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Research Report

Self-directed Support and personal outcomes

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Contents

1 Introduction

1.1 Project background

Scrutiny of the social care system in Scotland has been ongoing for several years and was brought into sharp focus by the coronavirus (COVID-19) pandemic. However, the evidence base in relation to social care and, more specifically, those who receive care and support, is limited. Before COVID-19, social care in Scotland was an area that was not widely researched. Research with a focus on protected characteristics is rare.

The report 'My Support My Choice: People's Experiences of Self-directed Support and Social Care in Scotland'[1] describes the experiences of social care users accessing Self-directed Support. It provides insights into the experiences of women, people with mental health conditions, people with a learning disability, blind and visually impaired people, Deaf people and people from ethnic minorities. It did not explore the extent to which Self-directed Support helps people achieve their personal outcomes. We commissioned this research to examine the experiences of people who receive Self-directed Support and the extent to which it helps them to achieve their personal outcomes.

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[1] Health and Social Care Alliance and Self Directed Support Scotland (2020), My Support My Choice: People's Experience of Self-directed Support and Social Care In Scotland [accessed: 6 April 2022].

Self-directed Support (SDS)

The Social Care (Self-directed Support) (Scotland) Act 2013 introduced Self-directed Support to allow greater choice and control for people using social care in Scotland. The Self-directed Support system aims to ensure a more personalised approach to social care, where users are equal partners in decisions about their care. It can be used in different ways, including for personal care, but also to support people to be involved in work, education and their community. Users should be supported to identify what matters to them and what they want to achieve with this support – also known as their personal outcomes.

Users should also be able to choose how much they want to be involved in arranging their care. Local authorities have a legal duty to offer four options to people who have been assessed as needing social care:

- Option 1 is a direct payment, which is a payment to a person or third party to purchase their own support

- Option 2 means the person chooses their own support but the local authority holds the money and arranges support on their behalf

- Option 3 means the local authority selects and arranges the support, and

- Option 4 is a combination of the above.

This research captures evidence about a range of different experiences of Self-directed Support, drawing together lessons learned about how these experiences interact with people’s protected characteristics. The findings increase our understanding and awareness of how the current system helps or prevents people from achieving their personal outcomes, and the impact this has on equality. This report supports our work in Scotland to ensure that equality is embedded into social care reform and the creation of a National Care Service.

1.2 Research aims

The overall aim of this research was to understand the extent to which Self-directed Support helps people who share specific protected characteristics achieve their personal outcomes.

To achieve this, the research explored the following range of topics:

- How are personal outcomes decided and how is this process recorded?
- To what extent do people feel their personal outcomes capture all their needs?
- What is the range of experiences people have in relation to achieving their personal outcomes?
- What has enabled or prevented people achieving their personal outcomes?
- What do people think needs to happen to ensure they achieve their personal outcomes?
- How is the achievement of personal outcomes monitored and recorded?
- What is the impact of contribution charges on achieving outcomes?
- Does the choice of SDS options influence whether personal outcomes are achieved?
- What has been the impact of advocacy on achieving outcomes?

1.3 Methodology

1.3.1 Method

The method was qualitative and comprised 25 semi-structured, in-depth interviews.

The sample was recruited using two methods:

- Most Self-directed support users and all personal assistants, advocacy workers and social workers responded to an invitation to participate publicised by third-sector membership organisations.

- A small number of Self-directed support users were recruited by a recruitment agency, approved by the Market Research Society (MRS), using a recruitment questionnaire agreed with us.[2]

Discussion guides for different participant groups were drafted and finalised in consultation with us. They were structured to prompt discussion of key themes in the research, including the process of agreeing and deciding personal outcomes and experiences of how much Self-directed Support helped users achieve their personal outcomes.

The interviews lasted one hour and took place between October 2021 and March 2022. All interviews were held by telephone or videoconference.

Qualitative data was analysed using a thematic content analysis approach. An analysis grid was developed to consider key research questions against key sample variables; for example, different protected characteristics. The grid was then populated with participants' views and experiences. Based on this, key themes were identified that formed the structure of the findings for the written report. Within these key themes, more nuanced findings were also sought. For example, inconsistent beliefs and behaviours, as well as any differences identified by different participant groups.

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[2] This type of recruitment relies on a network of MRS-trained recruiters to identify suitable individuals in their community and invite them to take part in the research. Recruiters may start from a database of their local contacts, but then build on this to engage a wider group of potential participants, for example, by using 'snowballing' recruitment techniques.

1.3.2 Sample

The sample included:

- 14 in-depth interviews with Self-directed Support users (nine individuals and five carers)
- seven in-depth interviews with personal assistants with experience of supporting SDS users
- three in-depth telephone interviews with advocacy workers with experience of supporting Self-directed Support users, and
- one group interview with four social workers.

All users were receiving Self-directed Support except one participant, who was trying to access it.

This sample of Self-directed Support users included disabled people, including those with a learning disability, and carers of disabled Self-directed Support users. The sample included:

- men and women
- people of different ages
- people from different ethnic backgrounds
- lesbian, gay and bisexual people,
- trans people, and
- people living in different local-authority areas.

The sample included people managing their own budgets and those who were not.

This sample captures a small number of experiences of Self-directed Support users. It reflects the experience of individuals motivated to participate in the research because they wanted to share these experiences. The extent to which these experiences reflect the experience of Self-directed Support users more broadly is unknown and would need to be the subject of further research.

1.4 Acknowledgements

Participants not only gave their time freely but also shared their experiences of Self-directed Support, including some that had been distressing. Everyone involved in this research would like to thank the participants for their willingness to contribute and make suggestions for improvements. This research was made possible by third-sector organisations that publicised the opportunity to participate and the people who agreed to do so.

2. Agreeing personal outcomes

2.1 Assessing and deciding personal outcomes

Experiences of the process of deciding personal outcomes varied in this sample of Self-directed Support users. While most reported negative experiences, a few were satisfied with how their personal outcomes had been agreed with their social workers and local authorities.

Based on the reports of both negative and positive experiences, this research identified some factors contributing to people's experiences of the process. These included:

- engagement from the social worker
- understanding the needs of the person whose personal outcomes were being decided
- support with identifying personal outcomes
- listening to the person whose personal outcomes were being decided
- accessibility and length of the process
- information about available options and how SDS works, and
- flexibility in adjusting the outcomes and how they could be achieved.

Each of these factors is discussed in more detail below.

2.1.1 Engagement

Self-directed Support users or carers reporting negative experiences often highlighted limited engagement with social workers or occupational therapists involved in decisions about their personal outcomes. For example, a mother whose daughter is a Self-directed Support user explained how their new social worker met her daughter only very briefly. She felt this was not enough for their social worker to understand her daughter's needs.

