

SDS during the pandemic: experiences of unpaid carers in 2021



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Introduction

In May 2020, Scottish Government and COSLA issued joint guidance on Self Directed Support (SDS) options 1 and 2 for local authority and Health and Social Care Partnership staff to use during the COVID-19 pandemic. The guidance suggested that those with SDS Options 1 or 2 should be able to use their budgets in a more flexible way during the pandemic in order to meet their outcomes.

We carried out a [brief survey last year](#), shortly after the SDS Covid 19 guidance was first issued, to gauge whether people in receipt of SDS option 1 or 2 had been made aware of this additional SDS guidance and also whether they had been able to use their SDS budgets in a more flexible way during the pandemic.

Of the 208 carers who responded, only 81 who were in receipt of SDS, had been made aware of the SDS Covid-19 guidance and of these, just over 1 in 5 had been able to use their SDS in a more flexible way since the start of the pandemic.

It has now been over a year since the SDS Covid-19 guidance was first issued, so we decided to repeat the survey again to see whether the implementation of the SDS Covid 19 guidance was more widespread and whether people who receive SDS options 1 or 2 had been able to meet their outcomes during the pandemic by using their budgets in a more flexible and creative way.

In partnership with the [SDS Collective](#), we put together a short online survey which was live between 5th – 30th August 2021.

