 62.5 per cent. Post-SDS no-one in this age group reports being ‘very satisfied’, the proportion who are ‘satisfied’ has roughly halved and those who are ‘mostly satisfied’ has reduced 20 per cent. The proportion of respondents in the oldest age group who are ‘not satisfied’ has decreased by around 20 per cent and ‘mostly satisfied’ by 15 per cent. While there is now 33 per cent of respondents aged 65+ who are ‘satisfied’, there are no longer any respondents in this age group who are ‘very satisfied’. In contrast, the satisfaction levels amongst the other two age groups have both substantially increased.
As we can see, respondents with a physical disability and those with a learning disability and a physical disability are more satisfied after SDS is introduced, with a corresponding drop in dissatisfaction rates. The proportion of respondents with a mental health issue who are dissatisfied remains unchanged, although a third now indicate they are satisfied.
SUMMARY OF MAIN FINDINGS

Uptake of SDS and national evidence

- From our desk-based research there appears to be a very low uptake of SDS, with only 20 per cent of those eligible doing so by 2015, and the majority of people are on option 3.

- There appears to be varying levels of SDS implementation across different local authority areas.

- There appears to be very little national evidence being gathered into people’s personal experiences of SDS, their perceptions of its impact on their personal outcomes and whether it is helping them have more choice and control over their support.

- Some of the data supplied by local authorities for Scottish Government national SDS reporting is patchy and inconsistent.
People are more likely to find out about SDS through contact with their social worker, the third sector, or someone known to them than online or through more official sources like the Scottish Government or local authority.

Around 70 per cent of respondents overall indicate they are informed about SDS, while 30 per cent indicate they know little or nothing about SDS.

The majority of respondents (82 per cent) have discussed SDS with a social worker, however 14 per cent have not and 4 per cent are unsure.

8 per cent of respondents do not know if they are on SDS or not.

Although people that have discussed SDS with a social worker feel more informed about it than those who haven’t, 25 per cent of those who have, still indicate knowing little or nothing.

22 per cent of respondents indicate that the information they received about SDS didn’t play a role in helping them choose the option they are on and 19 per cent are unsure whether it did or didn’t.

36 per cent of respondents have discussed SDS with a local advice centre but 27 per cent did not know they had a local advice centre.

None of the respondents stated that they heard about SDS at the GP or in hospital though this was mentioned in the ‘Other’ open question.

People’s depth of knowledge about SDS varies depending on which option they are on, their age, gender and characteristics.

Those on option 3 indicate far less knowledge about SDS than those on other options.

Respondents on options 3 and 4 are almost twice as likely to have found out about SDS from a social worker than those on options 1 and 2.

66 per cent of respondents on option 3 state that they know little or nothing about SDS, compared to 18 per cent on option 1, 34 per cent on option 2 and 10 per cent on option 4.
• No-one on option 3 indicates they are very informed about SDS compared to 33 per cent on option 1, 27 per cent on option 2 and 20 per cent on option 4.

• Overall, 74 per cent of female respondents indicate they are informed about SDS compared to 65 per cent of men. Men are more likely to indicate being very informed compared to women (28 per cent vs. 17 per cent) but more men than women also indicate they know only ‘a little’ (30 per cent vs. 19 per cent).

• As respondents get older the more informed about SDS they consider themselves to be. However, around a third of the oldest (65+) and youngest age groups (0-18 years) indicate knowing only a ‘little’ about SDS.

• Around one third of respondents who identify as having a mental health issue have not talked about SDS with a social worker.

• People with a mental health issue are substantially more likely to indicate that they only know only a ‘little’ about SDS (67 per cent) than those with a physical disability, a learning disability, or both.

• No-one with a mental health issue indicates they know a lot or feel very informed about SDS, compared to 35 per cent of those with a physical disability, 64 per cent of those with a learning disability and 39 per cent of those with both.
Choosing an SDS option

- 51 per cent of respondents are on option 1, 17 per cent on option 2, 10 per cent on option 3 and 11 per cent on option 4. 11 per cent of respondents are unsure what option they are on.

- The proportion of respondents on different options varies depending on their gender, age and characteristics.

