Children, Young People and Families’ Experiences of Self-directed Support
Briefing Paper - May 2018
Health and Social Care Alliance Scotland (the ALLIANCE)

This briefing follows the publication of the ALLIANCE’s ‘Personal Experiences of Self-directed Support’ research in May 2017[1].

Introduction

In early 2017, 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). This took the form of a desk-based analysis of existing research, an online survey, and focused one-to-one interviews.

SDS is defined as “the support individuals and families have after making an informed choice on how their Individual Budget is used to meet the outcomes they have agreed.”[2] It is aimed at shifting the balance of power from people who provide social care services towards those who access them, including disabled people and people living with long term conditions.

SDS is administered by local authorities, who are legally required to offer those eligible a choice of four different options over how their SDS budgets and social care services will be managed. Option 1 is a direct payment made to the individual; option 2 is when an individual chooses their support and provider but the local authority or third party manages the budget; option 3 is when the support and budget are managed by the local authority; and option 4 is a mixture of some or all of the first three.

This briefing explores the experiences of SDS by children, young people, and their families (CYP). By looking in greater depth at responses to our research questions from CYP, we aim to gain a better understanding of how they engage with and experience the process of SDS. We also hope it will contribute to a growing body of evidence to help improve SDS policy and practice.

Separate sections of this paper look in detail at CYP awareness, understanding and satisfaction with SDS, how they manage their support and whether it is enough to meet their requirements. The final sections set out a summary of the main findings and our recommendations.

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

[2] Self Directed Support: A National Strategy for Scotland, Scottish Government, 2010 http://www.gov.scot/Resource/Doc/329971/0106962.pdf

Foreword

Bruce Adamson, Children and Young People's Commissioner Scotland

This report is a timely contribution to discussion on disabled children and young people's opportunities to fully realise their rights to social care support.

The rights of disabled children and young people are outlined by the United Nations Convention on the Rights of the Child (UNCRC) and the United Nations Convention on the Rights of Disabled People (UNCRPD). Disabled children have the right, as detailed in article 19 of the UNCRPD to "access to a range of in-home, residential and other community support services, including personal assistance necessary to support living in the community and to prevent isolation or segregation from the community". The purpose of this is to allow them full enjoyment of the range of rights provided to all children within the UNCRC, the UNCRPD and other human rights treaties.

Properly funded Self-directed Support will enable disabled children and those with long term conditions to realise their rights, but as the ALLIANCE's research shows, the intentions of the SDS legislation to offer more choice and control appears not to have become a reality for many disabled children and young people, and their families.

Both the UNCRC (article 12) and UNCRPD (article 7) states that children with disabilities have a right to be involved in decision making about matters that affect them, in line with their age, maturity and developing capacity. Yet one of the most concerning findings from the ALLIANCE's report is that children and young people, with their families, were more likely than any other age group to state that it was social workers who made the decision about their SDS option. Feeding into this is a broader narrative around the depth of knowledge and understanding children and young people have about SDS and their rights to it.

If you consider the experiences of children and young people alongside those of other demographics, it is concerning that the ALLIANCE's research found that their satisfaction with their support decreases once SDS has been introduced. This is an interesting issue when considering the status of participants, with the majority stating that they received their preferred choice and were on Option 1 of SDS. This suggests that the way in which options are being offered to children, young people and their families isn't matched by the realities of managing their day-to-day support.