Another Self-directed Support user reported how she only met her social worker twice online. She felt this was why the social worker didn't understand her situation. She also recounted how other social workers later made suggestions that she felt revealed her first social worker did not properly understand her needs. Some advocacy workers involved in this research also pointed out that because of the COVID-19 pandemic many Self-directed Support users could only meet their social workers online, limiting the extent to which social workers could assess their needs.

Conversely, three participants who were satisfied with how their personal outcomes were agreed explained that this was because they had repeated conversations with their social worker to work out what exactly they needed and how this could be achieved. A carer whose child was a Self-directed Support user explained they had a long-standing relationship with their social worker, who knew her child from a young age. Over time, the carer and social worker met at various points to discuss how her child's needs had changed and how her personal outcomes needed to be adjusted to reflect this.

Social workers who took part in this research felt that time was critical for building a relationship with the people they supported and understanding their needs. They stressed the importance of working in partnership with potential and current Self-directed Support users to identify their personal outcomes and ways to meet them. However, some social workers also reported that they had limited time available due to having big caseloads and other competing priorities. In their experience, this limited how much time they could sometimes spend with individual clients, potentially making it more challenging to support them.

> 'In my role, I don't have enough time in the day. That first connection with the service user, with the family, is very important. If you want to help the person, and we're all in this work because of that, you need time, and time is very precious.'
>
> – Social worker

2.1.2 Understanding Self-directed Support user's needs

Depending on the level of engagement from social workers, participants felt their social workers had limited or good understanding of their needs and personal outcomes. Those with negative experiences often felt that social workers or people in their local authority making decisions about their care lacked understanding of their circumstances, what they wanted to achieve and how.

Conversely, the respondents with positive experiences felt that their social worker went through a process that allowed them both to understand what they wanted Self-directed Support to help them achieve.

> ‘She [the social worker] knows him very well. She’s been his social worker since he was six years old. We speak a lot and she visits as well. She has quite a high level of understanding of his needs.’
>
> – Carer

2.1.3 Support with identifying personal outcomes

Some participants also told us about the need to be supported to identify personal outcomes. For example, one participant who was critical of how their personal outcomes were agreed complained that they had very little interaction with the social worker during the meeting that had been arranged to discuss them. They were asked what they wanted to do, so they listed a few things but felt unsure what they wanted to get out of Self-directed Support or what they could get. They felt the social worker simply played back that list to them as their personal outcomes, without engaging and probing to help identify how Self-directed Support could help the respondent.

> ‘It just felt like, “tell us all you can, we’re going to pick A, B, C, then off you go and do that as one of your goals”. They didn’t offer me any help, they just listened to what I was saying and then threw it back at me.’
>
> – Self-directed Support user
>
> ‘I don’t really know what I would like myself. My condition is getting worse so I don’t really know what would work for me. It would be better if they set out a “menu of options”, i.e. this is what’s available, what you can have. You could find out more about it from them and then you can choose which bit you want to have.’
>
> – Self-directed Support user

This need for support in identifying personal outcomes was raised by some others. An advocacy worker explained that people sometimes struggled to identify their personal outcomes, so the advocacy worker helped clients with this part of the process to prepare for the meeting with the social worker. A personal assistant felt that some people needed this type of support to have an ‘equal conversation’ with social workers about identifying personal outcomes. Otherwise, as another personal assistant put it:

> ‘Too often I believe assessments are not done properly and they end up getting the sort of support service that suits the [local authority] rather than what suits them.’

Participants with positive experiences sometimes reported that their social worker probed what they said about their needs to help them articulate their personal outcomes. In addition, a participant living with dementia wanted their family members and relevant health professionals to also contribute to identifying their personal outcomes. Without this, they thought, the picture of their needs and personal outcomes would be limited and important information would be missing. However, they thought family members and health professionals should be involved in separate meetings to allow them to be open and honest.

Social workers who took part in this research talked about the importance of having an informal conversation first and listening to the difficulties people experience and what they would like to achieve. They explained they would then build on this initial conversation to probe for more information and discuss people’s needs and potential personal outcomes. They stressed that both social workers and advocacy workers had a role to play in supporting people to identify their personal outcomes.

Social workers also reported that family members and some health professionals were involved in the assessment process, provided the person being assessed gave their consent. However, a social worker highlighted some gaps in terms of involving relevant clinicians. They explained that psychiatric consultants were sometimes not involved when it would be important to get a clinical view of the risks of not providing a care package.

2.1.4 Listening to the person

In some instances, participants with negative experiences reported that their personal outcomes did not reflect what they said they wanted to achieve. They sometimes also felt that their social worker came to the assessment with preconceived ideas about the care they could receive. In their view, the decision about their care was made before the assessment, so their opinions about their personal outcomes did not have an impact on the final decision.

For example, a Self-directed Support user felt her local authority decided what her personal outcomes were and these did not reflect what she shared in her assessment. She recalled several instances when she was either not involved in the assessment process at all or the result of the assessment did not reflect what she said her personal outcomes should be.

In another case, a carer complained that the social worker and local authority didn’t listen to her when she explained that her adult daughter’s personal outcomes had changed since they were first decided when she was 17 years old.

2.1.5 Accessibility and length of the process

Some disabled participants reported that they struggled with certain aspects of the Self-directed Support application and assessment process. They felt that issues of accessibility were not considered. For example, one person reported how they struggled to complete the Self-directed Support forms because they were unable to hold a pen. They had to arrange for someone from a third-sector organisation to help them complete the forms.

In addition, another participant did not want the assessment to take place at their home but at another accessible venue. They were told there was no accessible venue where the assessment could take place locally, so instead the assessment had to be carried out online. They felt this led to a limited understanding of their needs and were unhappy the local authority could not find an accessible venue.

Social workers in this research described ways in which Self-directed Support related processes were adjusted to make them accessible. For example, they reported:

- using visual aids in assessments with people who have learning disabilities
- using large font for people with visual impairments, and
- using translation and interpreting services with people who have no or limited knowledge of English.

In addition, some social workers reported areas where more support was needed to make processes accessible. For example, a social worker explained that some local authorities required Self-directed Support users to read and sign contracts with care providers. In their experience, some disabled Self-directed Support users need help to understand and / or sign contracts, so the social worker supported them with this.

Some social workers and Self-directed Support users in this research also felt the assessment process could be too lengthy, with long waiting times until people received help. A social worker felt the process was too bureaucratic in some local authority areas and involved too many steps and levels of sign-off. Another social worker also thought that the tools used during the assessment process were sometimes too lengthy, repetitive and cumbersome for both prospective Self-directed Support users and social workers. They wanted the assessment process to be shorter, less bureaucratic and streamlined to improve people’s experience.