Who responded to the survey

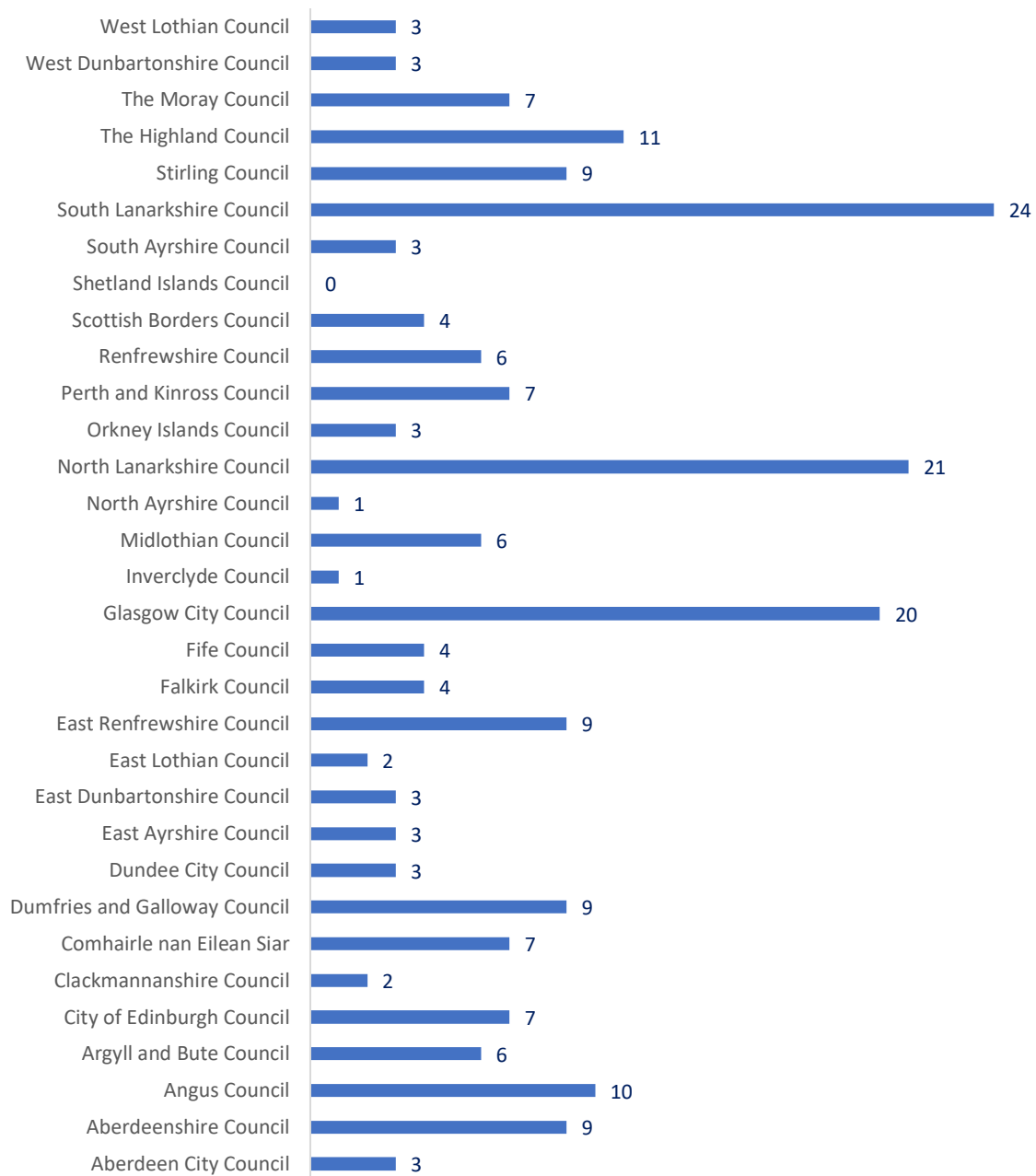


Figure 1: Number of responses received from each local authority area (n=210)

210 people from across Scotland responded to the survey. We received responses from carers and supported people across 31 local authority areas. Shetland Islands was the only local authority area we received no responses from.

The majority of those who responded (78%) were unpaid carers who provided support to a child or adult in receipt of SDS option 1 or 2.

Who responded	responses *
I have social care support needs and currently receive SDS Options 1 or 2	10%
I am an unpaid carer and receive SDS Option 1 or 2 to meet my care needs	10%
I am an unpaid carer and support someone who receives SDS Option 1 or 2	78%
Other / didn't specify	10%

Figure 2: Breakdown of who responded to the survey (n=210)

* respondents could tick more than 1 box to describe themselves. For example, around 6% of unpaid carers who care for someone with an SDS budget are also in receipt of a carers SDS budget for themselves.

Almost 2 out of 3 of those who responded to the survey told us that they (or the person they were caring for) received SDS Option 1. Figure 3 provides a breakdown of which SDS option(s) our respondents receive (or help to manage on behalf of the person they were caring for)

SDS Options	Number of responses
Option 1	138
Option 2	31
Option 3	6
Option 4	23
(Option 1 + 2)	(7)
(Option 2 + 3)	(4)
(Option 1 + 3)	(8)
(Option 1 +2+3)	(4)
Not sure	12

Figure 3: Breakdown of which SDS options the respondents received (n=210)

Awareness of the SDS Covid-19 Guidance

The SDS Covid-19 guidance states that

'local authorities should pro-actively communicate their approach to SDS Option 1 and 2 budgets during this period in a clear and transparent way to people using such support.'

In our survey, we asked those in receipt of SDS Options 1 or 2 whether they had been informed that they could use their SDS budgets in a more flexible way during the pandemic.

Around half of those who responded to our survey (n=102) were aware that they could use their SDS budgets in a more flexible way during the pandemic.

Only 19% of those who were aware that they could use their SDS budgets more flexibly during the pandemic, had been informed of this by their local authority.

Were people aware that they could use their SDS budgets more flexibly?	
No, did not know this	50%
Yes – informed by local authority	19%
Yes, informed by local support organisation	12%
Yes, informed via a different source	19%
(other carers/peers)	(2%)
(social media/online)	(9%)
(friends/family)	(2%)
(national organisation)	(3%)
(not specified)	(2%)

Figure 4: Number of people who were aware that they could use their SDS budgets flexibly during the pandemic (n=206)

Using SDS in a more flexible way

We asked those who responded to our survey whether they had been able to use their SDS budgets in a more flexible way during the pandemic.

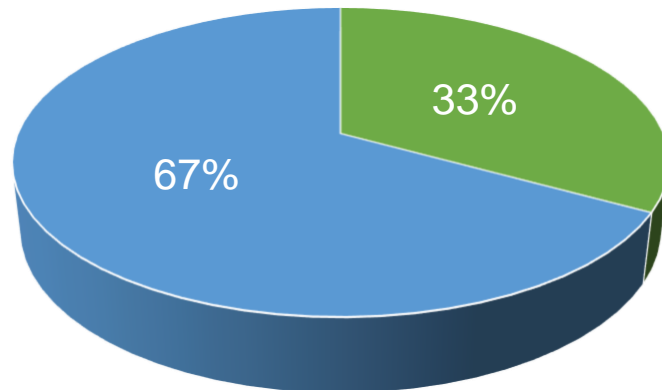


Figure 5: Number of people (%) who have been able to use their SDS in a more flexible way during the pandemic(n=205)

1 in 3 of those who responded to our survey had been able to use their SDS budgets in a more flexible way during the pandemic.