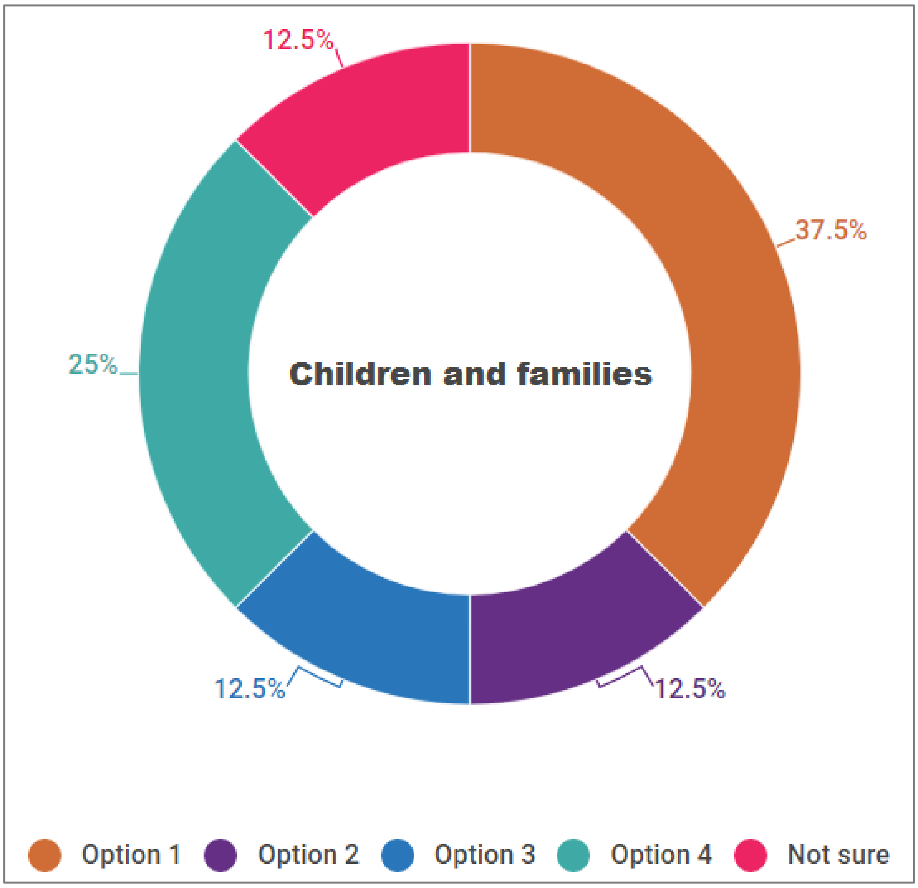
Moreover, the majority of participants stated that the support they received was not sufficient to meet their day-to-day needs. Yet the UNCRPD requires support provided to enable full participation in all aspects of life (article 9) and to allow them to fully enjoy their right to live in the community (article 19) and enjoy the full range of rights available to everyone.

The ALLIANCE's findings and recommendations highlight a lack of appropriate provision to enable children, young people and their families to positively access personalised, outcomes-focussed support through SDS. Without this provision, disabled children and young people are not able to fully realise their human rights.

Contents

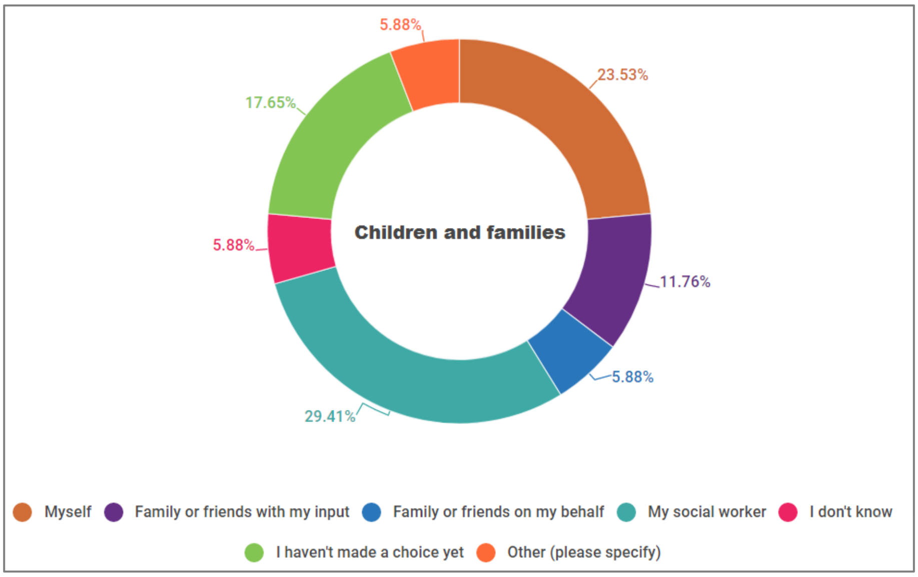
Choosing an SDS option

What SDS option was chosen by or for you?



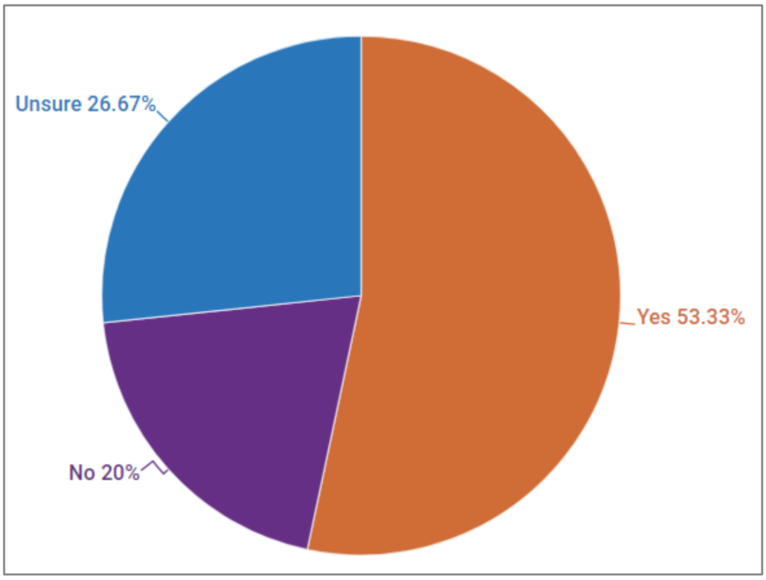
Children, young people, and families (CYP) were most likely to choose option 1. 37.5 per cent chose option 1, 12.5 per cent chose option 2, 12.5 per cent option 3 and 25 per cent option 4. 12.5 per cent of CYP indicated they were unsure which option was chosen.

