

**Have unpaid carers in  
Scotland been able to  
use SDS in a more  
flexible way during  
COVID-19?**

## **The use of SDS by Unpaid Carers during COVID-19**

**July 2020**

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# The use of Self-Directed Support (SDS) by unpaid carers during COVID19

## Introduction

On 14<sup>th</sup> May, 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.

One of the guiding principles underpinning the guidance was:

**‘To maximise flexibility and autonomy for the supported person in meeting agreed outcomes’**

Due to social distancing and the closure of some social care services during the COVID-19 pandemic, people with support needs and unpaid carers have been unable to access their usual support and care packages. The COVID-19 SDS guidance suggested that other support or items could be purchased instead, as long as it met the individual’s outcomes.

Supported people and unpaid carers should be able to use their budgets in new ways to meet their outcomes when workforce or other resources are affected due to sickness, self-isolation or shielding. This may include spend on transport to take the person to appointments, shopping delivery costs, laundrette costs and house cleaning where PA’s or providers would have supported the person with daily living tasks but are not able to do so currently. Other examples could include the purchase of IT equipment or website memberships to facilitate social interaction while physical distancing applies, or gym equipment as an alternative to a gym membership while clubs are closed and not charging as usual.

We wanted to find out whether unpaid carers and the people they care for, were aware of this new guidance and whether they had been able to use their SDS in a more flexible way during lockdown.

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We carried out a short online survey between 8<sup>th</sup> – 22<sup>nd</sup> June to find out the extent to which the guidance was being adopted and implemented across the different local authorities across Scotland and to hear about the experiences of unpaid carers. We also shared our initial findings with the SDS Collective<sup>1</sup>, who have helped shape some of the key recommendations for this report.

## Who responded to the survey

208 carers from across Scotland responded to the survey. We received responses from carers in 29 local authorities. We received no responses from carers in the following local authority areas:

- Clackmannanshire
- Orkney
- Shetland Islands

Almost 3/4 of the carers who responded to the survey told us that they (or the person they were caring for) received SDS Option 1. The table below provides a breakdown of which SDS option(s) carers were currently receiving (or helping to manage on behalf of the person they are caring for)

SDS Options	Percentage of carers who responded (n=208)
<b>Option 1</b>	<b>73%</b>
<b>Option 2</b>	<b>11%</b>
<b>Option 3</b>	<b>6%</b>
<b>Option 4</b>	<b>6%</b>
(Option 1+2)	(4%)
(Option 1+3)	(2%)
<b>Not sure</b>	<b>4%</b>

Figure 1: Which SDS Options were carers who responded to the currently receiving/managing.

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<sup>1</sup> The SDS Collective is a group of advocacy and campaigning organisations which have come together to promote improved practice in the development of Self-Directed Support in Scotland.