2.1.6 Information about SDS

Some participants who had negative experiences of agreeing their personal outcomes felt they were not given sufficient (or any) information on the process or about how Self-directed Support worked. For example, one person who struggled to identify his personal outcomes wished he had been told what support could be available through Self-directed Support to help him understand what he could achieve. Another participant pointed out that they were not given information on how Self-directed Support payments worked. For example, how they could retain money that was unused over a certain period.

Social workers listed the information they shared with prospective Self-directed Support users. This included information about:

- what Self-directed Support was
- what options were available
- what was involved in the assessment process
- how to get more information and advice from community brokerage organisations[3]; and
- how to make a complaint.

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[3] Community brokerage organisations provide impartial information, advice and support for people to help them plan and organise their support arrangements. They also make maximum use of community resources and informal support, helping people find creative solutions to meet their needs. See Evaluation Support Scotland (2015), Support in the right direction: The value of Independent Support, How it can help people understand and make informed decisions about Self-directed Support, page 8 [accessed May 2022].

However, a couple of social workers also reported that they sometimes came across Self-directed Support users who had not been provided with this information by their social workers. In particular, one stressed that information about independent advocacy was not always provided. They were unsure why this was the case and speculated that it may have been due to insufficient training of new social workers or low awareness of the resources available.

2.1.7 Flexibility

Participants with positive experiences of deciding personal outcomes highlighted the importance of being flexible in adjusting and refining the outcomes. In some instances this was because the process of deciding personal outcomes required an amount of ‘trial and error’ to work out what worked best for that person. At other times, the outcomes needed to change as someone’s circumstances changed or they got older.

> ‘We would discuss that. I think there was one year I had a budget for [an accessible] bike, and then we decided that due to his high sensitivity outdoors that it was going to be too risky to have an adjoining bike. If a dog barked or something else happened, it could be a bit risky. I think we just transferred it over to the hot tub, we decided that was a better option.’
>
> – Carer

2.2 Recording personal outcomes

This research also suggested variable practice in whether and how the assessment process and personal outcomes were recorded.

Two Self-directed Support users reported that they never received any written communication about their assessment process or personal outcomes. One of them only found out about their personal outcomes after submitting a data request to their local authority.

In addition, several had some written communication following their assessment that they found unsatisfactory. Some received letters that they felt did not reflect the assessment process or their personal outcomes. One recalled receiving what felt like a generic letter stating they could now start working towards achieving their personal outcomes. Another said the letter stated what additional evening care was allowed but it did not include any discussion of personal outcomes or how these would be achieved. One respondent had a written record of the personal outcomes agreed but felt this lacked an explanation of how these very general and vague outcomes would be achieved.

Participants with positive experiences of Self-directed Support were satisfied they had adequate records of the personal outcomes agreed. How detailed these records were varied. One participant explained they had a whole folder, including a record of their assessment conversations. Another was satisfied their brief record included the main information.

Some of the advocacy workers confirmed these reports. They explained that whether people received a record of their assessment and outcomes was variable and depended on where they lived.

Social workers involved in this research explained they always recorded the assessment process and what personal outcomes were agreed. In their practice, this record was shared with Self-directed Support users. One social worker, however, pointed out that sharing records had been more challenging during the COVID-19 pandemic. Social workers increasingly worked from home and were not allowed to print client records at home, but their access to offices and administrative support was more limited than in pre-pandemic times.

2.3 Capturing Self-directed Support users’ needs in personal outcomes

Participants with positive experiences of the assessment process felt satisfied that their personal outcomes reflected their needs. They explained they had supportive social workers or occupational therapists who made them feel comfortable and listened to them. As a result, they felt they were able to articulate what they wanted to achieve from Self-directed Support and what their needs – or the needs of the people they cared for – were. Two participants also stressed that personal outcomes change over time, and they were able to discuss this with their social workers and adjust them.

Conversely, those critical of the assessment process reported that their agreed personal outcomes did not reflect their needs or the needs of people they cared for. Several reasons were mentioned for this discrepancy between their needs and stated personal outcomes.

Too general and vague

A participant who was a carer for her daughter thought that her daughter's personal outcomes, agreed when she was 17 years old, were too general and vague to be useful. For example, one of the personal outcomes was to 'have opportunities to increase independence'. She felt the problem with this outcome was that it was completely unclear how this general outcome would be achieved.

> 'Do you see these as real outcomes? To me they're just so general and vague. Appallingly general and unspecific. It says: "I need to be kept active and stimulated." Well, yes, exactly, but how are we going to do that and what avenues are we going to explore in order to get there? How do they transfer from the general to the specific?'
>
> – Carer

Not being adjusted over time

A few respondents complained about the practice of copying over old personal outcomes during the outcome review process. One carer explained the old outcomes were just copied for the person they cared for without involving the Self-directed Support user or their carers in the process.

> 'In November 2020, my daughter then had a reassessment of her needs, which was a nightmare. That has been a horrendous experience, we were not involved in any planning for outcomes, these were all decided by a social worker [who copied old outcomes].'
>
> – Carer
>
> 'We wanted another complete discussion about what we would like her outcomes / needs to be, rather than just restating her 17-year-old needs, because she's changed.'
>
> – Carer

Not considering Self-directed Support user’s views

We heard from a Self-directed Support user who felt they lacked the support they needed during the assessment process to help them articulate their personal outcomes. As a result, their outcomes would not help them benefit from Self-directed Support fully.

Another Self-directed Support user reported that their initial personal outcomes were decided by the local authority without consulting them. After they asked for an assessment, this was organised, but nothing changed. They received a letter that stated that a review of their needs was carried out and that nothing needed to change. The letter did not include any of the points they raised during the assessment about what they wanted Self-directed Support to help them with.

2.4 Monitoring whether personal outcomes are achieved

Participants with positive experiences of Self-directed Support reported being able to adjust their support if their personal outcomes, or those of people for whom they cared, were not being achieved. Adjustments were mostly made as part of annual reviews of their personal outcomes and care package.

Another Self-directed Support user reported more frequent opportunities to make adjustments were available. A carer explained they were in ongoing contact with their son’s social worker, so they could ask for adjustments to how Self-directed Support was used. For example, if their son’s situation changed, they could ask to adjust the original plans for how their Option 1 lump sum payment would be spent. The social worker presented their case to the decision-making panel. In the carer’s experience, all such changes and adjustments to date were approved.

Not monitoring whether outcomes were achieved and adjusting them accordingly was part of the problem for some Self-directed Support users with poor experiences. For example, as mentioned previously, both a Self-directed Support user and a carer reported instances when old outcomes were copied over, with no regard for whether they or their families thought these were still relevant or being achieved.

Advocacy workers also noted that local authorities generally did not have the resources to monitor whether personal outcomes were being achieved. In their experience, local authorities considered such questions only if they got involved due to a crisis or advocacy workers contacted them about personal outcomes not being achieved.