Who chose the SDS option?



While the proportion of CYP stating that they chose their SDS option themselves was largely similar to the research respondents overall (23.5 per cent vs 27.5 per cent), fewer were involved in the decision-making process with friends or family (35 per cent vs 44 per cent). The most noticeable difference was the option to state that a social worker had made the decision on their behalf: with 29 per cent of CYP stating this compared to only 15 per cent of respondents overall.

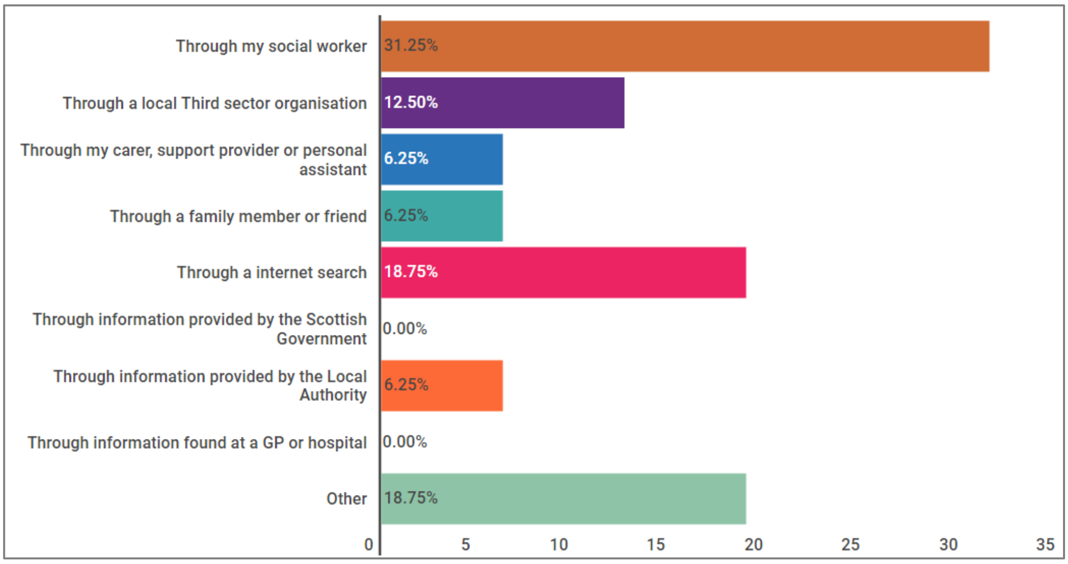
Did you get your preferred SDS option?



A much lower proportion of CYP than respondents overall got their preferred choice (53 per cent vs 71 per cent), and a correspondingly higher proportion did not. Also, a far higher number of CYP were unsure (26 per cent vs 16 per cent). Further research could help uncover the reasons why people were unsure, but it could be related to a wider lack of awareness and understanding about SDS and the four options.

Children, young people, and families’ awareness and understanding of SDS

How did you find out about SDS?