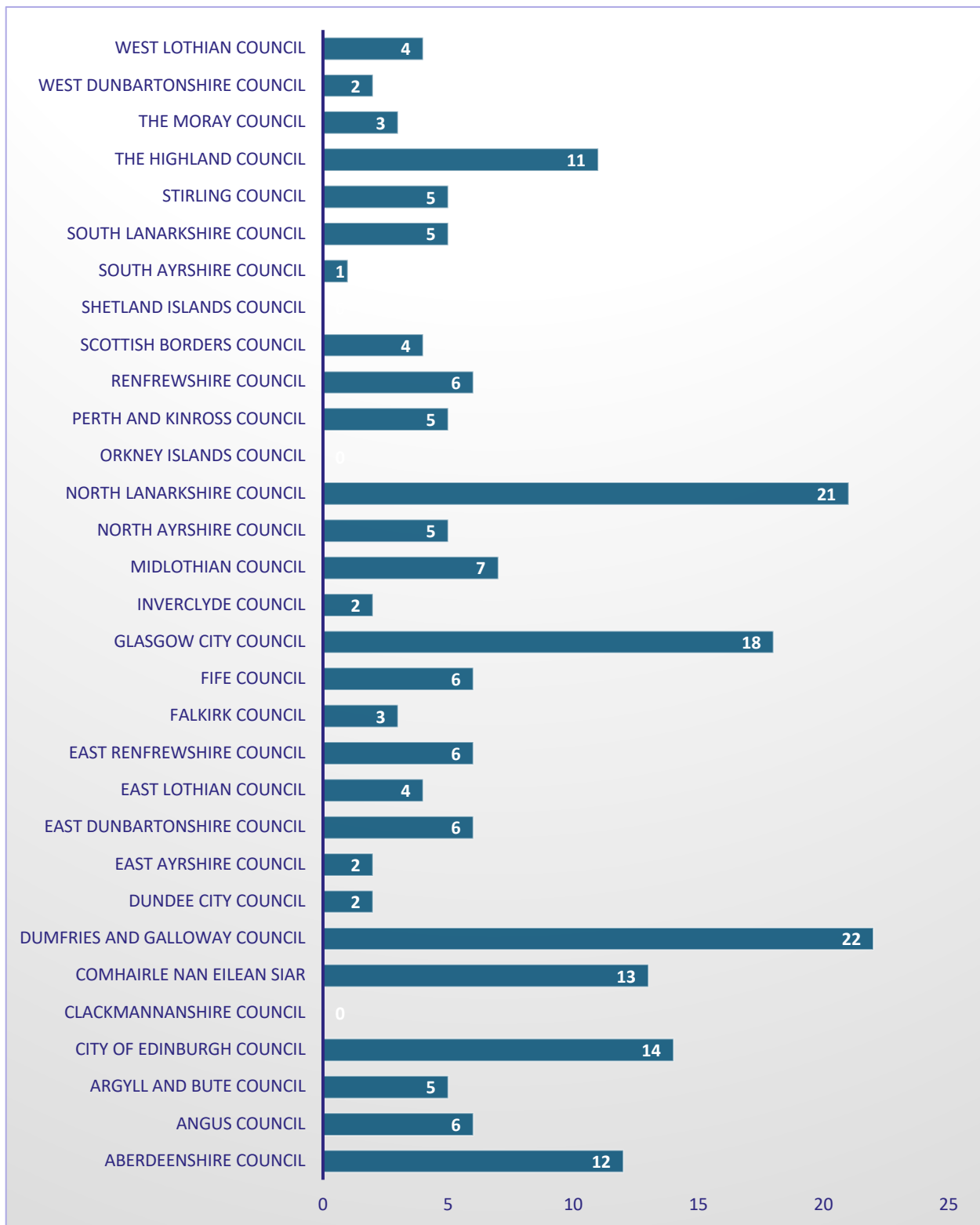


Figure 2: Number of carers from each local authority who responded to survey (n=208 \*5 carers did not specify which local authority they were from)

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## Were Carers aware that they could use SDS in a more flexible way in response to COVID-19?

The COVID-19 SDS guidance stated 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.'**

We asked carers whether they were aware that SDS could now be used in a more flexible way in response to COVID-19. Out of 205 carers who responded to this question, **60% had not been made aware that they could now potentially use SDS in a more flexible way.**

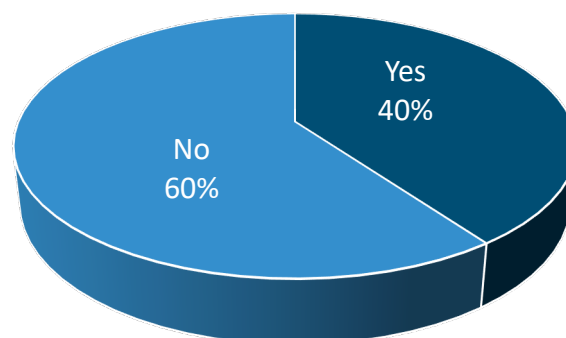


Figure 3: Number of carers who were aware that SDS could be used in a more flexible way (n=205)

Out of the 81 carers who were aware that they could use SDS in a more flexible way

- 28% told us that their local authority informed of this
- 25% of carers had received this information from a support organisation
- 47% told us they had received this information from another source.