Some social workers also reported challenges in adjusting personal outcomes and care plans when people’s situation changed. In particular, one social worker supporting older people with comorbidities and cognitive impairment explained that their clients’ needs could change very rapidly. However, the process of changing someone’s personal outcomes, care plan and budget was often too bureaucratic and lengthy to be able to quickly adjust to the change in their situation. Another social worker explained that they used to have a contingency budget to respond to such changes in care needs, but now there was little contingency allowed in the system due to financial pressures on local authorities.

3. Achieving personal outcomes

3.1 Self-directed Support users’ experiences of achieving their personal outcomes

The extent to which respondents felt Self-directed Support helped them achieve their personal outcomes varied considerably. They broadly fell into three groups:

- It did not help them achieve their personal outcomes
- It helped them partially achieve their personal outcomes, or
- It helped them achieve their personal outcomes.

Their experiences are discussed in more detail below.

3.1.1 Personal outcomes not achieved

Two participants felt that Self-directed Support did not help them achieve their personal outcomes at all. For both, the main barrier was linked to the failure of the assessment process to produce personal outcomes they felt captured their needs and how Self-directed Support could be used to meet them. One of them who complained about not being supported during the assessment process explained that they stopped using Self-directed Support altogether because they felt disappointed with the assessment.

> ‘Why would I buy into something where they’re not buying into me? They’re not doing anything for me … After that meeting, they sent me a generic letter but they’ve not tried to get in contact with me.’
>
> – Self-directed Support user

The other participant reported ongoing disagreements with their social worker over what the Self-directed Support budget could be used for as another reason for not achieving their personal outcomes. They explained that they always needed to check with the social worker if they wanted to use their budget for anything different from what was agreed before. The social worker often refused their requests to use their Self-directed Support budget in particular ways. For example, they asked to use their budget to pay for regular trips to Glasgow to buy special food and supplies for their digestion problems. Having made the request, they received a letter from the head of the social work department telling them to stop using their Self-directed Support money to pay for holidays. They also said they were not allowed to buy personal protective equipment (PPE), despite shielding during the COVID-19 pandemic.

3.1.2 Personal outcomes achieved partially

Several participants had mixed experiences in terms of achieving their personal outcomes (or those of people they cared for).

Some people achieved certain outcomes but not others.

One carer whose daughter was a Self-directed Support user felt that only very basic personal outcomes were achieved, not the important ones. Their daughter had access to a day care centre through Self-directed Support, which helped achieve two of her outcomes to some extent; meeting other people and having a routine and structure in her life.

However, the carer felt the quality of care and support in the day care centre was low and the staff were too stretched for their daughter’s personal assistant to be able to support her to achieve her personal outcomes. For example, her daughter’s personal outcomes included being able to engage in activities, such as going on days out or swimming. Due to staff shortages at the day care centre, the personal assistant for their daughter needed to help with other work and could not leave for days out or swimming with their daughter. The carer felt that as a result their daughter was often left on her own with colouring books.

> ‘The day service that we used after leaving school was not doing what they were supposed to. My daughter’s support worker was at the beck and call of the day centre all day. For example, if someone was having a meltdown in the corner, my daughter’s worker would be taken away from her to go help.’
>
> – Carer

Some people used to be able to achieve their personal outcomes but not anymore.

One participant explained that the personal care they received through Self-directed Support worked well where they lived before. It was flexible and the hours could be adjusted around the respondent’s hospital appointments and stays. Their care also included some allowance for extra hours on those days when they needed more care due to their health conditions and disabilities. In addition, they were able to pay a percentage of their Self-directed Support budget to the local authority to take care of the employer obligations associated with Option 1.[4]

Due to housing problems the participant had to move to another local authority area. After they moved, the new local authority said their budget could not be used to pay a care agency from another (adjacent) local authority area. As they had chosen Option 1, they were left to find and arrange new care themselves. Unlike in their previous area, they were not able to pay a percentage to the local authority to take on the administrative work associated with being an employer through Option 1. Due to a mix of staff shortages at local care agencies and the participant’s criteria for carers, they reported not being able to secure any permanent care for several months, despite having significant medical and personal care needs.

Some people felt they mostly achieved their personal outcomes but only because they were prepared to fight for them, all the time.

A disabled participant felt their Self-directed Support budget helped them achieve their personal outcomes most of the time, but doing so had been an ongoing battle with the local authority and social workers. For example, they explained that when exercise classes were stopped due to the COVID-19 pandemic they were able to use their budget to find a new yoga class. They felt yoga helped them significantly to keep their respiratory problems at bay and improve their health and wellbeing. However, they felt their budget was at constant risk, as the local authority wanted it reviewed every six months. They felt they could continue to benefit from Self-directed Support only if they were always well prepared to argue their case and protect their budget.

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[4] See explanation of Option 1 on page 4. With Option 1, SDS users become employers, with all the legal obligations that entails, such as payroll.

This experience of having to battle to achieve personal outcomes was reflected in advocacy workers' comments too. For example, an advocacy worker reported how a young disabled woman they supported used Self-directed Support to help her achieve her personal outcomes to live the independent and active life she wanted. However, this was only achieved after a long and stressful complaint process challenging the local authority's decisions. Eventually, it took an independent review and a media campaign to win her case and to get the support she felt she needed.

3.1.3 Personal outcomes achieved

Four participants felt Self-directed Support helped them achieve their personal outcomes or those of the people they cared for. For two of them, it is used mainly for personal care, which they felt was organised to fit their care needs and help them maintain their independence. They were satisfied that they managed to find agencies and personal assistants with whom they felt comfortable and who were able to support them in the way they needed. They both explained that finding these people was not easy and took time, but at the moment their care worked. They also felt supported by their social workers to find the care they needed and to adjust their personal outcomes and care package if their situation changed.

The other two participants shared their positive experiences of Self-directed Support being used to support the people they cared for beyond personal care. One participant whose son was a Self-directed Support user felt their social worker strived to find ways to meet his needs. They reported that they were in ongoing contact with the social worker and if certain solutions did not work, they would adjust them. For example, they would try different things to alleviate their son's health conditions and adjust them until they found something that worked. They also recalled how the social worker supported them to find respite care when there was no place that could meet their respite needs where they lived.

> 'We found there weren't any services within this area that could meet my son's needs for us to get respite. So, we built our own respite, it's very creative, where we go to the same property, we rent it four or five times a year, and we take extended family with us to support us. It's what the social worker and I call creative respite. I'm lucky, she's a very proactive social worker. She admitted herself that it's probably the most creative package she's ever done.'
>
> – Carer

The other participant reported that Self-directed Support made a positive difference to her sister's life, as it allowed her to remain living independently in her home and carry on with social and other activities outside her home. She felt that in this way it helped her sister maintain good quality of life after her dementia diagnosis.

