



**Lanarkshire**  
Carers

# The Use of Self-Directed Support by Unpaid Carers in South Lanarkshire During COVID-19

November 2020

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## Context

The Social Care (Self-directed Support) (Scotland) Act 2013 came into effect in 2014 and is designed to ensure that local councils listen to people and provide the right support to them. There are five main principles; involvement, information and choice, collaboration, dignity and a right to take part in the life of your community.

Individuals can choose to access Self-directed Support in one of the following ways:

- ▶ Option 1: you take a direct payment
- ▶ Option 2: you decide and the local council arranges support
- ▶ Option 3: after talking to you, the local council decides and arranges support
- ▶ Option 4: you use a mixture of ways to arrange your care and support

During the Coronavirus (COVID-19) pandemic, guidance on self-directed support was produced on 14 May 2020 and an amended version was published on 31 July 2020 by COSLA and the Scottish Government, for local authorities and Health and Social Care Partnership staff.

This guidance was designed for those who provide self-directed support in adult and children's services whether they are managed by a local authority or an integration authority. It is also for organisations who help people get the most from social care and providers delivering option 2. It is not intended to replace statutory guidance and is only relevant for the duration of COVID-19 pandemic.

The guidance sets out the joint position of COSLA and the Scottish Government relating to Options 1 and 2 during COVID-19 with an aim to support local provision of Self-directed support to ensure the safety, dignity and human rights of people. Guidance for provision of Option 3 was produced by COSLA and the Scottish Government on 17 April 2020 entitled "Guidance for Commissioned Services during COVID-19 Response".

South Lanarkshire Health and Social Care Partnership shared the information from COSLA and the Scottish Government on 14 May 2020 with all social workers and relevant staff, highlighting it as a top priority in their information bulletin and stating "it is critical that social care support is maintained with minimal interruption during this period with SDS budgets continuing." A reminder of this information was also issued a few months later. Letters and frequently asked questions sheets in relation to guidance for self-directed support options 1 and 2 since May 2020 have also been issued to carers, guardians, parents and supported persons.

### **Rational**

The Coalition of Carers in Scotland (COCIS) conducted a survey of unpaid carers in Scotland in June 2020 to find out if carers were aware of this new guidance and whether they had been able to use their Self-directed Support in a more flexible way during lockdown. They published their findings in July 2020 however there had been a low representation of carers from South Lanarkshire (5 responses). Due to the data available and its presentation, it was not possible to separate out the 5 South Lanarkshire responses from this report. In order to better understand the views of carers, the Senior Management Team in South Lanarkshire Health and Social Care Partnership requested, on 25 August 2020, that Lanarkshire Carers undertake a local review.

Lanarkshire Carers survey questions were designed to allow the same data set as the Coalition of Carers in Scotland July 2020 report to be established as well as using the

opportunity to gather the views of carers using the Self-directed Support options. This enables the use of some data as a benchmark for comparison. A targeted engagement and consultation exercise was then progressed to determine the South Lanarkshire response, any key issues arising from carers accessing Self-directed Support either for themselves or for their cared for. Any key themes identified will be highlighted and some suggested recommendations made for consideration by senior planning officers as a direct response and onward progression to the SMT for further discussion.