- More female than male respondents are on option 1 (57 per cent vs. 44 per cent). The proportions of those on options 2, 3 and 4 are roughly similar between the genders. Far more men than women are unsure what option they are on (16 per cent vs. 7 per cent).

- Two thirds of those aged 40-65 are on option 1 compared to around one third of those aged under 18 and a half of those aged 18-40 or 65+.

- 25 per cent of those aged under 18 are on option 4 compared to no-one aged 65+.

- None of the respondents aged 40-64 are on option 2, compared to a quarter of those aged 65+, a fifth of those aged 18-40 and an eighth of those aged 18 and under.

- No respondents with a mental health issue are on option 1, compared to 65 per cent of those with a physical disability, 36 per cent of those with a learning disability, and 53 per cent of those with both.

- 44 per cent of respondents chose their option either alone or with the support of family/friends and 37 per cent of respondents had their option chosen for them by family or friends or a social worker.

- The proportion of respondents who chose their SDS option or had it chosen for them varies depending on their gender, age and characteristics.

- Roughly the same proportion of male and female respondents indicate they chose their SDS option alone or with support from family/friends, however more men made the choice alone compared to women (30 per cent vs. 24 per cent).

- One quarter of women have had their SDS option chosen for them by family or friends compared to a fifth of men.
A substantially greater proportion of respondents aged 40-65 indicate they chose their SDS option themselves compared to other age groups (53 per cent).

29 per cent of those aged under 18 had the choice made by a social worker – substantially higher than other age groups.

Those aged 18-40 and 65+ are more likely than other age groups to have the choice made on their behalf by family or friends.

Over half of respondents on option 1 (60 per cent) and option 2 (60 per cent) state that they chose their SDS package themselves or with input from friends or family.

The majority of respondents on options 3 and 4 indicate that a family or friend or social worker made the choice on their behalf. 50 per cent of respondents on option 4 indicated a social worker made the choice.

Over two thirds (71 per cent) of respondents indicate they got the option of their choice, however 29 per cent either did not or are unsure.

The vast majority of respondents on options 1 and 2 indicate that this was their preferred choice.

Over 40 per cent of respondents on option 3 indicate this was not their preferred choice.

Nearly 40 per cent of those on option 4 are unsure if this is their preferred choice.
Waiting for support

- 12.5 per cent of respondents had their SDS package put in place within a matter of weeks of being assessed and 35 per cent of respondents had it within 3 months.

- 14 per cent of respondents had to wait up to 6 months for their SDS package to be put in place, 22.5 per cent had to wait up to one year and 29 per cent waited a year or longer.

- Overall, 51 per cent of respondents had to wait up to a year or more to have their support packages put in place after being assessed.

- There are variations in waiting times depending on which SDS option is chosen.

- Over 40 per cent of those on option 3 have their package in place within a matter of weeks, whereas the same proportion of those on option 2 have waited a year or longer.
Managing SDS

- People use SDS predominantly for social, educational and recreational purposes, personal care and respite services.

- Respondents on option 1 use SDS across a wide range of services and support, and a far higher proportion use it for personal care than those on options 2 or 3.

- More respondents on option 2 use SDS for social, educational and recreational purposes than any other group.

- Almost two thirds of all respondents (60 per cent) state that they use or purchase a service from a local private or third sector provider as part of their package.

- Around 20 per cent of respondents indicate they receive local authority services.

- Over 40 per cent of respondents use SDS to employ a Personal Assistant (PA) who they either recruited themselves, was recruited for them by their family, or is a family member/friend acting as a PA.

- Respondents on option 1 are twice as likely to use a PA than a service provider.

- No respondents on option 2 indicate that they used a PA.

Meeting people’s requirements

- 51 per cent of respondents state that the amount of hours they are given in their SDS package is not sufficient to meet their needs for each day, and 14 per cent are unsure.
Satisfaction with SDS

- Generally, for those who were in receipt of social care before SDS, satisfaction has increased after its introduction (22 per cent increase in those who are ‘very satisfied’ and ‘satisfied’).