Some personal assistants echoed these experiences. For example, one felt that the person they worked for was getting what they needed out of Self-directed Support. Another personal assistant commented that 'when Self-directed Support is set up properly, it can work fantastically well'.

3.2 Factors enabling or preventing Self-directed Support users from achieving their personal outcomes

Based on the experiences of Self-directed Support users and carers outlined above and the views of the advocacy workers, social workers and personal assistants who took part in this research, several factors enabling or preventing people from achieving their outcomes were identified. These include:

- availability and quality of care
- financial constraints
- choice and control issues
- equality issues
- poor implementation of SDS
- impact of different SDS options
- impact of the COVID-19 pandemic, and
- advocacy.

Each of these factors is discussed in more detail below.

3.2.1 Availability and quality of care

Limited availability of care options, carers and personal assistants was cited in a number of cases as a major issue and a barrier to meeting Self-directed Support users' care needs and outcomes. This was seen as a major challenge by all groups of participants. Examples of problems varied and included: lack of personal assistants in rural or remote areas; staff shortages limiting the number of hours agencies could provide to Self-directed Support users and the time carers could spend with people they cared for; and limited options for respite care in some areas.

> 'The carer shortage. It doesn't really matter which option you have if you can't find a personal assistant or carers. That's been a particular challenge.'
>
> – Social worker

A participant whose daughter was approved for 35 hours of care per week reported that they could only receive 20 hours as the agency providing care was unable to offer more. They were also unable to recoup the unused hours and benefit from that part of their Self-directed Support budget in some other way. Personal assistants and advocacy workers also pointed out that in some rural areas there might not be any private providers, so Self-directed Support users could only choose Option 3 in those instances.

> 'We have the hours of support from the council that no one is able to fill ... The council was paying for 35 hours, but the agency wasn't prepared to give more than 20 hours' support. We would love to know what happened to the rest of the money that we were supposed to be getting.'
>
> – Self-directed Support user

Difficulties in finding carers and personal assistants were sometimes made worse when people had particular criteria they wanted their carers or personal assistants to meet. For example, a disabled Self-directed Support user who was clinically vulnerable wanted their carers to be non-smoking and not to have children to limit their risk of being exposed to COVID-19. Due to staff shortages, having these additional criteria led to a situation where they could not find carers for months.

Problems with availability of care sometimes also affected the quality of care negatively. For example, some people disliked having to use agency carers as they thought they ‘were rushed off their feet’. Some also felt there was little or no continuity of care when their care was provided by agencies. Continuity of care is seen as an essential part of good quality of care that meets their needs.

In addition, Self-directed Support users, advocacy workers and personal assistants pointed out that quality of care was also highly variable and presented challenges in meeting peoples’ needs and outcomes. For example, an advocacy worker supporting a disabled Self-directed Support user explained that personal assistants working with her needed to have a high level of skill that was very difficult to find. Other Self-directed Support users also felt that quality of care and skills were highly variable across different carers they had over time. Some personal assistants thought that there was no monitoring of the quality of care provided by personal assistants for users on Option 1.

3.2.2 Financial constraints

Participants with negative experiences of Self-directed Support often felt that decisions made by social workers and local authorities about their care were finance-driven rather than based on the personal outcomes people wanted to achieve. For example, several Self-directed Support users talked about Self-directed Support related meetings where they felt social workers came with a particular budget in mind and worked their way ‘backwards’ to agreeing outcomes or care packages on that basis, rather than being open to understanding the personal outcomes respondents wanted to achieve. Some also reported that social workers sometimes attempted to reduce their budget as part of social work outcome reviews, which left them feeling they would need to always be ready to fight their case to keep their budget.

> ‘Sometimes the care package is designed to suit the budget that’s available, rather than the budget being designed to suit the care package.’
>
> – Personal assistant
>
> ‘He [their social worker] said, “For people like these, we think that the figure we have in our head is enough”. So even before the assessment was off the ground, they had a budget figure in their head, which she was going to get irrespective. So it didn’t matter how much her needs were, they had a figure.’
>
> – Carer

Advocacy workers and personal assistants also reflected this view that Self-directed Support care decisions are often made based on finances rather than people’s needs and personal outcomes. As one advocacy worker explained, financial constraints often limited how much Self-directed Support could help users achieve their personal outcomes as they would not be provided with the sufficient budget to do that. For example, they might struggle to find personal assistants who would take on care roles involving very limited weekly hours of care. In addition, local authorities often set pay rates for personal assistants, which stopped some people from hiring more skilled personal assistants because their day rate was higher. This was an issue even if they were prepared to pay for a smaller number of hours but receive higher quality care – they were not allowed to do that by their local authority.

Social workers who took part in this research also reported sometimes struggling with having to justify to their managers why someone needed their budget increased. Some social workers reported situations when they could not secure budget increases for their clients due to financial constraints and were told to find other, more creative and innovative ways to meet client needs within existing budgets. In addition, they explained that they sometimes had to weigh the costs of different care options and consider this as part of care decisions. For example, they compared the costs of Self-directed Support allowing someone to live independently at home against the cost of residential care.

3.2.3 Choice and control issues

Another major issue highlighted by this research concerns the lack of flexibility in how Self-directed Support users could use their personal budgets to meet their outcomes. There was a widespread perception that local authorities and social workers wanted to retain control over how SDS budgets were used, which people felt was reflected in the highly prescriptive rules about budgets.

Various examples of prescriptive rules and the lack of flexibility from social workers and local authorities were given, including:

- not allowing people to pay for a service outside their area, even when that was the best service available and no other such service existed in their area
- requiring only care agencies and providers from the local authority’s approved list to be used, even when a better provider was available
- linking the budget to a certain number of hours of care and pay rate, so the same budget was not allowed to be used for fewer hours of care of a better quality or paid at a higher rate
- imposing their own methods for achieving certain personal outcomes, rather than what people wanted; for example, refusing a weekend respite requested by a participant and offering them a weekly massage instead

- not allowing family members to be hired as personal assistants from the Self-directed Support budget, and
- not allowing people to use their SDS budget to pay for their personal assistants' subsistence expenses on a day out.

> 'Naively, I thought that a direct payment was: you're allocated a budget and as long as you do not go over that allocated weekly amount, you should then be allowed to spend that budget as flexibly as you like. But no, it's earmarked for X agency to provide X support only.'
>
> – Carer

> 'She was trying to tell me what I could spend the money on, and it took away the respect, dignity and choice that should be around that. It's not her money. I think that's what a lot of the problem is with Self-directed Support, that's what people have the issue with.'
>
> – Carer

When disagreements broke out over how SDS budgets could be used, a couple of participants reported that they felt either intimidated or anxious by the way their social workers responded to budget issues. For example, one person said that her request to use £500 of unused money for weekend respite care was refused, and the social worker threatened to take back the money from her bank account. She said she found the social worker rather intimidating in that situation. Another participant, who challenged the number of care hours allowed in their budget, felt anxious their social worker might respond by reducing their budget.