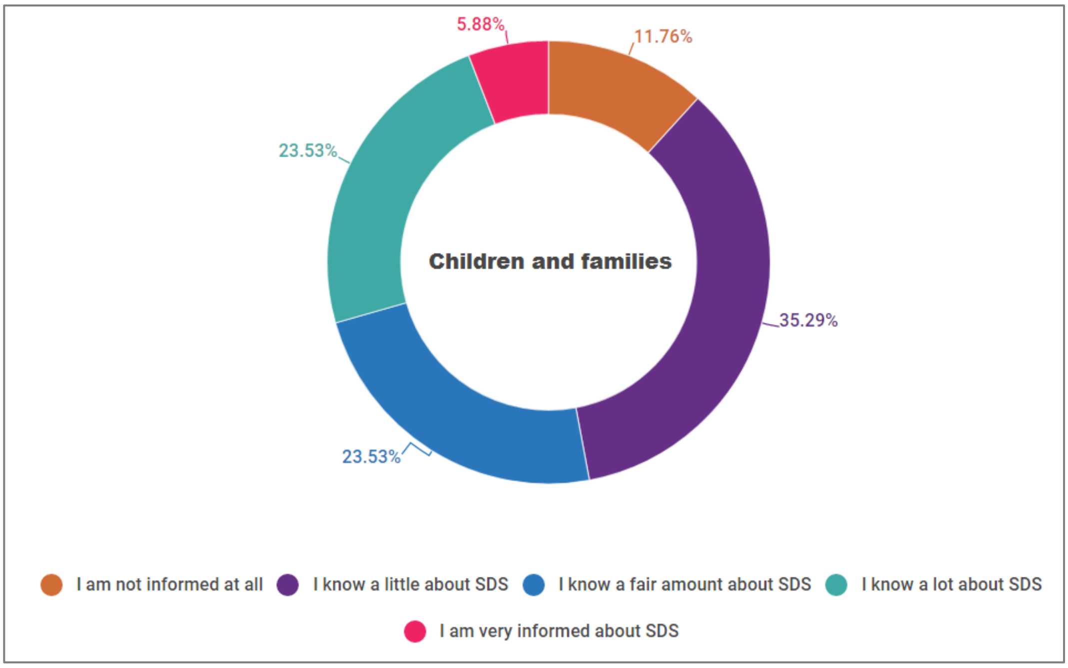
Children, young people, and families (CYP) predominantly found out about SDS from their social worker (31 per cent), internet search (19 per cent), local third sector organisations (12.5 per cent) and family members or friends (6 per cent). This would suggest that CYP have less of a social circle to find out about SDS and rely heavily on internet-based information.

The low proportion of CYP who find out about SDS through the Scottish Government or local authority suggests that public sector awareness raising initiatives may not be having an impact. No CYP stated that they heard about SDS through their GP or other health service setting, which indicates there are potential opportunities to inform and educate that are being missed.

Much like the overall research respondents, children, young people, and families were likely to find out about SDS through a third sector or local organisation. This indicates that CYP have a similar level of engagement and connections with third sector organisations to overall respondents. However, further investigation is recommended to find out if this is the case and how to develop services accordingly.

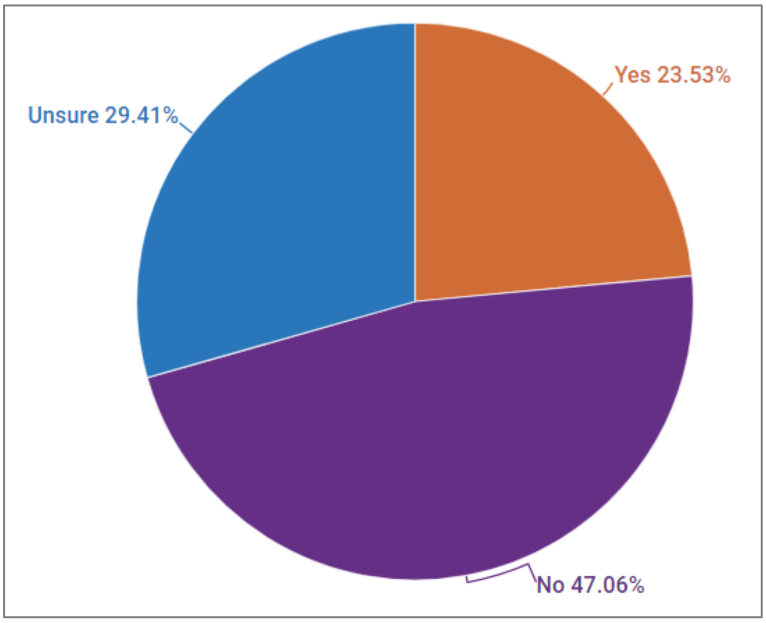
Those who answer ‘Other’ to this question responded that they found out about SDS through third sector organisations and other parents.

How informed do children and families feel about SDS?



Only around one third of CYP (30 per cent) consider themselves well informed compared with about 40 per cent of overall research respondents. It is concerning that nearly half of CYP do not feel well informed about SDS (47 per cent vs 30 per cent of overall respondents). CYP are also slightly less likely to state that they know a fair amount about SDS (23.5 per cent vs 29 per cent).