- The proportion of people not in receipt of social care before SDS who are satisfied with their support has substantially increased with its introduction.

- For those who were in receipt of social care prior to SDS, shifts in satisfaction levels vary according to which option people are on.

- Post-SDS, those who are ‘very satisfied’ include 39 per cent on option 1, 12.5 per cent on option 2, 14 per cent on option 3, and 14 per cent on option 4.

- Post-SDS, 19 per cent of respondents on option 1 are dissatisfied with their support, 0 per cent on option 2, 43 per cent on option 3, and 14 per cent on option 4.

- Those respondents on option 1 who are ‘very satisfied’ increase from 19 per cent to 38 per cent and those who are not satisfied decreases from 37 per cent to 19 per cent.

- Pre-SDS a quarter of people on option 2 were unsatisfied with their support whereas none indicate dissatisfaction after its introduction. The proportion of those who are ‘very satisfied’ remains unchanged at 12.5 per cent pre- and post-SDS, however the number of those who are ‘satisfied’ increases from none to 37.5 per cent.

- The proportion of those on option 3 who are dissatisfied increases very slightly by around 5 per cent following the introduction of SDS. Those that are ‘satisfied’ increases from 12.5 per cent to 43 per cent. 14 per cent also indicate they are now very satisfied, compared to none before.

- Satisfaction levels of respondents on option 4 change significantly with the introduction of SDS. Prior to SDS, 75 per cent were mostly satisfied and 25 per cent were ‘satisfied’ or ‘very satisfied’. With the introduction of SDS, 43 per cent are now ‘satisfied’ or ‘very satisfied’; ‘mostly satisfied’ drops to 29 per cent; and 14 per cent are either dissatisfied or indifferent.
- A substantial proportion of people who were not in receipt of social care prior to SDS are now dissatisfied (28 per cent) or indifferent (17 per cent) about their support.

- Prior to SDS, 41 per cent of women and 27 per cent of men were dissatisfied with their support. After SDS was introduced, 15 per cent of women are dissatisfied and 28 per cent of men.

- The proportion of men and women who are ‘satisfied’ or ‘very satisfied’ with their support after SDS is introduced increases. The figure for women more than doubles from 16 per cent to 42 per cent.

- The proportion of those dissatisfied with support after SDS is introduced reduces for all age groups except the youngest, for whom dissatisfaction almost doubles from 33 per cent to 62.5 per cent. Those aged 18-40 and 40-65 have the greatest increase in satisfaction levels.

- Respondents with a physical disability and those with a learning disability and a physical disability are more satisfied after SDS is introduced.

- The proportion of respondents with a mental health issue who are dissatisfied after SDS is introduced remains unchanged, although a third indicate they are satisfied.
Recommendations

1. The ALLIANCE is concerned that SDS is not being implemented according to its underlying rights-based values and principles, and will therefore neither achieve transformational change in social care culture and services, nor help improve people’s lives. We recommend that a focused and systematic response is developed involving the Scottish Government, local authorities, the third sector, people accessing services, unpaid carers and other relevant stakeholders.

2. We are troubled by reports that people do not think their SDS package is sufficient to meet their daily requirements, or are unsure. We encourage the Scottish Government and local authorities to acknowledge the issues with SDS funding and service delivery and work with other relevant stakeholders, including people who access services and the third sector, to develop solutions. This could be done as part of a wider national conversation about the future of social care and SDS.

3. Health and Social Care Partnerships should instigate greater collaboration between health services (community practitioners, GPs and hospital settings) and social care colleagues to promote integrated and preventative approaches through SDS. Good practice of this approach has been developed in various areas (e.g. Highlands, East Ayrshire, Forth Valley) that COSLA and NHS Scotland could help spread.

4. In 2015 an estimated 20 per cent of those eligible were in receipt of SDS. If this number does not substantially increase by 2018 we call for a national review and implementation of corrective measures.

5. In order to address low uptake and poor understanding of SDS, we recommend a targeted campaign co-designed by the Scottish Government, local authorities, Health and Social Care Partnerships, social workers, the third sector, people who access services, unpaid carers/family/friends and other relevant stakeholders.