This was an increase to the figures from our survey last year when just over 1 in 5 had been able to use their SDS budgets for alternative support when their usual support or services were limited or unavailable.

Out of the 67 respondents who have been able to use their SDS budgets in a more flexible way during the pandemic, the majority (69%) used it to purchase equipment for themselves or the person they care for.

Around 27% of those in receipt of SDS Options 1 or 2 had been able to use their budgets to employ relatives during the pandemic, and 18% told us they were given greater flexibility over the hours and tasks that support staff could undertake as a result of the Covid-19 SDS guidance.

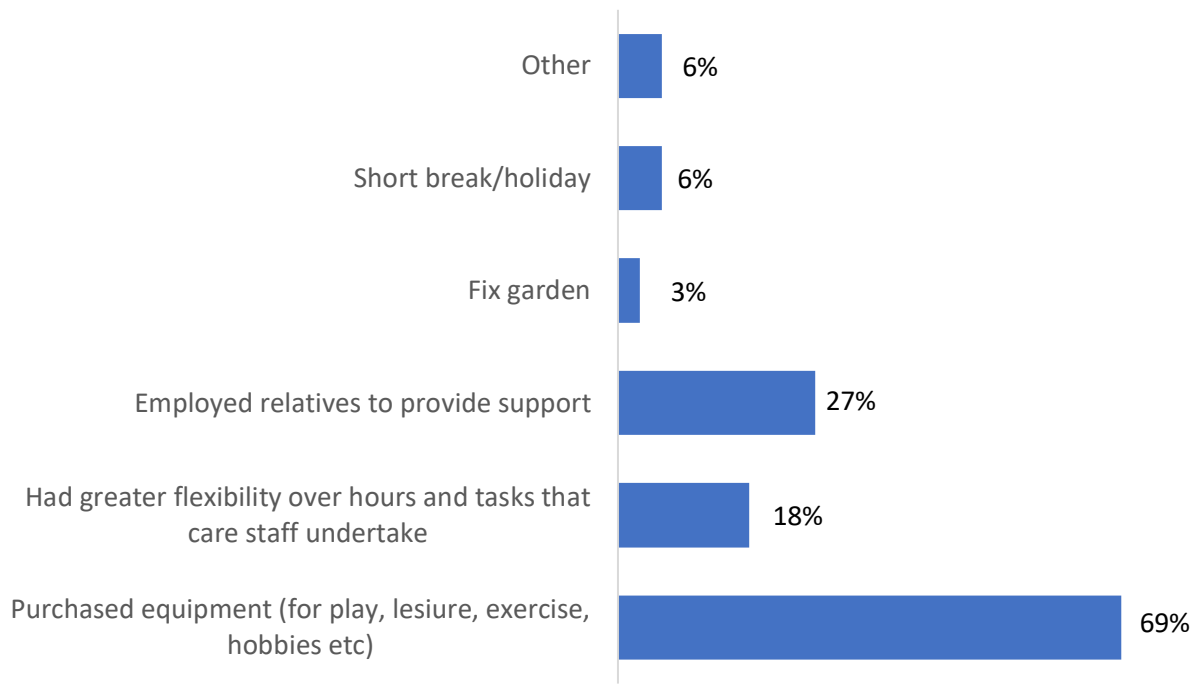


Figure 6: What did people use their SDS budgets for during the pandemic (n=67)

Barriers to using SDS in a more flexible way

134 of those who responded to our survey had not been able to use their SDS budgets in a more flexible way. The reasons for not being able to use their SDS budgets flexibly included:

(1) Not being made aware that SDS could be used more flexibly during the pandemic

57% of those who had been unable to use their SDS budgets for alternative support during the pandemic told us that it was because no one had informed them that this was possible.

“My daughters support was cancelled during lockdown and no other provision was made for her during this time, although the local authority continued to pay my daughter's provider in full via option 3 I was not advised that option 1 or 2 could provide a more flexible use of the SDS budget for my daughter. Additionally, as an unpaid carer, I receive a carer's budget as a direct payment and was advised I could not use this during lockdown - therefore no flexible approach there either.”

(2) Being told by council/social worker that it wasn't allowed

28% of those who had been unable to use their SDS budgets more flexibly told us that this was because their request to use their SDS budgets on alternative support had been refused by their social worker or local authority. Many were told that they were not allowed to spend their SDS budget on anything other than what was originally agreed in their support plans.