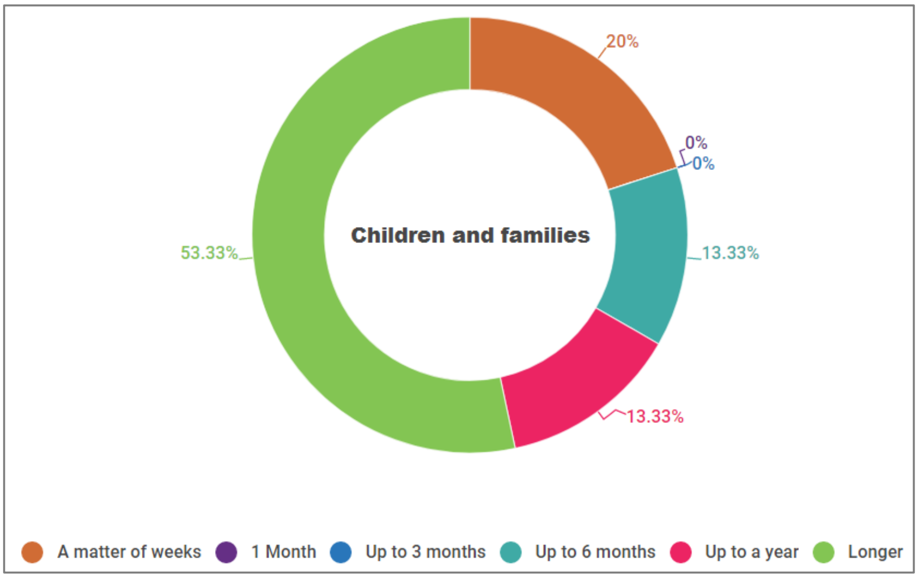
Did the information received help children and families choose an option?



Nearly half of children, young people, and families (47 per cent) felt that the information they received about SDS did not help them to choose an option and 29 per cent were unsure. This is noticeably more than double the proportion of overall respondents answering ‘No’ and ‘Unsure’ (22 per cent and 19 per cent respectively). Further research could help identify the reasons for this disparity. It is concerning that only around a quarter of CYP (23.5 per cent) said that the information had helped.

Waiting for support

How long did you wait for your SDS package?



It is clear from these findings that children, young people, and families have waited for an unacceptably long period of time for support, and indeed far longer than research respondents overall. 66 per cent of CYP waited up to a year or more compared to 53 per cent of overall respondents.

Using and managing SDS

What services children, young people and families use SDS for

Type of service	Children and families (%)
Respite	52.94%
Social/Educational/ Recreational	47.06%
Personal Care	35.29%
Other	29.41%
Domestic Care	17.65%
Equipment and Adaptations	11.76%
Health Care	0.00%
Housing Support	0.00%
Meals	0.00%
Unsure	0.00%

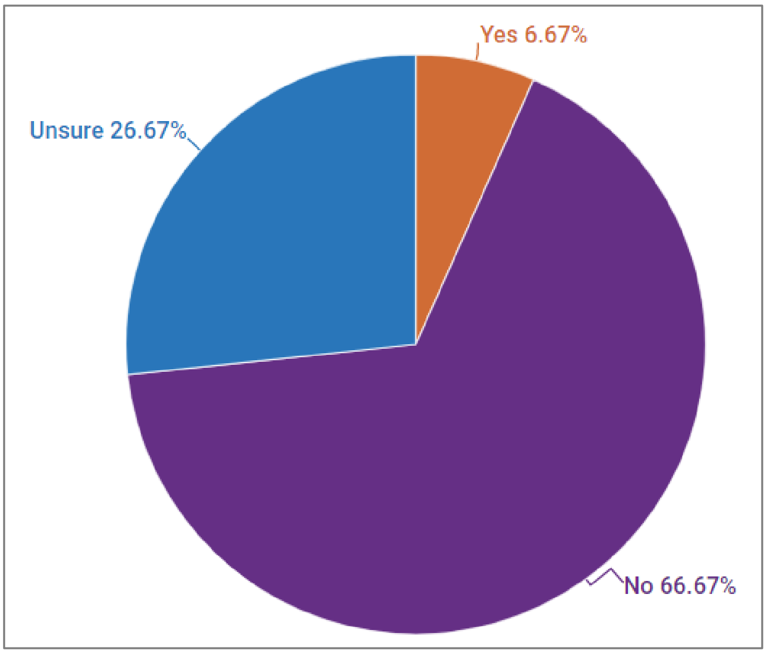
Children and families mainly use SDS to support respite, social/educational/recreational activity, and personal care. This is similar to overall respondents, although CYP are slightly more likely to use SDS for respite (53 per cent vs 47 per cent). Those who chose other options took the opportunity to reiterate they hadn’t been given a budget at the time of taking part in our research.

How children, young people and families manage their SDS

How SDS is managed	Children and families (%)
I purchase services from a local private provider	40.00%
My family recruited a PA on my behalf through advertising	30.00%
I purchase services from a local third sector provider	30.00%
I receive services that I chose from the local authority	30.00%
I receive services from the local authority that I had before I chose SDS	30.00%
I employ my own PA who I recruited through advertising	20.00%
I use SDS for short breaks	20.00%
I use SDS to give my family a short break	10.00%
I employ a family member or friend as a PA	0.00%

Children, young people and families mostly use SDS to purchase services from local private providers (40 per cent). They were slightly more likely to employ a PA recruited by a family member than overall respondents (30 per cent vs 22 per cent) and are far more likely to continue to use services chosen by the local authorities (30 per cent vs 14 per cent).