6. To gain a fuller picture of SDS, local authorities and the Scottish Government must ensure robust qualitative research is regularly shared on people’s personal experiences and their perceptions of the impact it is having on their lives, to complement current statistical and financial data.

7. The changes required in statistical data collection due to the introduction of SDS should not lead to poor or incomplete information being gathered or prevent the establishment of a strong base level against which progress can be monitored.
8. Most people would appear to find out about SDS through personal interaction, therefore social work departments should prioritise direct discussions about SDS with people who access services during any contact about reshaping their support. Particular attention must be given to this in mental health settings.

9. Health and Social Care Partnerships and others should make SDS information and support more readily available and accessible in health settings like GP practices and hospitals, and through Allied Health Professionals.

10. Social work departments should introduce regular review processes for everyone in receipt of SDS, designed to encourage people to fully explore all four options to best establish the most appropriate arrangement that meets their outcomes.

11. People on option 3 should be a particular focus for approaches that help increase their empowerment and the level of choice and control exercised over their support. As these approaches are increasingly mainstreamed, we expect to see a shift in numbers from those on option 3 to options 1, 2 and 4. If not, further investigation at national and local authority level will be required.

12. Social workers should be mindful of the impact an individual’s gender, age and social care requirements may have on their opportunities to make autonomous or supported decisions around SDS.

13. We strongly recommend further national and regional investigation into the causes and consequences of the different SDS options chosen and who makes the choice, depending on a person’s gender, age and social care requirements.

14. Substantial investment in and promotion of local advice and independent advocacy provision must be made to support people during the SDS assessment process.

15. There are extensive delays in getting some people’s SDS packages underway, particularly for those on options 2 and 3. Urgent action is required to further investigate and create mandatory time limits that will be closely monitored. This could be considered by the Scottish Government’s National Review of Targets and Indicators being undertaken by Sir Harry Burns\(^2\).

16. Local authorities must make greater efforts to increase people’s awareness and understanding of, and access to, services and support available from the third sector.

\(^2\) Scottish Government’s National Review of Targets and Indicators, Sir Harry Burns, expected Spring 2017

http://www.gov.scot/Topics/Health/Quality-Improvement-Performance/Review-Targets-Indicators
17. Despite a rise in satisfaction levels, our findings suggest worrying dissatisfaction amongst some people, depending on their SDS option, age, gender and social care requirements. Further national and regional investigation is needed and social work departments should be mindful of this when engaging with people about SDS.

18. To support ongoing improvement to SDS we recommend creating (a) a pro-active feedback system whereby local authorities regularly seek people’s views; and (b) a national independent ‘whistle-blowing’ mechanism for those delivering and accessing SDS to raise concerns.
APPENDICES

Appendix A – Desk-based research

From September to October 2016 we carried out a rapid desk-based enquiry into existing research on SDS in Scotland. Indicated below are the sources we identified:


- Want the Same As You, Dr Susan Elsley and Children in Scotland, 2015 - http://www.childreninscotland.org.uk/sites/default/files/SDS_report-re.pdf

Overview of Local Authority updates on SDS implementation since 2014

The ALLIANCE gathered information from local authority update reports. Below is a list of local authorities from whom we were able to access information.

Aberdeenshire Council
Angus Council
Argyll & Bute Council
Clackmannanshire Council
Dundee City Council
East Ayrshire Council
East Dunbartonshire Council
East Lothian Council
East Renfrewshire Council
Edinburgh City Council
Falkirk Council
Fife Council
Glasgow City Council
Inverclyde Council
Midlothian Council
Moray Council
North Ayrshire Council
Orkney Islands Council
Renfrewshire Council
Scottish Borders Council
South Ayrshire Council
South Lanarkshire Council
Stirling Council
West Dunbartonshire Council
West Lothian Council
Appendix B – Online survey questionnaire