> 'She [the social worker] told me she was going to get them to take the money out of the account. She was quite threatening and intimidating. It's not the kind of relationship that you feel you can move forward on in a positive way.'
>
> – Carer

Social workers recognised the culture of local authorities varied in whether they preferred more traditional care models or championed empowering SDS users to control how they received care and support. One social worker also felt that the COVID-19 pandemic made carers and social workers become more creative in how Self-directed Support could be used because some of the regular provision was shut down or limited. They listed ways support was adapted in this situation, including supporting carers to turn their gardens into places of respite while they were unable to access other respite.

3.2.4 Equality issues

The research also found that some Self-directed Support users who shared certain protected characteristics experienced inequality in accessing Self-directed Support and being able to achieve their personal outcomes. The main issues concerned:

- accessibility of Self-directed Support processes and communication
- prejudice about people with specific protected characteristics, and
- difficulty meeting the cultural needs and preferences of SDS users.

As previously mentioned, some disabled participants pointed out instances when reasonable adjustments were not made to make Self-directed Support processes or communication with their social worker accessible. One participant explained that no help was offered with completing forms although they were unable to hold a pen. Another reported that they asked to meet their social worker at an accessible venue but was told there was no such venue where they could meet locally. A Deaf participant said they asked their social worker for face-to-face meetings, but the social worker carried on with communication by phone and email. An advocacy worker also noted that Self-directed Support users with communication difficulties and people with learning disabilities sometimes felt they had to accept care decisions because the complaints process was not accessible to them without the help of advocacy workers.

> ‘The process of applying for self-directed support was difficult. You have to fill in all these forms … Well, I can’t hold a pen!’
>
> – Self-directed Support user]

Advocacy workers supporting people from ethnic minorities also raised issues around accessibility due to language barriers. They explained there was a very low awareness of Self-directed Support among potential users from ethnic minority groups. In addition, when English was not people's first language, language barriers presented further obstacles to understanding what care and support was available through Self-directed Support and how to access this care. The advocacy workers also explained that sometimes families took control of Self-directed Support users' payments because they were unable to manage the process themselves due to language barriers.

Prejudices about disabled and LGBT people were also highlighted as affecting access to care and support to achieve personal outcomes. An advocacy worker felt that social workers' prejudices about what disabled people could do and achieve sometimes affected what personal outcomes and support social workers were prepared to agree. For example, the advocacy worker felt that social workers did not understand and appreciate that the disabled woman they supported was a highly intelligent person with aspirations to live an independent and active life. They also reported that LGBT people could struggle to find care due to care agencies' prejudices.

This was reflected in the experiences of one participant who had recently transitioned and struggled to find care due to prejudice. They reported various instances of such prejudice. One care agency said its carers might take offence at being asked to provide care to a trans person. In another situation, this participant found out that a care agency had a policy of not working with LGBT clients. Other care agencies refused to provide care, saying that they would be unable to provide specialist medical care for a trans person, although they had explained they no longer needed this kind of medical care.

A social worker also reported that people with mental health conditions had less access to Options 1 and 2 due to perceptions that they were unable to manage their employer obligations. Another social worker reported that they supported people with mental health conditions to use Option 1 but acknowledged that their access to this option had been variable.

In addition, some participants raised issues about the need to meet the cultural needs and preferences of Self-directed Support users. One participant from an ethnic minority group reported that their culture was not considered in how their care was organised. For example, their food choices and cooking habits were not considered, nor were the times when people showered in their culture. They therefore wanted a carer from the same or a similar ethnic background to reassure them that their cultural needs and preferences would be met. Advocacy workers supporting Self-directed Support users from ethnic minorities confirmed that this was common, in their experience.

Other participants at times expressed a similar need to feel they shared some common ground with their carers. Having a carer who was similar to them made them feel more comfortable with their carers and more confident their needs would be met. For example, the participant who had recently transitioned was very pleased they now had a trans carer who they felt understood what they had experienced and how they felt. An advocacy worker explained that a young disabled woman they supported wanted her carers to be young women too, to feel more connection with them. These and similar comments indicated a need for diversity in the caring workforce that reflects that of Self-directed Support users.

More broadly, some advocacy workers discussed limited understanding of inequality and how equality should be considered in when implementing Self-directed Support. For example, one advocacy worker thought that local authorities sometimes seemed unaware that Self-directed Support users could experience disadvantage and barriers linked to multiple protected characteristics. In their experience, when local authorities addressed equality issues experienced by Self-directed Support users, they tended to focus on one protected characteristic rather than considering intersecting inequalities.

3.2.5 Poor implementation of Self-directed Support

There was a widespread perception that Self-directed Support was a wonderful idea that broke down in practice when implemented by local authorities. Some issues with poor implementation emerged across interviews, including limiting Self-directed Support to critical care, huge variations in how it works between different local authorities and low awareness and understanding of Self-directed Support.

Some Self-directed Support users, advocacy workers and personal assistants believed that Self-directed Support was only allowed for critical care in some local authorities. For example, an advocacy worker explained that social workers categorised user needs as mild, moderate, significant and critical. They felt that over time it became more and more difficult to receive Self-directed Support for anything other than critical care needs. This view was echoed by some Self-directed Support users who felt that this approach betrayed the core purpose of Self-directed Support, which was to support people to achieve their personal outcomes and not to simply exist.

Some Self-directed Support users, advocacy workers, personal assistants and social workers involved in this research were also critical of the so-called ‘postcode lottery’ and wide discrepancies in how Self-directed Support was implemented between different local authorities. For example, a personal assistant said they believed there was inconsistency in what constituted a personal outcome across local authorities, resulting in 32 different interpretations of what a personal outcome is. A social worker found the assessment process more bureaucratic and lengthier when members of their own family tried to access Self-directed Support in a different local authority to the one they worked in. Other differences concerned who was entitled to Self-directed Support, what budgets could pay for and whether there was support for people to meet their related employment obligations.

These discrepancies created a sense of unfairness, as different people were seen to have access to different support based on where they lived. Discrepancies were also seen to create confusion over what Self-directed Support could be used for. In addition, as it is not transferable from one local authority to another, this created practical difficulties for people if they moved areas because they would need to start the process of applying for, and arranging, their Self-directed Support and care again.

Social workers highlighted some of the reasons for these differences in implementation by different local authorities. Some suggested local authorities varied in their culture and the extent to which the leadership championed Self-directed Support as a shift to giving people more control and choice over their care. Others pointed out variations in the infrastructure supporting social workers, resulting in different experiences in different places. For example, some thought that having a strong community brokerage service in place that could support people through advocacy, payroll and budget management services was very important for Self-directed Support to work well. However, it was acknowledged that the availability of community brokerage services varied between local authorities.