“I have been told twice by Glasgow City Council social work that this is only available to people receiving direct payments”

“My sons disability social worker point blank refused to consider alternatives saying SDS "wasn't there for fun". She then lied on the review paperwork in June this year claiming she had discussed alternatives with us. Shameful backtracking and lying.”

“Funding requested but because old plan in place was not allowed as it didn't meet the "outcomes" even though we were already going through a re-evaluation of the plan. It took too long to redo care plans. Lost out on all respite care during lock downs (April 2020 - Oct 2020) then when

returned to respite, it was on reduced hours. Then stopped again in second lockdown (Jan 2021-April 2021)."

"My son's social worker stopped his SDS and when I asked for it to be reinstated so I could employ a cleaner and gardener I received a nasty email from her boss. I am a single parent, trying to care for my son and work from home and I am on the verge of breaking."

"When finding out that our son was more susceptible to the virus he was added to the CEV list. We kept him home for almost four months until he had his first vac. When he began to withdraw socially and become more anxious in his behaviours we asked if we could use the Carers budget to provide social interaction with a switch console. Something fun that would draw him out. We were told no as it couldn't be used for entertainment purposes. We pointed out it was to encourage social interaction which is part of his care plan and were still refused."

"I suggested flexibility and told it was an inappropriate use of an SDS budget even though met outcomes. LA refuse to move money from payroll account to their Paycard account so several thousand pounds is locked up and unused. Decisions on what is an appropriate or not spend is completely arbitrary and has taken years to get anywhere near a good discussion. The guidance on finance does not include any of their exclusions"

"I asked on many occasions to use the budget to let my profoundly disabled son use the budget to let friends take him out to give him and us a break when we had no formal support. This was rejected on many occasions. I have gone from 35hrs to no hours but nobody tried to help to utilise the budget to help me. I had to give up work too."

(3) Still waiting to hear back from council / social worker

Around 14% of those who have been unable to use their SDS flexibly are still waiting to hear back from their local authority or social worker about their request.

"The social worker who was organising my sons SDS has left her job and we have not heard from anyone else"

"Pandemic prevented assessment of needs. Been promised but nothing done."

(4) Didn't require any additional flexibility

A small number of carers and people with support needs (7%) told us that they were aware that they could use their SDS on alternative support, but chose not to as they did not require any additional flexibility at the time.

"I had no need to change the support received, but would not have been aware that this was an option if I hadn't been in contact with the Falkirk Carers Centre"

(5) Lack of support or services to spend budget on

We also heard from carers and supported people, who although were aware that they could use their budgets on alternative support, were still unable to do so because there was a lack of alternative supports that would suit their needs or the needs of the people that they were caring for.

"Wasn't able to get the support we normally get due to Covid and no respite available during that time. When two carers are required for hoisting etc. it is very difficult to get extra care as many companies will not take us on."

"Didn't use any SDS as couldn't recruit someone appropriate during the pandemic"

"Lack of support services for children, suitable activities and not sure what was ok. We didn't want to get into trouble"

(6) Worried about repaying money spent on alternative support

Some carers and supported people were led to believe that any SDS monies spent on 'alternative support' would be recouped by the local authority and so this deterred them from using their SDS budgets on anything other than what was originally agreed in their plans.

"Worried we would need to pay it back and questioned about usage"

"Was told this money would be recouped"