1. Are you answering for yourself or on someone’s behalf?
2. Gender of person requiring support
3. Age of person requiring SDS
4. Status of SDS
5. Where do you live?
6. How do you identify according to the Scottish Government’s categories of support needs?
7. Were you in receipt of social care before getting or considering SDS?
8. How satisfied were you with the support you were receiving before SDS?
9. How informed do you feel about SDS?
10. Have you had a discussion with your social worker about SDS?
11. Have you been in touch with your local advice centre about SDS?
12. Did the information you received about SDS help you in choosing which option you wanted to meet your support needs?
13. How did you find out about SDS?
14. How much do you know about each option?
15. What option was chosen for or by you?
16. Who made the choice about your option of SDS?
17. Was the option you got your preferred choice?
18. How long did it to take from applying for SDS to getting it in place?
19. What services do you use SDS for?
20. How do you manage you SDS?
21. How satisfied are you with the support you are now receiving through SDS?
22. Do you feel like you have enough hours to meet your support needs for each day?
23 – 26. If you receive Option 1/2/3/4 please give your answer to the following statements
I like having control over my budget
I like employing my own staff
I like managing my support around my life
I like the flexibility of using my budget for what I need
I feel there is good support to help me manage my budget
I feel social work keeps in touch with me regularly enough
I feel capable of providing monitoring returns on how I use my budget
The support I receive enables me to do live independently
When my needs change I feel I am able to change my support
Appendix C – Semi-structured interview guide

Introductory question
- Tell me about yourself/the person you support, and how you became aware of SDS?

Follow up
- What was your experience of social care prior to SDS?
- What were your expectations of having support through SDS?

Route to SDS
- Can you talk me through your experience of getting to the point of having your needs assessed for SDS?

Follow up
- What information and support (if any) did you have that helped you with this process?

Assessment
- What was your experience of engaging with your social work department?

Follow up
- Were there any positive/negative aspects of the assessment that stick out?

The choices
- Can you talk me through how the choice of SDS was presented to you by your social worker and how you came to a decision about which one would meet your outcomes?

Follow up
- How did the choice you made contrast/correspond to the way in which your social care was being delivered prior to SDS (if they had it)?
**After being deemed eligible (if they were)**
- Can you talk me through the steps that then occurred to support you to put your support in place?

**Follow up**
- How were you treated by your social work department?
- Did you feel supported to arrange the support you wanted? Were you equipped to arrange the support you wanted?

**Arranging support**
- Can you tell me about how you managed to put support in place?

**Follow up**
- How long did this take and what were the pros/cons of doing so?
- Were you supported by an Independent Living Centre or Brokerage service?

**Managing SDS**
- Since arranging your support, can you tell about the support you now receive and how you feel it is meeting your day-to-day needs (and longer-term outcomes?)

**Follow up**
- In what ways do you think SDS has impacted your experience of social care?
- How do you think your choice and control is put into practice by having SDS?

**Conceptualising SDS**
- Do you feel that SDS is enabling you/your family to live the way want?

**Follow up**
- How is it meeting your expectations/ambitions?
- If there were any way it could be improved to meet your outcomes, what would it be?
Appendix D – Consent form

- I confirm that I understand the purpose of this research and the researcher has answered any queries to my satisfaction.
- I understand that my participation is voluntary and that I am free to withdraw from the project at any time, up to the point of completion, without having to give a reason and without any consequences. If I exercise my right to withdraw and I don’t want my data to be used, any data which have been collected from me will be destroyed.
- I understand that I can withdraw from the study any personal data (i.e. data which identify me personally) at any time.
- I understand that anonymised data (i.e. data which do not identify me personally) cannot be withdrawn once they have been included in the study.
- I understand that any information recorded in the interview will remain confidential and no information that identifies me will be made publicly available.
- I consent to participating in the project.
- I consent to being audio recorded for the purpose of more accurate note-taking.

Please select one

Yes  No

PRINT NAME

Signature of Participant

Date
About the ALLIANCE

The ALLIANCE is the national third sector intermediary for a range of health and social care organisations. The ALLIANCE has over 1,900 members including large, national support providers as well as small, local volunteer-led groups and people who are disabled, living with long term conditions or providing unpaid care. Many NHS Boards and Health and Social Care Partnerships are associate members and many health and social care professionals are Professional Associates. Commercial organisations may also become Corporate Associates.

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

The ALLIANCE has three core aims. We seek to:

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