## Methodology

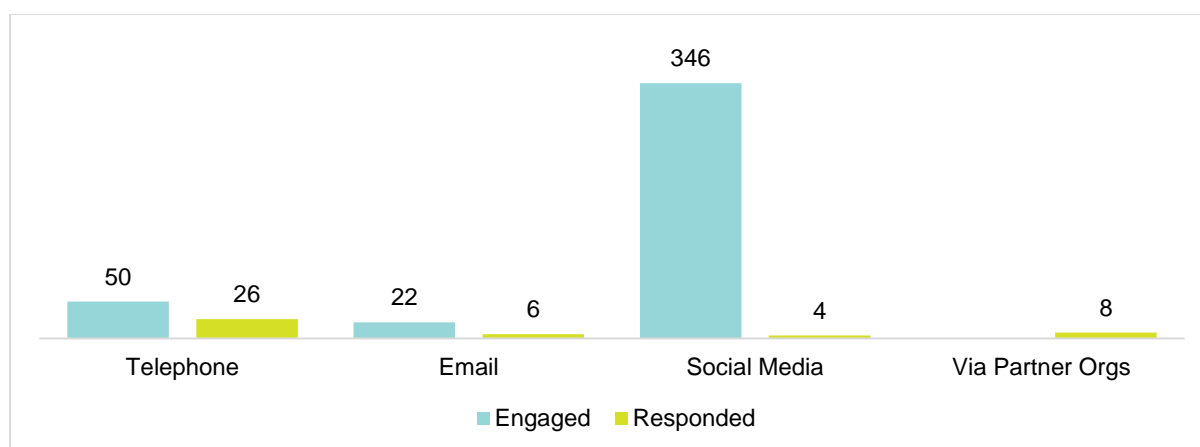
Lanarkshire Carers conducted a survey of carers, which ran from 11 September 2020 to 9 October 2020 and was reopened following information shared with partner organisations and request from carers from the 27 to 30 October 2020. Any carer residing in South Lanarkshire who was in receipt of self-directed support either for themselves or the person they cared for, which-ever option they received, was eligible for this survey.

Carers known to Lanarkshire Carers who we could identify as being in receipt of self-directed support were invited to take part in this survey. We also used our social media channels to engage with a wider audience to inform of the opportunity to provide feedback.

Partner organisations that may come into contact with carers receiving self-directed support were contacted and were keen to support this survey, discussing directly with individuals and passing it on through their networks and social media channels. Partners who were contacted included Take Ctrl South Lanarkshire, Alzheimer Scotland, Action for Children South Lanarkshire, Haven Forth & Blantyre, Reach Autism, ARCH, Lanarkshire Links, Self-directed Support Network South Lanarkshire and Clydesdale Community Initiative.

Carer Support Workers from Lanarkshire Carers also provided additional feedback on the experiences that they came across whilst supporting carers and provided some feedback from carers who had not wished to complete the survey. Staff from other organisations were also invited to provide feedback on their experience supporting carers and this has been included.

### Carer Engagement



418 carers were made aware of the survey through Lanarkshire Carers communication channels. 44 carers in receipt of self-directed support responded to the survey, 8 of which responded via communications initiated by partner organisations.

## Survey Results

The majority of carers responding to this survey were in receipt of 'option 1: direct payment' (25 carers). This option commonly involves the carer employing a Personal Assistant or purchasing services from a provider of their choice. During the COVID-19 pandemic the provision of these services were adversely affected.

The low response of those receiving 'option 2: you decide and the local council arranges support' is noted (1 carer), with additional feedback from Take Ctrl South Lanarkshire suggesting they were only aware of 2 individuals who were in receipt of option 2.

We can see from the benchmark figures in the table below that the higher results of 'option 3: after talking to you, the local council decides and arranges support' (14 carers) may not be reflective of the situation in other council areas.

| SDS Option        | No. of carers | % of carers | Benchmark % |
|-------------------|---------------|-------------|-------------|
| Option 1          | 25            | 57%         | 73%         |
| Option 2          | 1             | 2%          | 11%         |
| Option 3          | 14            | 32%         | 6%          |
| Option 4          | 3             | 7%          | 6%          |
| No response given | 1             | 2%          | 4%          |

A number of carers, particularly those receiving option 3, did not understand that they were in receipt of a self-directed support budget. Of the 26 carers taking part by telephone, 16 did not realise that is what they had until it was discussed with them and explained.

15 carers asked us to contact them for support relating to their answers following completion of the survey.