Does SDS meet children, young people and families' requirements?

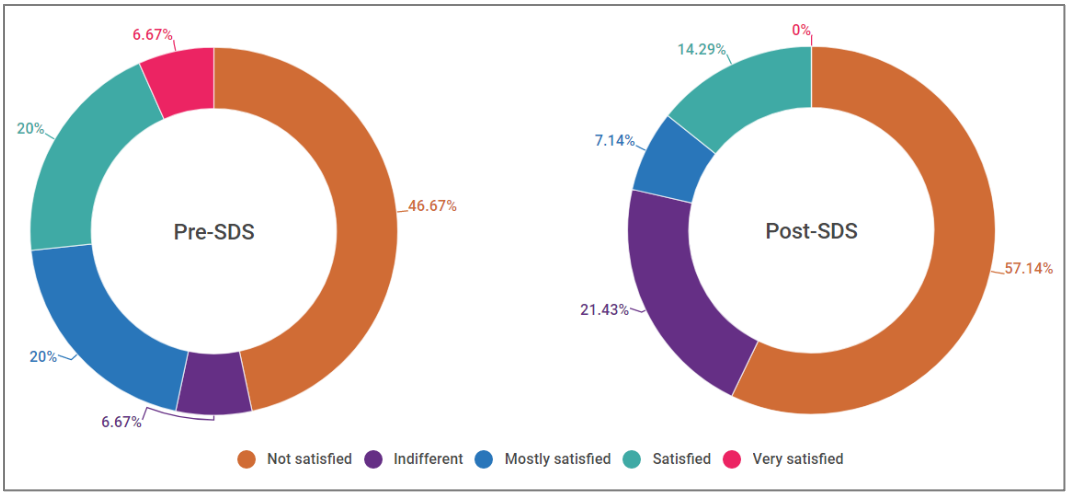


We asked children, young people, and families to tell us if they felt like they have enough hours to meet their support needs for each day. We phrased the question like this because although the move to SDS is intended to shift the language from one focused on 'hours of support needed' to a personal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

It is extremely concerning that two thirds of CYP said they did not have enough hours a day to meet their needs. This is substantially higher than the half of overall respondents that stated this. A substantially lower proportion of CYP stated that they had enough to meet their needs compared to overall respondents (6 per cent vs 35 per cent).

Satisfaction with SDS

Children, young people, and families' satisfaction with support pre- and post SDS



It is concerning that CYP satisfaction with social care support decreased after the introduction of SDS. As the charts show, the proportion of those who were 'mostly' to 'very satisfied' fell from 46 per cent to 22 per cent. The proportion of CYP who felt unsatisfied after moving onto SDS increased from 46 to 57 per cent. The proportion of CYP feeling indifferent towards SDS increased from 7 per cent to 21 per cent.

Summary of main findings

Uptake of SDS and data

- 37.5 per cent of children, young people and families were on option 1.
- 12.5 per cent of CYP were on option 2.
- 12.5 per cent of CYP were on option 3.
- 25 per cent of CYP were on option 4.
- 12.5 per cent of CYP were unsure which option they are on.

Choosing an SDS option

- Children, young people, and families indicated knowing only a ‘little’ about SDS.
- 29 per cent of CYP had the choice made by a social worker – substantially higher than other age groups.
- 53 per cent of CYP stated they got their preferred choice, lower than the average of 71 per cent.

Children, young people, and families’ awareness and understanding of SDS

- Children, young people, and families found out about SDS through:
    - Their social worker (31 per cent)
    - Internet search (19 per cent)
    - Local third sector organisations (12.5 per cent)
    - Family members or friends (6 per cent).
- Only around one third of CYP (30 per cent) consider themselves well informed compared with about 40 per cent of overall research respondents.
- Nearly half of CYP (47 per cent) felt that the information they received about SDS did not help them to choose an option and 29 per cent were unsure.

Waiting for support

- 66 per cent of children, young people and families waited up to a year or more compared to 53 per cent of overall research respondents.

Managing SDS

- Children, young people, and families mainly use SDS to support respite, social/educational/recreational activity, and personal care.
- CYP mostly use SDS to purchase services from local private providers (40 per cent).

Meeting children, young people, and families’ requirements

- Two thirds of children, young people and families said they did not have enough hours a day to meet their needs, compared to half of overall respondents.