Self-directed Support users in this research also thought there was limited awareness of what they were entitled to and who could qualify. Some described Self-directed Support as a well-kept secret. Some felt social workers also appeared to lack good understanding of Self-directed Support. For example, a Self-directed Support user who was also a student social worker noted that they had not yet been taught about Self-directed Support as part of the curriculum for social work studies.

Some of the previously discussed challenges, such as lack of flexibility in how Self-directed Support can be used and workforce shortages in the care sector, were also seen as factors contributing to poor implementation. Many felt that to benefit people often had to be able to withstand a long and stressful battle with local authorities and social workers.

3.2.6 Impact of different Self-directed Support options

SDS users felt the option they chose affected opportunities to achieve their personal outcomes. Options 1 and 2, which give more control, were perceived as enabling them to achieve their personal outcomes to a greater extent than Option 3, when local authorities selected and arranged support. However, Option 1 was also seen as bringing significant challenges, with limited or no mechanisms in place to support people to overcome them.

Option 1

SDS users, advocacy workers and personal assistants with experience of Option 1 agreed that when it worked it allowed for far superior support than more traditional forms of social care. Social workers stressed that people should be able to achieve their personal outcomes with all options, but some acknowledged that Option 1 provided more flexibility. In those instances, care could be organised to fit around the people’s lifestyle and tailored to meet their needs and aspirations. SDS users could also ensure their carers or personal assistants had the skills needed to support them.

However, getting to this point was seen as a long process of trial and error to find the right carers. For example, one participant using Option 1 explained it took them years to assemble the team of carers they had now, which worked well to support them. The process of getting Option 1 to work well sometimes involved long and stressful challenges to secure the support that they wanted.

Other challenges arising from Option 1 were linked to its main advantage – having choice and control. With this option, Self-directed Support users become employers with all the obligations this includes. However, as many of our participants pointed out, the system provides limited support for people to manage their obligations as employers. Social workers felt there was adequate community brokerage services in their areas, including payroll and budget management services, but acknowledged that provision of this support varied across local authorities.

> ‘When you’re going for Option 1, there’s an enormous burden to take on, you’re becoming an employer, and community brokerage is helpful to support you with that.’
>
> – Social worker

Some Self-directed Support users, as one participant using Option 1 explained, handled this situation by paying their carers to deal with employer obligations on their behalf. In another case, a respondent paid a percentage of their budget to their local authority to take care of these obligations. However, they were unable to carry on doing this when they moved to another local authority.

Other participants said had no support and were left with responsibilities they found difficult to meet due to their health condition or disabilities. As a result, they sometimes had no care while they tried to find and employ carers. Some personal assistants also noted that when people found it difficult to meet their employer obligations their relationship with their personal assistants sometimes broke down. This in turn led to a high turnover of personal assistants, with a negative effect on people's care and ability to achieve personal outcomes.

When Self-directed Support users were unable to find and arrange their own care, they were often left without care for periods of time, since they were seen as responsible for managing their care. There were limited or no mechanisms in place for local authorities to support people with Option 1 during the gaps in care provision.

As mentioned previously, one participant in this situation with significant health problems and disabilities had been without care for several months at the time of this research. An advocacy worker also felt that during the COVID-19 pandemic social workers ignored Self Directed Support users using Option 1 because they were considered to be in charge of their own care. Any gaps in care provision tended to be mainly filled by family and friends, undermining their independence.

Social workers suggested that gaps in care experienced by Self-directed Support users using Option 1 should be addressed by them temporarily switching to Option 4, with the local authority arranging care during that time. Once someone found new carers or personal assistants, their Self- directed Support option could be switched back to Option 1.

Option 2

Two participants using Option 2 were satisfied this worked well for them, as it allowed them choice but without the responsibilities of becoming employers. Both were able to find an agency and personal assistants who could meet their needs.

Some others saw this option as beneficial too. For example, an advocacy worker thought that, after Option 1, Option 2 worked best to support people to achieve their personal outcomes because it also came with more control and choice. A respondent with Option 1 suggested that Option 2 potentially worked best for many people as it allowed choice but removed challenging obligations. However, they thought that local authorities were reluctant to offer this.

Option 3

Option 3 was generally disliked by Self-directed Support users participating in this research. It was seen as not being flexible enough to be tailored to meet individuals' needs.

Other participants who had received care organised by their local authority complained of having no continuity of care and not being able to arrange care hours that suited their routine and lifestyle. In addition, some advocacy workers also thought this was the least likely option to help people achieve their personal outcomes.

Option 4

How this option worked depended on what combination of the options above Self-directed Support users chose. For example, a carer whose son had a combination of Option 1 and Option 2 thought this arrangement worked very well for them. Option 1 involved payment of a lump sum that was used to buy equipment, attend relevant training and for respite. Option 2 was used to pay for personal assistants provided by the local agency that they chose. In addition, both the family and their personal assistants were supported by a social care charity that provided advice, guidance and support if any issues arose.

Conversely, one participant whose daughter's Option 4 included very little of Option 1, and was mostly Option 3, reported a negative experience. This was because they found the local authority inflexible in what it allowed the family to access using Self-directed Support. They found they could not use the budget to pay for what they saw as the best care for their daughter. Instead care had to fit in with prescriptive rules about the type of care, who should provide it and under what conditions it could be paid for.

3.2.7 Impact of the COVID-19 pandemic

As mentioned, some participants reported that the COVID-19 pandemic had an impact on Self-directed Support assessments, meaning they were often done remotely rather than face to face. This affected Self-directed Support users in different ways. For some, it created accessibility problems. For example, they struggled to understand information when they could not see the person providing it. For others, remote assessment potentially limited how well social workers could understand their situation, needs and what they wanted to achieve. For example, one participant complained that their social worker lacked some basic understanding about them because they never met in person.

Some Self-directed Support users, advocacy workers and personal assistants also highlighted other ways in which social distancing measures affected available support and opportunities. For example, an ex-army Self-directed Support user said it became more difficult to get army charities to visit and support them. A personal assistant explained that it became more difficult to achieve some personal outcomes when people's ability to access services was more limited. For example, trying to achieve social interaction at a day centre was challenging when everybody had to be socially distanced, especially since person they were supporting is Deaf.

However, as mentioned previously, a social worker felt that the COVID-19 pandemic also brought about some positive practices. In their view, it pushed social workers, Self-directed Support users and carers to think creatively about how personal outcomes could be achieved. A participant gave an example of using Self-directed Support to buy a dog for someone who felt this would give them emotional support and improve their quality of life. Another social worker cited instances of Self-directed Support users paying for Xbox subscriptions so they could maintain their social connections during lockdown. One social worker also felt they were allowed to reduce the bureaucracy associated with Self-directed Support during the pandemic, which they felt was positive, and they wanted to retain some of those changes.