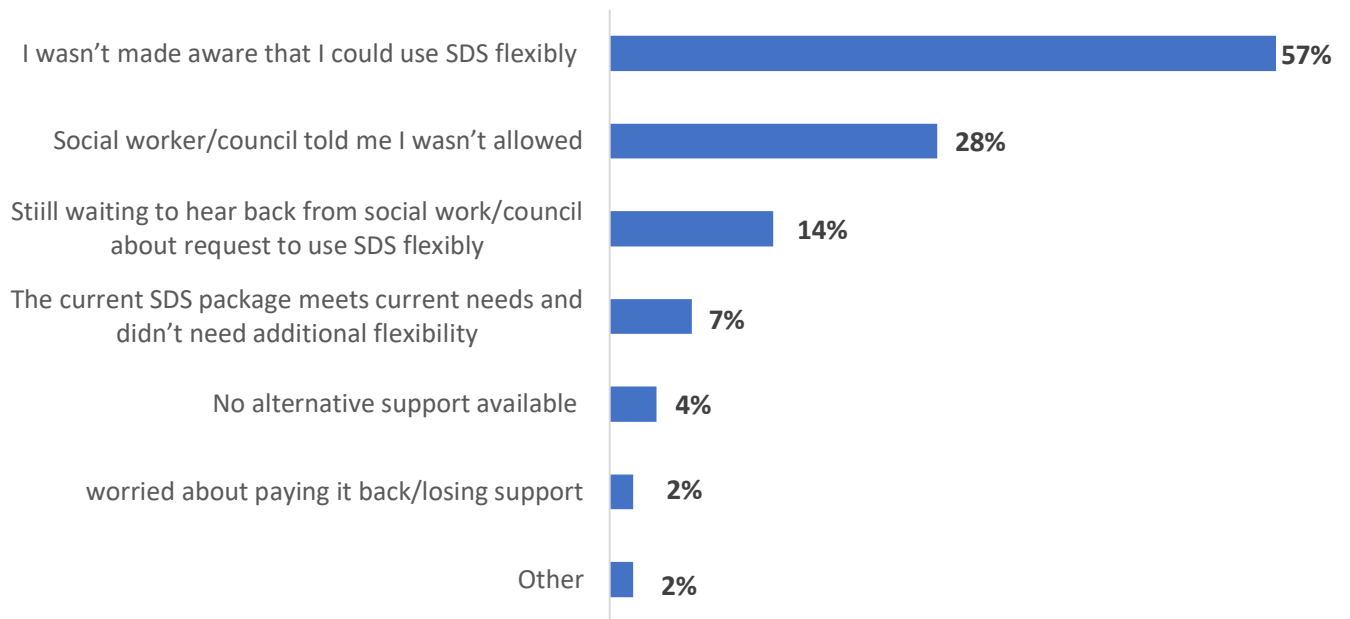


Figure 7: Reasons people gave for not being able to use their SDS budgets in a more flexible (n=134)

Regional Variations in implementing the SDS Covid-19 Guidance

Due to the small number of responses from some of the local authority areas, we are unable to provide an in-depth analysis of how well the recent SDS Covid-19 guidance has been shared, adopted, and implemented by each local authority area.

In 5 of the local authority areas, we received 10 or more responses to our survey. We have therefore put together a summary of the responses from those 5 local authority areas.

Local authority area	Aware of the SDS Covid-19 guidance?	Been able to use SDS on alternative support?
Angus (n=10)	50%	33%
Glasgow (n=20)	53%	11%
Highland (n=11)	10%	18%*
North Lanarkshire(n=21)	45%	35%
South Lanarkshire (n=24)	70%	43%

Figure 8: breakdown of responses from 5 local authority areas

* In Highlands, 1 of the respondents reported that they had used their SDS on alternative support even though they were unaware that this was allowed under the Covid-19 SDS Guidance – “We’ve had no extra advice or support locally but have carried on ourselves trying to find options”

Accessing SDS during the pandemic – key themes

Carers and supported people who responded to the survey also provided additional information about their experiences of accessing SDS during the pandemic. Some of what carers and supported people told us this time about their experiences of SDS was similar to what we heard in 2020 when we undertook our [first survey](#) .

We have summarised the key themes arising from the feedback from carers and supported people who responded to the survey.

(1) Positive impact of SDS Flexibility

A number of carers who had been able to use their SDS budgets in a more flexible, shared that this had been a positive experience for them:

“I found it very very helpful being told I could use money for other things. Lockdown and restrictions were difficult and even the process and zoning up with ideas on what we might spend money on and then doing it and receiving products by mail eased the struggle a bit.”

“I found the flexibility to use the money I received during the pandemic absolutely essential for my own mental and physical needs. It has been the only viable way for me to cope as an unpaid carer. Life saving and enlightened.”

“Enjoy the flexibility and control we have with SDS. Means we have a dedicated team to support our son with complex needs.”

“Having the flexibility to use the SDS for buying things to support our child’s special interests has been most useful.”

“The change to allow family members support an individual was a good one. I would like to see this change retained in the future.”

(2) Too much bureaucracy

Despite the SDS Covid-19 guidance being issued, many carers and supported still had to contend with a lot of bureaucracy, meetings and paperwork in order for requests to use SDS budgets more flexibility to

be listened to and approved (or rejected!). During the pandemic, supported people and carers needed services and social work teams to be far more responsive to requests for flexibility.