### General feedback from carers about Self-directed Support

*"Mixed understanding of SDS flexibility by social workers, Most social workers are not aware that the SDS budgets can be flexible in line with carer needs. In my experience, I have found social work don't fully understand the SDS process and expenditure."*

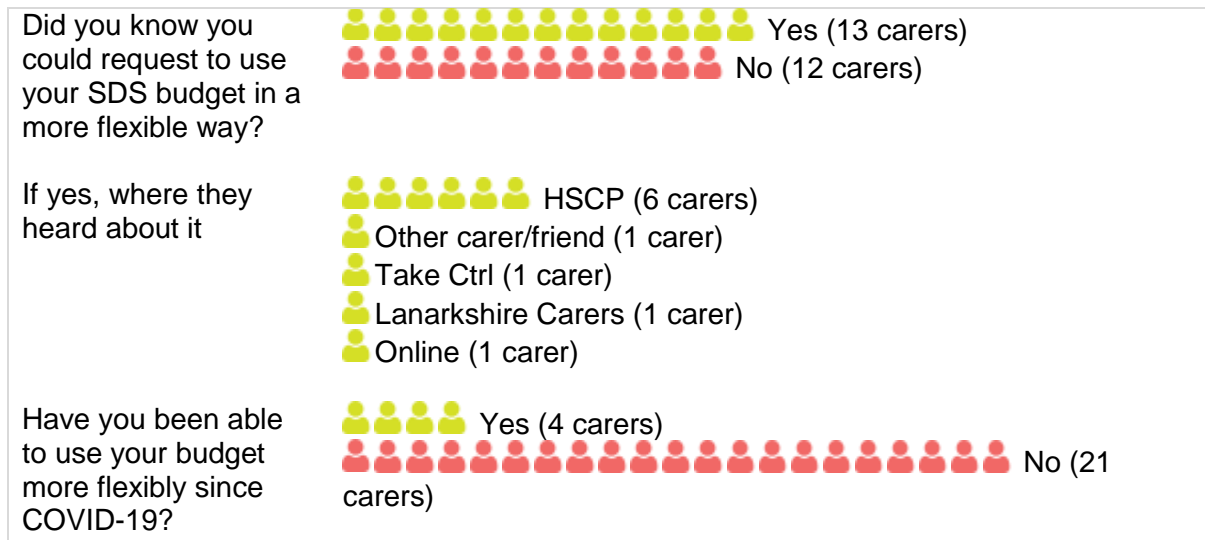
*"Carers usually need a lot of support and information regarding SDS. It is an excellent resource that can alleviate the barriers carers from minority ethnic backgrounds face but unfortunately the information about this is very low in these communities. Social workers need to be more proactive in providing this information to these communities."*

*"Should I be getting this budget of SDS as we have not seen any of it since COVID-19 started. I am unsure if my daughter should have it or not, obviously no placement yet as we are unable to go."*

*"Carer worked in Social Work and knew about the flexibility of SDS but found that most of Social Work were not up to speed."*

### Option 1: Direct Payment

13 carers were aware they could use their budget in a more flexible way: 6 were made aware through the Health and Social Care Partnership, 2 through support organisations they engage with, 1 through a carer/friend and 1 found out online. 4 of these carers had requested to use their budgets more flexibly. 12 carers receiving option 1 did not know they could request to use their budget more flexibly and had not requested to do so.