3.2.8 Advocacy

Three Self-directed Support users had some experience of using advocacy to help them receive the support they wanted. All looked for support after a period of finding it difficult to get Self-directed Support to meet their needs and trying to resolve this themselves, with no success. One reported that their advocacy worker helped them to pay for yoga from their budget. The other two were still in the process of challenging how they could use their budget to meet their needs better.

Participants agreed that advocacy workers helped them in several important ways. Some explained that advocacy workers understood their situation and needs and so were able to help them communicate these to their local authorities. Others said their advocacy workers knew Self-directed Support and other relevant legislation and rules well, so were able to argue their case in front of social workers and local authorities. One participant also said that having an advocacy worker made them feel more confident and not alone in trying to secure the care they needed.

Advocacy workers in this research also discussed different ways in which they supported Self-directed Support users to achieve their personal outcomes. These included support with: identifying personal outcomes; preparing for and going through the assessment process; and challenging local authority decisions about their care and budget and how the budget could be used. Where these challenges were successful, advocacy was instrumental in helping people achieve their personal outcomes. Reflecting on what such help achieved, one advocacy worker argued that Self-directed Support users without advocacy workers fared worse.

For this reason, they thought that Self-directed Support could be improved if people had a right to advocacy rather than it being optional help that some were not aware existed. Participants from all groups also felt that more work was needed to ensure that all prospective and current Self-directed Support users were given information about advocacy services available in their area.

4. Conclusions

This research aimed to understand the extent to which Self-directed Support helps people achieve their personal outcomes. We explored this with a small but diverse group of participants, drawing out themes by protected characteristic when this was possible. The extent to which the experiences recorded by this study reflect experiences of people using Self-direct Support more broadly is unknown and would need to be the subject of further research.

The experiences of the Self-directed Support users captured in this report were very mixed in whether and how much Self-directed Support helped them achieve their personal outcomes. For a few people, it worked well to help them assemble a team of suitably skilled carers, organise care tailored around their needs and routines, and fund equipment, respite or other items and services they needed. For others, Self-directed Support was associated with inflexibility to tailor care to their needs and an ongoing struggle with social workers and local authorities over their Self-directed Support budgets and how they could be used.

Based on these experiences and the views of advocacy workers and Personal Assistants, the following improvements were identified for Self-directed Support to better help all people achieve their outcomes. Within this, more work is also needed to overcome barriers that Self-directed Support users with particular protected characteristics experienced in achieving their personal outcomes.

Self-directed Support assessment process

- Support should be provided during the assessment process to help potential and current Self-directed Support users articulate and communicate their personal outcomes and what could help them achieve them. People may also need more than one conversation with their social worker to work out the best approach and goals for their care.
- In some instances, the assessment process would benefit from involving the views of family or health professionals, potentially in separate meetings to enable them to be honest and open.
- Social workers and local authorities must ensure that the assessment process is as accessible and inclusive as possible and remove the barriers experienced due to inaccessible processes and communication or prejudice.

- Self-directed Support needs to allow for regular re-assessments of peoples' personal outcomes, which are meaningful and reflect changes in their situation over time. Mechanisms are also needed for people to raise issues with meeting their personal outcomes and adjust their care if the original provision was found not to be working.

Choice and control

- The research suggested that local authorities' overly prescriptive and inflexible approach to how Self-directed Support can be used was a common experience among some participants. By being prescriptive and inflexible, local authorities and social workers limited the potential for Self-directed Support to benefit people and help them meet their outcomes.
- Self-directed Support users' views on what support they feel would help achieve their outcomes, therefore, needed to be reflected much more in local authorities' and social workers' decisions about how their budgets can be used.

Purpose of Self-directed Support

- There was a sense among some participants that the way Self-directed Support was implemented betrayed the very spirit and intention of this model of social care. As they argued, Self-directed Support was brought forward to enable people to achieve their personal outcomes and good quality of life. In reality, they felt it was limited to providing critical care, restricting significantly who can be supported and how.
- Some Self-directed Support users, advocacy workers and Personal Assistants felt that decisions were too often made to fit a certain budget, rather meet personal outcomes. Financial constraints were felt to be another factor undermining the core purpose of Self-directed Support and the reason this model of care was introduced.

Support for people with Option 1

- Option 1 was perceived to provide most opportunity to achieve personal outcomes due to the choice and control being transferred to Self-directed Support users. However, with this, people also became employers with all the obligations this involved. They also became responsible for organising their care, with sometimes no or limited support available for those struggling with their employer obligations or experiencing protracted gaps in care provision due to not being able to find and arrange suitable care.

- Participant’s reported a need for infrastructure and mechanisms to support those people who need help with their employer obligations and fill gaps in care at those times when they are unable to find adequate care need to be available and promoted in all local authorities

Equality

- The research found Self-directed Support processes and communication were sometimes not accessible to disabled people or people with English as a second language. Reasonable adjustments need to be made to overcome any disadvantage arising from communication or accessibility barriers. This should include providing information in different languages to prevent some ethnic minority groups being disadvantaged when accessing Self-directed Support.
- The research also found some disabled and LGBT Self-directed Support users felt they experienced prejudice from social workers or care agencies, which limited what they could use their budget for or made it more difficult to access care. This suggests more work is needed to embed equality and good practice in the sector to ensure equal treatment for all Self-directed Support users. Consideration is needed on how best to achieve this. For example, though inspection or built-in requirements around procurement or commissioning. In addition, people would benefit from directories listing care providers championing equality, which they could use to help them select care agencies.
- Peoples’ cultural needs and preferences must be acknowledged and reflected in their Self-directed Support assessment and care plans, including in their daily routines, or cooking and food preferences.

Workforce

- Staff shortages in the care sector were highlighted by many participants in this research as a major barrier in implementing Self-directed Support, as intended by this care model and legislation. Some Self-directed Support users and advocacy workers struggled to believe that it could be improved significantly without addressing the workforce shortages. A more diverse workforce would also help reflect and meet cultural needs of different groups of SDS users.

- While this is a much broader challenge in the care sector, some advocacy workers argued that local authorities needed to improve planning and commissioning of services to meet care needs in their area and address any gaps in care provision. This would help them identify and understand the diverse needs of people in their area, including those needs relating to specific protected characteristics. Social workers also called for more campaigns giving recognition to carers and Personal Assistants, which could promote the difference they make and attract new staff to the sector.
- Local authorities need to be more flexible in allowing Self-directed Support users to choose care providers they want – even if they were outside of their area or not on their approved list. This may also help alleviate pressures elsewhere in their local care system.

Contacts

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