“Each time we contacted our LA to use the funds differently from usual we were told no as it didn’t meet the care plan in place!”

“Generally very positive experience. However, everything took a long time to happen eg Assessments, feedback, responses and authorisations. Flexibility is often quoted, but in reality there seems to be many hurdles and much box ticking processes.”

“Had to push for permission to buy items which took a few months to authorise in both cases.”

“I have transferred from the option of council doing everything to managing it myself it has taken a lot longer than it should have. The decision was approved over a month ago and we have still not received payment and have had to pay wages from own money.”

“I was allowed to allocate some money from the budget to buy items useful during lockdown. It was not straightforward however and required a huge fight to be allowed to do this. It was only allowed for a tiny part of the budget and the remaining unused budget remains unspent. I would like to be able to use this now, but honestly can’t face another fight, despite SG guidelines.”

“We had wonderful support from local SDS when we were looking for help but then we couldn’t make any changes without social work review.& when I tried to chase this up was told my husband was low priority..not a pleasant cycle to be in.”

(3) More focus on Rights, not resources

Decisions about support available to supported people and carers tend to be based on what resources are available, rather than based on whether a person’s rights are being met.

“Because some items hadn’t been individually itemised in my son’s plan the social work assistant persistently contacted me about the money spent and that I may need to pay it all back out of my own

money. Our previous social worker always put a general statement in our plan summing up the type of things we could purchase and when he was seconded we were not given a named person to take over. Nobody ever informed me that what I was doing wasn't allowed. The total lack of empathy, understanding and knowledge of how SDS is meant to work by the new person involved with us led to a very stressful time. Every year the local authority asks for thousands of pounds back that I have left in our budget. This year they have agreed for me to use some of the £4000 accrued money to purchase a hoist and tracking for our garage so that my son can access a swing. Initially they wanted me to forego my respite care to pay for it. Again that shows a total lack of understanding about how demanding and tiring caring for a loved one is. I feel very let down by the lack of positive support - the lasting impression I have is that they are only interested in the financial aspect as opposed to the needs of the young person and family."

"We have zero trust in social services here, the message is that care is driven by the budget and that's far more important than the person and if you dare to complain you're always in the wrong. No such thing as good conversations here."

(4) Recouping of unspent budgets

During the pandemic, many carers and supported people were left with unspent SDS budgets due to services being closed or lockdown restrictions. Instead of working with them to consider how these budgets could be used on alternative support, many local authorities sought to 'claw back' all unspent budgets. Carers also expressed concern that local authorities might reduce their SDS budgets for the following year if they had deemed that families had 'coped' with reduced budgets and support during the pandemic.

"not a penny spent but Council quick to claim it back as unused funds!! Not had respite since Feb 2020"

"Absolutely shambolic in Dumfries and Galloway, we could have been making lives better but social work refused at every turn and then when your package money built up (because we couldn't use it) the council reclaimed it because they don't want you having more than £2000 in the account."

"Although we have been able to use the SDS budget to purchase

alternative support and equipment. We haven't been able to spend the entire budget and have been left with a considerable underspend. The council wanted us to return the underspend without any discussion about how we could potentially use the underspend once restrictions were lifted.”

“We have given back 10's of thousands of pounds in unused budget during the pandemic but my son and our family have struggled but nobody would allow us to spend the budget in any other way. Very sickening!!! What is the point of having the budget??”

“We could not use respite care at all because we have been Shielding since March 2020, my husband is a primary school teacher and has been living in rented accommodation for that time, which was/ is a huge financial strain. To have that money sitting there and not being able to use it, was quite upsetting, particularly, when the money was claimed back by the council.”

“Upsetting experience because it was all about reclaiming the funds by LA They have direct access to the account so they just take what they want.”

(5) Lack of support from social work

With some exceptions, the general view of supported people and carers who responded to this survey, was that social work was not able to provide them with the support and advice that was much needed during the pandemic.

“I phoned for support a number of times. I was told when I was unwell following surgery and existing support failed that as we had option 1 it was up to me to find an alternative and that option 1 means social work no longer have a duty of care. Prior to this they had not noted my phonecall to say I was having surgery.”

“Limited support- we have a good Social Worker but so busy we just struggled on. Our budget is small but we now have the issue that needs have changed and we don't know what's ok and what's not to spend the money on.”