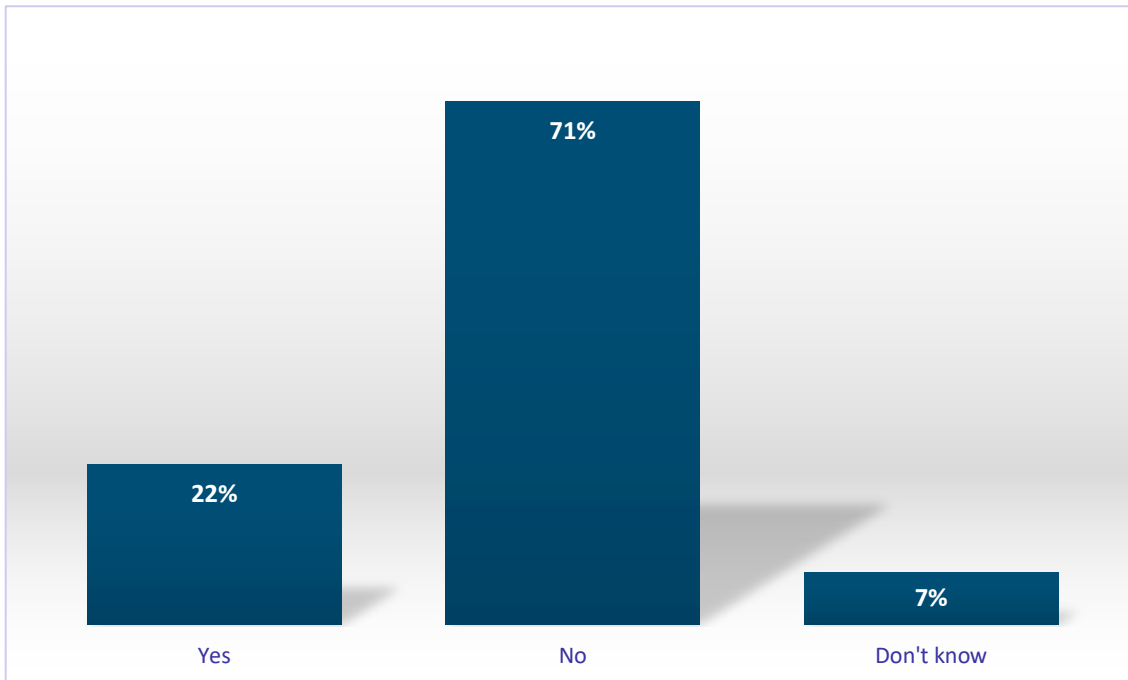
These other sources of information included:

- Social media / Facebook
- Other carers / friends
- Scottish Government website

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## Have carers been able to use SDS in a more flexible way?

We also wanted to find out how many carers had actually been able to use SDS (either for themselves or the person they care for) in a more flexible way since COVID-19.



*Figure 4: Responses to question on whether carers have been able to use SDS in a more flexible way (n=207)*

**Only 1 in 5 carers who responded to the survey have been able to use their SDS in a more flexible way during lockdown.**

We looked to see if there was any correlation between the SDS options that carers (or the people they care for) received and the likelihood of being able to use their budgets in a more flexible way.

We found that:

- 28% of those receiving SDS Option 1 had been able to use their budget in a more flexible way
- 4% of those receiving SDS Option 2 had been able to use their budget in a more flexible way
- 17% of those receiving SDS Option 3 had been able to use their budget in a more flexible way.

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- No one receiving SDS Option 4 had been able to use their budget in a more flexible way.

For carers who had been able to use SDS in a more flexible way during lockdown, we asked them to specify the types of support or equipment that they were able to purchase instead of their usual support. We were able to organise the responses into the following 4 categories:

- Purchased new technology
- Increased choice over PA/support worker hours and tasks
- Purchased Equipment
- Paid Family members to provide support

#### **Purchased new technology, or digital subscriptions (n=6)**

This included purchasing iPads or laptops so that they (or the people they care for) could keep in touch with friends and groups that were now all online:

*“An iPad so my son could keep in touch with clubs respite and friends”*

*“Bought a subscription for digital concert hall and refunded our account just this week after learning of different use.”*

#### **Increased choice over PA/ support worker hours and tasks (n=13)**

This included paying PAs to carry out different tasks from normal, or for doing different or additional hours which better suited the needs of the person requiring care:

*“Having the PA start earlier as my brother not attending his centre.”*

*“I can choose the times I get my support”*

*“Directly employing an out of hours staff team in addition to daytime agency support, including for respite/short breaks provision. Staff taxi service.”*

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*“Used PAs to provide support online and going to the shops for groceries and picking up medications.”*

*“Support over FaceTime rather than direct face-to-face contact.”*

*“Grandad is going through periods of sun downing and we have been able to reorganise carers hours etc.”*