Satisfaction with SDS

- Children, young people, and families’ satisfaction with social care support decreased after the introduction of SDS: the proportion of those who were ‘mostly’ to ‘very satisfied’ fell from 46 per cent to 22 per cent.
- The proportion of CYP who felt unsatisfied after moving onto SDS increased from 46 to 57 per cent.

Recommendations

1. The ALLIANCE is concerned that SDS is not being implemented according to its rights-based values and principles and will therefore not achieve transformational change in social care culture and services or help improve people's lives. We recommend that a focused and systematic response is developed involving the Scottish Government, Health and Social Care Partnerships, local authorities, the third sector, people who access services, unpaid carers, and other relevant stakeholders. Public bodies need to acknowledge the issues with SDS funding and service delivery, and work with other relevant stakeholders to develop solutions. This could be done as part of a wider national conversation about the future of social care and SDS.

2. A better picture of children, young people, and families' experiences of SDS is needed. We recommend that the Scottish Government, Health and Social Care Partnerships and local authorities work together to ensure robust qualitative data is regularly gathered on how CYP engage with and experience SDS and collect their views on how it is helping to make a positive difference to their personal outcomes and improve their lives.

3. Action is required to address the low uptake of SDS amongst children, young people and their families and empower them to take greater control of their options.

4. Public bodies should introduce regular reviews for CYP in receipt of SDS, designed to encourage them to fully explore all four options and best establish the most appropriate arrangements to meet their personal outcomes.

5. Public bodies must make greater efforts to increase CYP awareness and understanding of SDS through social work departments and health settings.

6. Action is urgently required to reduce the unacceptably long periods of time that children, young people, and families are waiting for SDS packages to be put into place.

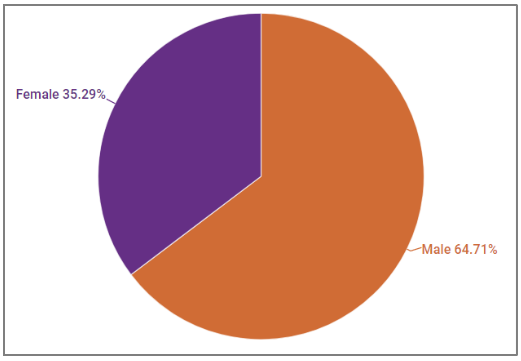
7. The ALLIANCE is extremely concerned that two thirds of children, young people and families do not think, or are unsure, their SDS package is sufficient to meet their daily requirements. Satisfaction levels could be improved across all four SDS options. To address these issues there should be regular reviews of the quality and quantity of services and supports available, independent oversight and scrutiny, and mechanisms for redress for people when things go wrong.

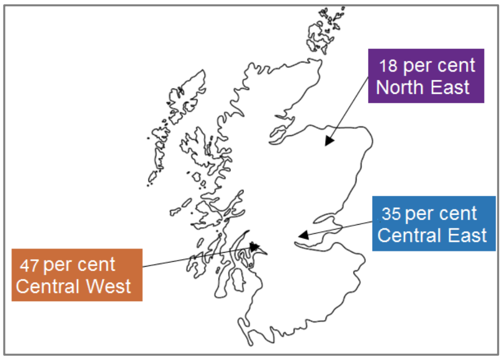
Appendix 1: ALLIANCE research participants

102 people participated in the full ALLIANCE SDS research survey. This briefing relates to the 17 participants who self-identified as children, young people, and families (CYP).

To maximise participation, we enabled people to respond directly or with support: 35 per cent of CYP answered the survey directly and 65 per cent did so with support.

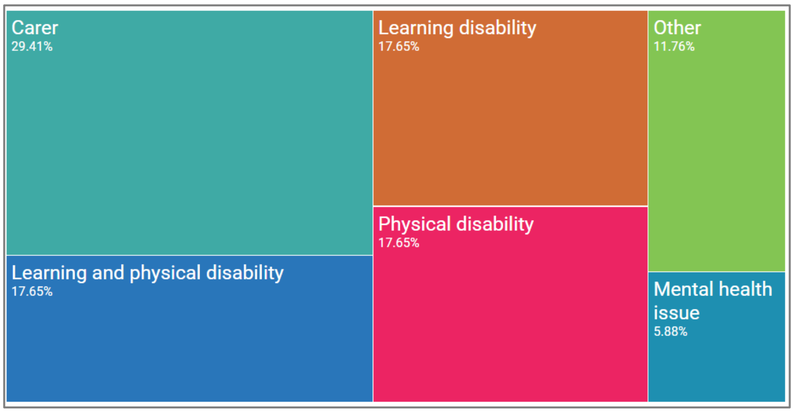
Age and geographic location of the children with families' accessing SDS





Further research is needed to better identify the personal experiences of those in the 0-18 age group and other parts of Scotland.