“Felt very alone and under pressure to find PA with no support or direction from social work, it came to a point where we were ready to hand the budget back”

“Getting information was like pulling teeth and quite often I was sharing info that care manager was unaware of”

“I chose not to advise our LA that I had purchased home gym equipment, weights and a bike as despite some of my Carers budget going on a gym membership they were against the budget being used for anything that would be helpful whilst in lockdowns or shielding. At the end of the budget year they can have my accounts and receipts and we’ll see what happens...I am more than happy to challenge them through their complaints process if there is an issue.”

“I have been completely abandoned by social services and bullied into backing off. It’s appalling that unpaid carers have been left to struggle alone in extremely difficult circumstances.”

“I tried talking to my social worker but she couldn’t even answer basic questions on the direct payments and did not ever mention flexibility.”

“Zero information came from the council about spending our budget differently. We had one phone call from social work in the whole of the first year of lockdown, despite having very complex needs adult to care for. Not impressed at all by them. Zero info on sds options, zero info on acquiring ppe etc”

“We’ve never felt more alone. Support was a 5min phone call once a week. I’ve been left sickened as sons sds package has been reabsorbed into local authority budget. He’s missed out in thousands of pounds worth of support. My daughter (young carer) got zero support even though she was going through assessment for support.”

Summary and Recommendations

The Covid-19 pandemic led to many of the services for disabled children and adults, and for older people, to shut down or reduce significantly. In many instances, there was no contingency or back up, and unpaid carers were left to pick up the pieces with no or very little additional support. For many carers, this increasing demand on their caring role came at a very heavy cost to their own health and wellbeing.

The Covid-19 SDS guidance was first issued in May 2020 to ensure that supported people and unpaid carers were not left without vital support during the pandemic and that maximum flexibility was offered to ensure that alternative support, services or equipment could be purchased if the usual source of support was no longer available.

However, testimonies from supported people and unpaid carers across Scotland have shown that the SDS Covid-19 guidance was not implemented in the way that it was intended, and for many unpaid carers, there was very little flexibility offered in terms of support for themselves or for the people that they were caring for.

Our findings highlighted that despite the additional SDS Covid-19 Guidance, many unpaid carers and supported people still faced increasing levels of bureaucracy and red tape to access even the basic level of support during the pandemic. At a time when the system needed to be far more responsive and flexible, many were still finding that their requests to use SDS budgets in an alternative and flexible way were being delayed due to bureaucratic processes in place.

There are many lessons to be learned from the experiences of unpaid carers and supported people during the pandemic. With regards to SDS, our recommendations for policy and decision makers are as follows:

(1) Any flexibility and personalisation of support offered during the pandemic should remain in place post Covid-19

Much of the flexibility that was outlined in the SDS Covid-19 guidance was not new or in addition to what is already in the SDS legislation. Therefore, offering people flexibility and personalisation of support should not be seen as something that is only offered in

'exceptional' circumstances, but should be seen as the norm for SDS.

(2) Better accountability from local authorities

There are countless examples of where the primary SDS legislation or SDS Covid-19 guidance has not been implemented in the way that it was intended. This has subsequently led to a huge variation in how SDS is interpreted and presented to supported people and carers by practitioners across (and within) different local authorities. Currently, there is no accountability when local authorities or HSCPs fail to implement the SDS legislation and guidance or to reflect the underlying principles of SDS. There needs to be better accountability and transparency around decisions that are made locally about SDS.

(3) Less bureaucracy, and more autonomy

More autonomy and less red tape is needed to enable supported people, unpaid carers, and practitioners to make decisions about how budgets can be used to meet agreed outcomes. Far too much time and resources are being wasted on decisions which require multiple sign offs at local authority level. For example, once an individual's outcomes and budget has been agreed, it is not the best use of any social worker's time and resources to then micro manage exactly what that budget is spent on. Supported people and unpaid carers should be trusted to use the budgets to meet their agreed outcomes.

(4) Make it easier for people to switch SDS options

Supported people and unpaid carers should be able to switch to different SDS options without the unnecessary need for a full re-assessment of their needs. Carers have told us that there is often a lengthy delay for a re-assessment of their needs, and that any existing support stops until a re-assessment is carried out.

(5) No 'clawback' of unspent SDS budgets during the pandemic

If individuals have been unable to spend their SDS budgets due to Covid restrictions, then maximum flexibility should be offered to allow supported people and carers to use unspent budgets to address any unmet needs as a result of the pandemic.