### **Purchased equipment for play/garden/household (n=15)**

This included a wide variety of items ranging from exercise equipment, art materials, musical instruments, household appliances, and garden equipment:

*“Purchased some musical instruments and some sensory equipment for the house and purchased a new mattress that needed replaced.”*

*“Used for a summer hut to allow my autistic son to regulate when hyper sensory.”*

*“Sensory toys and experiences, making the garden more accessible, groceries/toiletries”*

*“Purchased a trike for my son as carers were unable to take him out.”*

*“Purchased a piece of play equipment for the garden for my child who the SDS is for.”*

*“Running gear and exercise machine.”*

*“I could use it to buy art and craft materials, printer/ink, items that could be educational.”*



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## Paid family members to provide support (n= 9)

This included paying relatives to provide additional support at home particularly where care providers were unable to provide any services or where the household were shielding:

*"I pay my daughter to help me with her disabled sister as we have cancelled Homecare for the duration on shielding."*

*"I used it to pay a family member who decided to live with us when lockdown started to provide support."*

*"I became a P.A. for my Son instead of using agencies."*

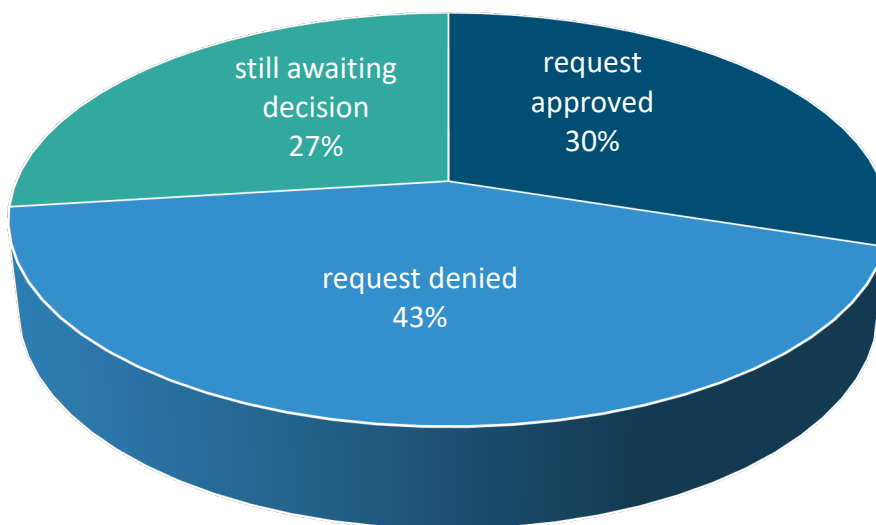
*"First time using it and my social worker has said I can pay a family member to look after my son."*

*"Brother employed to do extra caring for me to help."*

## Responding to carers' request to use SDS flexibly

We asked carers to tell us what happened when they requested more flexibility from their local authority with regards to their SDS packages. 70 of the carers in our survey shared some further information about their experiences of contacting their local authority to request using SDS in a more flexible way.

The responses varied across the different local authorities. Some local authorities appeared to have responded fairly positively to requests for SDS budgets to be used more flexibly, for example North Lanarkshire, and Edinburgh. Other local authorities were less enthusiastic, and requests to use SDS in a more flexible way were either refused outright, or in some instances carers were left waiting for a decision on their request.



*Figure 5: The response from local authorities when carers requested more flexibility with SDS during COVID-19 (n=70)*

### Carers who had their requested accepted

Around 30% of those who had asked to use SDS in a more flexible way, had their request accepted by the local authority. However, it is worth noting that:

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- A number of carers had to initiate the request; no one from their local authority had been in touch to let them know that they could use their SDS budget in a different way during COVID-19.

*"I had asked in March if I could use it for something else but they weren't sure initially and it took a whole month before they decided I could buy the requested item."*

*"It was fine but we had to ask. It was not offered and we didn't know about the guidance."*

- Their request to use SDS in a more flexible way was only approved under certain conditions or requirements.

*"I was told that if I wanted the current provision that my son receives to continue I would need to accept option 1 and manage the direct payment. This had been previously managed between our care provider and the local authority. I was put in a position where I had to accept this situation otherwise my son would have not been able to receive the support."*

*"They authorised an iPad but said that was all we could buy, nothing else"*

#### Carers who had their requested declined

43% of the carers who had asked to use their SDS in a more flexible way, had their request declined by their local authority. Some of the reasons given to carers for not being able to use SDS in a more flexible way included:

- The SDS budget had to be used to continue paying existing care providers or services.