Category of social care requirement



We asked CYP to self-identify using the Scottish Government's categories of 'client group'[3]. Given the low response rate, it is difficult to draw any firm conclusions for those who identified as having a learning disability, a mental health issue, or as an unpaid carer. It is also clear that further research is necessary to uncover the experiences and relevant issues for these CYP.

Access to social care before SDS and current SDS status

53 per cent of CYP who took part were already in receipt of social care before applying for or accessing SDS. At the time of our survey, 59 per cent of CYP were in receipt of SDS, 6 per cent were being assessed, 12 per cent had social care but were not on SDS, 12 per cent had been assessed but deemed ineligible and 12 per cent were unsure of their status.

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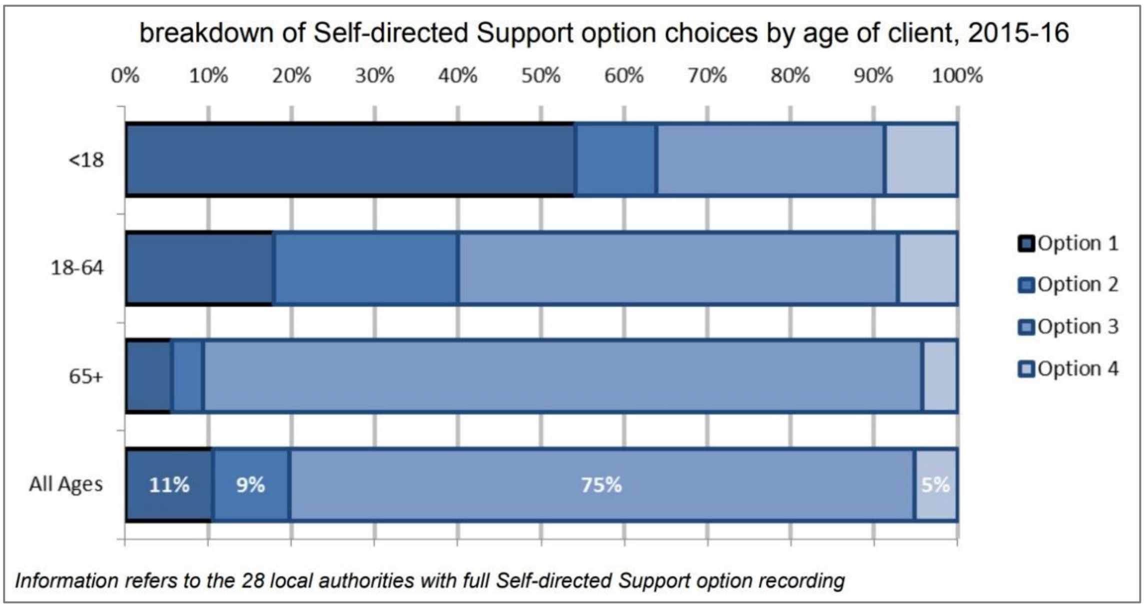
[3] Data under Development: Self Directed Support, Scotland, 2014-15, Scottish Government, 2016 http://www.gov.scot/Resource/0050/00502637.pdf

Appendix 2: Desk-based research

In 2015/16, councils spent £3.4 billion on social work services, supporting almost 208,000 adults in non-residential care and over 17,000 children and their families.[4]

Of the social care clients who made a choice regarding their services and support in 2015/16, 3 per cent were aged under-18.[5]



Key findings from Third Sector research

- Families and young people describe the negative impact of the transitions process on their stress and anxiety levels and this is often related to timescales for decision-making.
- Young people and families were not always clear about how decisions were being made and this applied across all professionals involved in the transitions process.
- In all local authorities, families drew on support from third sector organisations, carers' networks, independent advocacy, and brokerage services to gain further confidence and information about the transitions process.
- In general terms, there is a need for more information for young people and families about Self-directed Support itself and about support and services that are available for young people beyond school.
- There is mixed evidence that young people are involved in agreeing their own personal outcomes. Young people are also less likely to be involved if they have complex communication support needs.[6]

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[4] Self-directed support 2017 progress report http://www.audit-scotland.gov.uk/uploads/docs/report/2017/nr_170824_self_directed_support.pdf

[5] Self-directed Support, Scotland, 2015-16 - http://www.gov.scot/Resource/0052/00522283.pdf

[6] Working Together to Make It Happen: helping young people move on successfully, SDS Consortium, December 2015 http://www.sensescotland.org.uk/media/2241275/sds_consortium_report_pdf.pdf.

About the ALLIANCE

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

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

The ALLIANCE has three core aims. We seek to:

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

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