(6) Support social workers to be navigators, instead of gatekeepers of local services and support

There is a recognition that many social workers are dealing with a

number of competing priorities which ultimately prevents them from building good relationships and trust with supported people and unpaid carers. Social workers should be given more autonomy over decisions about agreed budgets and outcomes, and be supported to become 'navigators' of local services and support, instead of 'gatekeepers'.

(7) Decisions about support should be rights led, and not resource led

Decisions about social care support should be led by a need to meet an individual's human rights, instead of resource led. This requires a rethink of any eligibility criteria which prevents people from receiving support unless their needs are deemed to be critical.

(8) Access to independent information, advice and guidance on SDS options

Carers and supported people told us that they did not always feel confident in employing family members or transferring between different SDS options because they did not have enough information or support from their local authority to do this. Good Information and access to advice and support are vital at all times to ensure that self directed support is working well for people, and this has been particularly evident during the pandemic. The independent third sector organisations are well placed to provide this type of information and advice, and local authorities should be working in close partnerships with these organisations to ensure that people are well informed about their rights with regards to SDS.

(9) Examples and case studies of where individuals have been able to use their SDS more flexibility should be shared widely with local and national decision makers.

There are some great examples of the benefits that a more flexible approach to SDS can bring to an individual's life and outcomes. It's important that these examples are shared more widely so that lessons can be learned about the benefits of having a more flexible approach to SDS.

Updated guidance

On 11th February 2022, Scottish Government issued [updated Guidance on SDS during the pandemic](#). This is intended to cover all SDS options and addresses some of the issues that carer and supported people had raised with us in the survey. In terms of maximizing flexibility, the guidance emphasises the importance of social worker autonomy:

'it is best practice to provide social workers with coaching and support to enable them to make decisions about budgets for an individual's care and support within agreed financial parameters, ensuring accountability and transparency.'

It also recognises the vital role that [Support in the Right Direction \(SiRD\)](#) independent support organisations play in offering valuable independent support and advocacy to individuals and carers:

'Local authorities and health and social care partnerships should proactively ensure individuals and carers accessing or seeking social care support are aware of these organisations, enabling flexibility of choice. This is an overarching expectation, but is particularly important during the pandemic period.'

The importance of allowing flexibility to supported people and unpaid carers to employ family members is highlighted and local authorities are directed not to take a blanket approach to requests:

'An individual can employ a family member as a PA with agreement from the local authority... There should be no blanket policy to refuse permission to employ a family member as a PA. Decisions to refuse should only be based on a reason specific to the individual case.'

However, with regards to unspent budgets, the guidance does very little to address the concerns that supported people and unpaid carers raised with us in the survey. Unspent budgets are being 'clawed back' without any conversation between the supported person/unpaid carer and social worker about the possibility of using unspent budgets to meet any unmet needs as a result of the pandemic. There is no suggestion of a flexible approach with regards to this in the updated guidance:

'All unspent funds in Direct Payment accounts should be returned to the local authority or health and social care partnership in the usual way.'

The updated guidance reiterates that we are still living through a pandemic and that SDS should continue to be used flexibly in response to the pandemic circumstances. However, the testimonies from carers and supported people in our survey have highlighted that implementation has been inconsistent and many local authorities and health and social care partnerships have failed to use the SDS guidance to inform their practice.

In order to ensure that supported people and unpaid carers are able to benefit from the flexibility outlined in the updated SDS guidance, it is vital that local authorities and health and social care partnerships communicate in a clear and transparent way how this guidance will now be adopted and embedded in their local practice.

Further Information

The Self Directed Support guidance for Local Authorities and Health and Social Care Partnerships, which was updated on 11th February 2022, can be viewed and downloaded from here:

<https://www.gov.scot/publications/guidance-self-directed-support-sds-during-pandemic/documents/>

Independent Support organisations are able to help with advice in relation to using Self Directed Support, and provide people with support in accessing an assessment, as well as information about payroll and insurance those wishing to employing Personal Assistants (PAs). To find a local Independent Support organisation in your local area, visit the **SDS Scotland** website and click 'find help' in the top right corner.

The **Self-Directed Support (SDS) Collective** consists of people using social care services, unpaid carers and SDS advocacy, support and campaigning organisations. Their aim is to work together to promote improved practice in the development of self- directed support throughout Scotland. To find out more about the work of the SDS Collective: <https://thesdscollective.wordpress.com/>

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