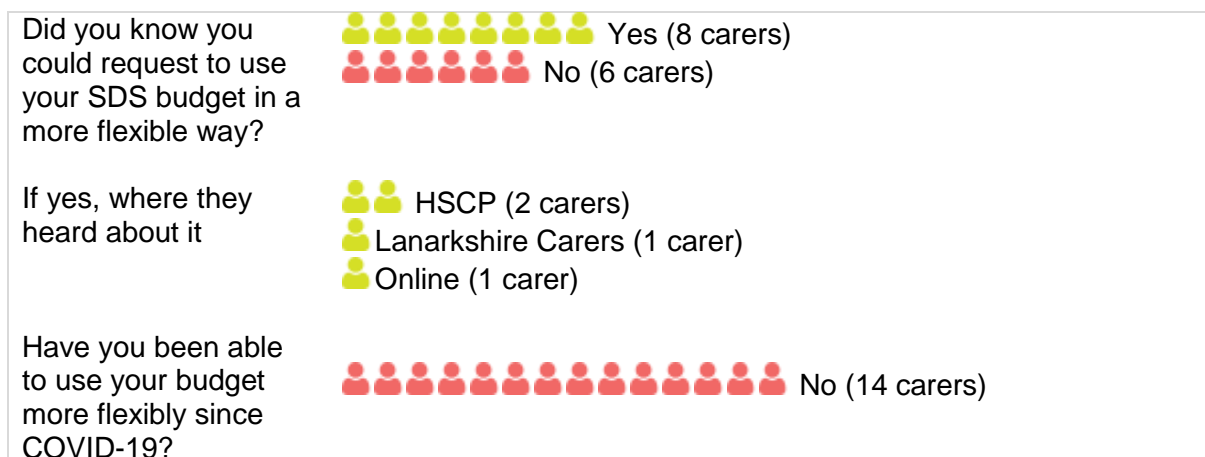
### Option 2: you decide and the local council arranges support

One person answered indicating they were in receipt of Option 2. They had heard about the flexible use of their budget through Take Ctrl South Lanarkshire, however they felt their support package was adequate and remained unchanged.

### Option 3: after talking to you, the local council decides and arranges support

8 carers were aware they could use their budget in a more flexible way: 2 were made aware through the Health and Social Care Partnership, 1 through support organisations they engage with and 1 found out online.

6 carers receiving option 3 did not know they could request to use their budget more flexibly and had not requested to do so.



#### Option 4: you use a mixture of ways to arrange your care and support

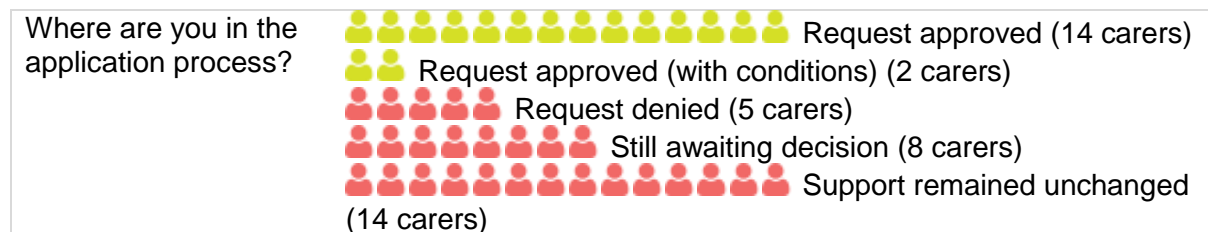
3 responses from carers in receipt of option 4. One of these carers knew they could use their budget more flexibly and received this information from South Lanarkshire Health and Social Care Partnership, but despite having their request approved they did not feel they had been able to do so.

1 carer did not know about the flexible use but is still awaiting a decision for their application and is very unsure of their entitlement.

The other carer said they did not know about the flexible use. They had their SDS request approved but with conditions, but no additional information was given.

#### Self-directed Support Assessment Process

We also asked carers to tell us where they were in the application process for self-directed support and provide feedback how they found this process.



#### Feedback from carers

“very difficult process. took 3 years. very stressful - social worker very awful. Not happy at all about how long this took to get awarded.”

“I found easy to get. I do have a good social worker.”

“A year to do the assessment, in the substantial / critical bracket. Didn’t get the appropriate say, my views weren’t taken into account. Nor were my daughters. Sent back to locality still not got the support despite declining health & wellbeing of both Child and Carer. Lost all faith! Not dignified, not respectful and not in the interest of the service user.”