*"Have to pay the provider even if the service was not provided."*

*"The money is tied into his respite and they won't release it."*

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*"I couldn't use it for anything else. I was to use it to pay for my son's usual services which are still open. I kept him safe at home since the announcement of lockdown. His disability prevents him from understanding social distancing, covering coughs and sneezes, touching things etc."*

*"Was told no because community OT offer this service (even though I've pointed out several times that community OT can't do anything during lockdown)"*

- **Told that SDS budget could not be used to purchase items and that they should contact a charity instead.**

*"Asked local area coordinator to request an iPad to allow my son to stay in touch with his services online. I was told this wouldn't be agreed. I asked for him to check anyway and pointed out SDS was meant to be flexible. I was grudgingly told ok but he didn't make the rules. In the end he put me in touch with Leonard Cheshire who provided an iPad, case and Amazon echo. They have been amazing but I do feel they were suggested so the LA didn't have to be approached."*

*"They said flexible spending was not available and suggested that I contact charities about grant funding."*

- **SDS budgets could not be used in a flexible way unless the supported person or unpaid carer were in financial hardship.**

*"They told me unless I could prove financial hardship due to covid then I still couldn't use it for anything else."*

*"That it's not allowed. When asked again - and pointed out the guidance I was told only if I could provide evidence of being financially affected by covid would they possibly consider anything. The evidence was not enough."*

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- In some instances, no explanation was provided by the local authority for rejecting the request to use SDS in a more flexible way.

*"I was called by a social worker in April and I asked if I could use my sons SDS budget to help during lockdown. She said she'd enquire and get back to me. She got back and told me No, not at the moment. I asked for this to be put in writing but never got it."*

*"They called me and said in no way can it be used differently. Then sympathised and said 'you will have the money eventually took back from you as it's not been spent'"*

#### **Carers who are still awaiting a decision on their request**

27% of carers who requested to use SDS in a more flexible way are still awaiting to hear back from the local authority.

*"They have ignored us, passed us to 4 different staff members, actively refused most of the items my son asked for and put barriers in place and made it so difficult for my son to use his SDS budget. They have refused to answer why."*

*"I asked if I could purchase a piece of IT to support my child during lockdown. Still waiting on a response - two e-mails unanswered."*

*"I'm still waiting to hear back, I've been waiting since end of March."*

## Employing family members to provide support

The COVID-19 pandemic put many families who were receiving social care support at serious risk of reaching a crisis. Due to social distancing, furloughing of support staff, or members of the household shielding, many supported people and unpaid carers were left without any additional support. Local Authorities were asked to consider allowing people to use their SDS budgets to employ family members during this period. With regards to employing family members, the COVID-19 SDS guidance states that:

**‘PA employers may employ family members where this is deemed appropriate, under exceptional circumstances. During this period, there may be increased reliance on family members, particularly when PA employers or PA’s themselves are shielding or self-isolating. Family members may be the only people available who can provide support on a temporary basis, and be a necessary adjunct to the social care workforce at this time.’**

In our survey, only 35 carers had asked their local authority if they could use their SDS to employ a family member. Out of those 35 carers, 14% had already asked their local authority prior to COVID-19 and were already employing family members to help out with the caring role. A further 6% are still awaiting a decision from their local authority as to whether they can employ a relative to provide social care support.

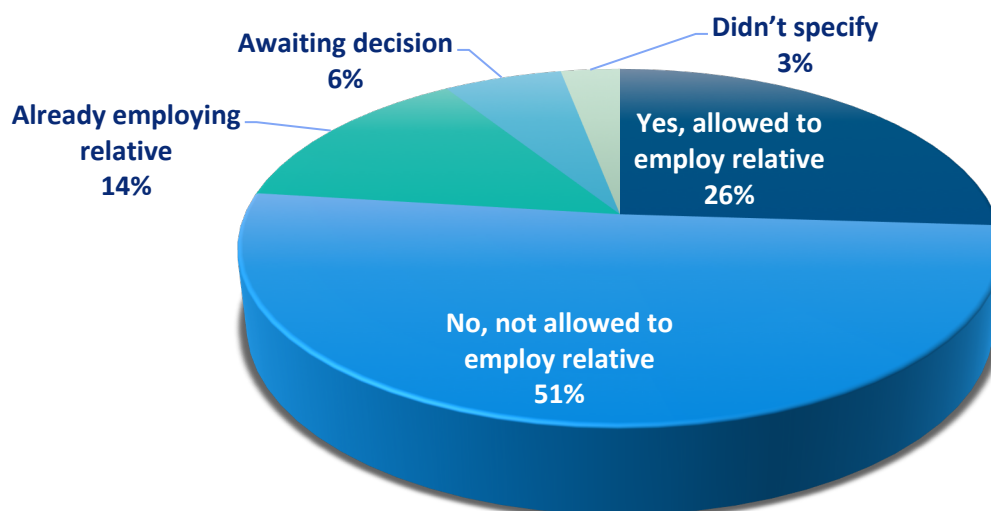


Figure 6: response from local authority when carers requested to use SDS to employ relatives (n=35)

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Around **half (51%)** of all carers who had asked their local authority if they could use SDS to employ family members during lockdown, were told ‘No’. Some of the reasons given by local authorities for refusing the request included:

*“No, not allowed. Was told they should be doing it free in this time of need!”*

*“They said that was inappropriate use of direct payment.”*

Only around 1 in 4 carers who asked to use SDS to employ family members had their request accepted. In some instances, the request was only granted after the carer challenged the original decision:

*“Initially I was told by SDS adviser this should not be happening and it was only when I highlighted the guidance Social Work approved request.”*

For some carers, the request to employ family relatives was only granted with fewer hours, and there appeared to be very little support for carers who had taken on the role of an ‘employer’:

*“Yes, but only for few hrs otherwise had to register with HMRC and the hassle that goes with it”*

*“Only allowed to do this for 3 months at reduced hours which I believe is unfair as my family member is doing far more for me than my previous paid support.”*

*“They said yes but I have to keep evidence as I’ve never done it before I don’t know about payroll or anything like that I’m a bit confused to be honest”*

## Implementation of SDS guidance by local authorities

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

In 7 of the local authority areas, we received more than 10 responses to our survey from carers. We have therefore put together a summary of the responses from those 7 local authority areas.

<b>Local authority</b>	<b>Aware of the SDS guidance?</b>	<b>Been able to use SDS in a more flexible way?</b>
Aberdeenshire (n=12)	<b>42%</b>	<b>8%</b>
Comhairle nan Eilean Siar (n=13)	<b>8%</b>	<b>0%</b>
Dumfries and Galloway (n=22)	<b>36%</b>	<b>5%</b>
Edinburgh (n=14)	<b>86%</b>	<b>57%</b>
Glasgow (n=18)	<b>56%</b>	<b>11%</b>
Highland (n=11)	<b>0%</b>	<b>0%</b>
North Lanarkshire (n=21)	<b>38%</b>	<b>38%</b>

*Figure 7: breakdown of carer responses in 7 local authority areas*



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## Key issues

The survey, although limited in terms of responses received, did highlight a number of key issues

1. Unpaid carers were generally unaware of the additional SDS guidance which was issued on 14<sup>th</sup> May, and therefore unaware that they could make a request to use SDS for alternative or more flexible support if their existing support was no longer available. It would appear that a number of local authorities have failed to *'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'*.
2. Many carers were told that they had to continue paying their current care providers and therefore were not able to use their SDS to purchase any alternative support or equipment to use at home. The guidance states that: *'Commitment has been made to provide funding for additional costs incurred as a consequence of the COVID-19 pandemic via local mobilisation plans/ the COSLA Financial Template. This applies across all SDS Options, including where flexibility in the use of Option 1 and Option 2 budgets relating to COVID-19 incurs additional costs.'* - People with support needs and unpaid carers should have been made aware that they could request additional funds to cover any extra costs incurred as a result of having to purchase alternative support during the lockdown period.
3. Some of the examples of 'more flexible use of SDS' which were highlighted by carers in this survey clearly fall within the general guidance for SDS and should not be viewed as exceptional use, or something which is only applicable in a crisis situation. We strongly support and commend those local authority areas that have taken a pro-active approach both to communicating and encouraging flexibility, in line both with the guidance and with the existing self-directed support legislation. For example, the survey illustrated good practice reported in Edinburgh and North Lanarkshire to enable people to react flexibly, including by employing family members as Personal Assistants in a temporary capacity.