#### Examples of purchases / Requests for purchases

| Purchases made   | Purchases denied   |
|--|--|
| <ul style="list-style-type: none"> <li>• A new printer to print off things like crosswords and puzzles.</li> <li>• Garden furniture to entertain my son during lockdown.</li> <li>• Poultry house, run, feed and four hens</li> <li>• Mobility aids</li> <li>• PPE and that made a great difference to me</li> <li>• I bought some aids</li> </ul> | <ul style="list-style-type: none"> <li>• Garden slabs</li> <li>• Tricycle</li> <li>• Bike (told it had to be second hand)</li> <li>• Landscaping for garden</li> </ul> |



## Key Insights and Themes

We gathered additional feedback from carers, carer representatives and partner organisations who were able to inform of their experiences. Some common themes that came from this feedback are highlighted below:

### ***Carers find advice and information about self-directed support confusing and during COVID-19 this advice was not felt to be sufficient***

- Examples of flexible use would have been helpful to give some consistency and avoid postcode lottery style outcomes
- There was not enough information around employment of family members
- Carers need more information and support with self-directed support options
- Many carers don't understand or know their choices
- Carers are frightened to get it wrong

### **Feedback from carers and carer representatives**

“Carers don't know they can use it any other way than the care package they already have in place”

“Carers are confused about Self-directed Support budgets and are scared to spend their budget with the fear they may spend it incorrectly and have to pay it back”

“There is a fear that if individual budgets aren't spent then they will not receive the same, which will be needed in the following year”

“More information, preferably in carer's first language, if English is not first language. Information broken down into smaller chunks, more open discussions and more personalised support”

“No information about flexibility or options was given - carer had one call at start of lock down from social work to ask whether son was accessing any services, but nothing was open and nothing was recommended because of this.”

“I have just got a letter from council dated 26 September 2020 stating that I can use budget more flexibility - 6 months late”

“Got my budget eventually after almost a year. Now I have no idea what to do with it as no one is allowed in my house”

### ***Unpaid carers have been filling the gaps in support***

- Slow access to mobilisation monies and carers not having access to contingencies to pay for replacement care
- When care provider withdraws care, carer reported having to go through whole assessment process again to change to direct debit payment which is very stressful
- Decisions on flexible use or new assessments too slow

### **Feedback from carers and carer representatives**

“There are no options during Covid-19. It’s had to be care at home - looking after son 24/7 myself. His day activities have all stopped apart from a couple of hours a week from the xx Centre.”

“How can the Council get away with not having defined time lines for SDS requests?”

“no placement yet as we are unable to go”

“Wish there could be more done to vary my son’s day. Other than 2 hours a week from xx and one full day at xx my son is in his room the whole time.”

“Support non-existent until October when I felt it was safe for my son to resume his day activities albeit reduced service. I hadn’t been made aware that possible to use in more flexible way - the support just stopped. No alternative was offered. My son’s allocated social worker did not contact us at all. No contact whatsoever from social work. They didn’t have to drop off the face of earth. I understand that everything had to stop but just a phone call or email would have made us feel less alone. Thankfully CCI gave us support throughout by telephone which did help.”

“Lock down has been very frustrating and stressful for the family. Clubs cancelled, has gone from 5 days out and about and feeling like he has a social life to being almost entirely housebound due to health conditions within close family. Was able to return to xx two days a week, but with resurgence in cases this has been withdrawn optionally by the family to maintain bubble at home.”

“unpaid carers filling in the gaps in support when cared for is unable to attend day care centres”

### ***Social worker’s knowledge and understanding of Self-directed Support is varied and inconsistent***

- Unclear to some social workers who does the assessments even though it is their role
- Use of language; self-directed support is referred to as ‘budgets’
- Be more proactive in providing the information / options to carers
- More knowledgeable themselves as this is very varied between different staff
- Knowledge of flexible use of self-directed support is not good enough

### **Feedback from carers and carer representatives**

“laughable nearly 7 months we have been confined to the house and Council now send letter saying that you can use the budget flexibly. When the social worker does to get back to you they don’t have a clue how to use. I was told use it what ever way I want, just don’t use it and bring the council into disrepute”