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4. The time taken for decisions to be made about whether someone can use their SDS in a more flexible way was a huge source of stress for many carers and the people that they are caring for. The guidance states that *'Local authorities should consider increasing social worker autonomy in funding decisions for new or existing Option 1 and 2 arrangements. Proportionate oversight is advised at this time to streamline processes, reduce bureaucracy and speed up the time taken to get budgets, supports or care in place.'* – it is apparent that this has not been happening in practice in a number of local authority areas.
  
  5. Some carers have had to temporarily take on the role of 'employer' and accept SDS Option 1 in order to carry on receiving support from a new provider or family member. There appears to have been very little support or guidance offered by the local authorities on managing an SDS Option 1 and this has left carers feeling overwhelmed by the perceived administration and responsibility of managing their own budgets.

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## Recommendations

As the guidance states, the underlying principle is **‘to maximise flexibility and autonomy for the supported person in meeting agreed outcomes’** This should be at the forefront of all conversation and interactions in relation to self-directed support, and with that in mind, we would like to propose the following recommendations.

1. The SDS guidance issued on 14<sup>th</sup> May 2020 stated that due to the exceptional circumstances, local authorities should consider more flexible and creative solutions to meet the support needs of those receiving SDS. Many of the examples that carers gave in this survey should not be considered exceptional, and some of the innovative solutions carers have come up with to meet their support needs have been better at achieving their outcomes. We would therefore like to see the **flexibility and personalisation of support offered during lockdown to remain in place post COVID-19**.
2. There have been some welcome examples of Local Authorities who have reduced bureaucracy around decision making at this time, reflecting the recommendation in the guidance that *‘Local authorities should consider increasing social worker autonomy in funding decisions for new or existing Option 1 and 2 arrangements.’* We would like to see the **principle of reduced bureaucracy to remain in place post Covid-19** as it would enable people to better tailor and adapt their support to meet their needs, particularly in times of crisis and transition.
3. There were examples of people being able to move from one SDS Option to another. For example, moving from Option 1 to Option 2 or 3 where they no longer wish to manage their support, or moving to Option 1 if they wish to employ a PA or a relative. We would like to see **the flexibility to move from one SDS option to another made easier**, and for those considering SDS option 1 for the first time to be signposted to support organisations who can assist with this.
4. The pandemic has compounded the need for prompt and clear timescales for responses to people's questions about their support. Despite the obvious

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challenges, we would highlight and **encourage increased accountability and transparency about what timescales people should expect** when raising questions about changes to support and care arrangements

5. The survey also highlighted the lack of transparency and consistency from Local Authorities around decisions to employ relatives or purchase equipment. We would like to see **greater transparency in the decision making processes to employ relatives and purchase equipment**, and to have clear and accessible policies in place to explain these decisions.
6. **Complaints procedures in Local Authorities should be kept open and accessible** so that carers and people needing support have a direct means of holding Social Work services to account if they do not feel they have been able to get the right support and/or information.
7. 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 also has been evident during the pandemic. We acknowledge the crucial importance of the role of independent third sector organisations in providing people with information, advice and support, and **encourage all areas to work closely and in partnership with the third sector organisations** providing this.
8. Information about self-directed support, including **information about responses and additional guidance during the pandemic, should be made available in a variety of accessible formats, both online and in print format**. All local authorities and partners should share this information as widely as possible through their networks, connections and in person. Doing so would improve the quality of life for disabled people, people living with long term conditions, and unpaid carers alike.
9. **All staff who are involved in assessing the support needs of unpaid carers (or the people they provide care to) should be made aware of the SDS guidance** which was issued on 14<sup>th</sup> May 2020, and provided with any additional operational guidance regarding SDS in their local authority area.

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## Further Information

The Self Directed Support guidance which was issued to Local Authorities and Health and Social Care Partnerships on 14<sup>th</sup> May 2020 can be viewed and downloaded from here:

<https://www.gov.scot/publications/coronavirus-covid-19-guidance-on-self-directed-support/>

A FAQ was also produced to help explain the guidance in Plain English. This can be viewed and downloaded here:

<https://socialworkscotland.org/briefings/faqs-for-sds-option-1-and-2/>

Independent Support organisations are able to help with advice and support around using Self Directed Support, and enables people to find support with 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.