“Phoned social work at start of lockdown and no flexibility was mentioned”

“I am a carer and work in social work so know about flexibility of SDS and I have found that most social workers are not up to speed”

“what chance have we got if the social worker can’t explain it properly”

“I’ve had 3 social workers in the last year all voicing the views and opinions on the budget, it’s like the social worker lottery”

“If this is the way forward SDS training should be made mandatory not picking up bits and pieces as they go. Never giving a straight answer always doubting themselves doesn’t give carers much faith in the system”

“In my experience, I have found social work don’t fully understand the SDS process and expenditure”

“Mixed understanding of SDS flexibility by social workers, most social workers are not aware that the SDS budgets can be flexible in line with carer needs.

## **Key Issues**

There appears to be inconsistencies in advice from social workers and a feeling of a lack of knowledge among some social work staff of the self-directed support process. This results in confusion for carers and a feeling described by one as a “postcode lottery” in relation to allocation of social workers rather than postcode.

There is a mix of terminology applied that leaves carers confused with what they are in receipt of. Many do not understand that they are in receipt of self-directed support rather than they have a carers or cared-for budget. Some see self-directed support as only if they are in receipt of a direct payment.

The lack of uptake of Option 2 (the carer decides and the local council arranges support) is of concern. The Social Care (Self-directed Support) (Scotland) Act 2013 tells us that the law is there to ensure “local councils listen to what people want so that people are able to get the support that is right for them.” The prevalence of option 3 (when after talking to you, the local council decides and arranges support) may indicate that the approach being taken is more local authority led than carer/care for led, with the decisions being made more by staff than by carers.

Some carers feel that the letter issued on 22 September 2020 advising of “creative” rather than flexible use of self-directed support options is the first they have been told about it and that the information comes “6 months too late”.

Due to a lack of information or ability to use self-directed support options more flexibly, many carers express a concern of not being able to use their funding allocation. Others have tried to change to options that would cost the council less money, achieve more for the carer or cared for and are still unable to do so.

The length of time for assessments has been raised as a concern, it appears to be quite varied with some processed within a good or reasonable time frame and others being delayed. Stories such as paperwork being held up 3 weeks until the staff were next rotated into the office have been heard.

## Conclusions and Recommendations

The amount of carers and partner organisations that participated in this local follow up to the national survey highlights that this approach achieved more insightful information specific to South Lanarkshire. Comparisons can be drawn with some of the information presented in the national survey, but due to the difference in numbers responding, the SDS options in place and method of engagement it is more appropriate to look at this report in its own merit. Lanarkshire Carers can facilitate a discussion looking at the process and findings of this work to enable the SMT to identify future actions.

### **A reminder of the original recommendations from the COCIS report (July 2020):**

1. *Flexibility and personalisation of support offered during lockdown to remain in place post COVID-19.*
2. *Reduced bureaucracy around decision making reflecting social worker autonomy*
3. *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. *Increased accountability and transparency about what timescales people should expect when raising questions about changes to support and care arrangements*
5. *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*
7. *Good Information and access to advice and support are vital at all times*
8. *Information about self-directed support available in a variety of accessible formats, both online and in print format.*
9. *All staff who are involved in assessing support needs of unpaid carers made aware of the SDS guidance which was issued on 14 May 2020.*

The research in South Lanarkshire confirms that the above report recommendations are relevant and appropriate along with consideration of the additional information and carer responses we have gathered. In particular, how good information, advice and support is delivered needs to be considered. Some communications were understandably challenging, particularly during the early stages and as services were changing very fast. The HSCP should utilise an improved partnership approach to Self-directed support communications, working with different third sector organisations and various communication mechanisms to impart the numerous updates needed. This may have helped to ensure that the pertinent pieces of information reached the places they were most needed. An example of this could be that whilst some of the letters issued by the local authority referred to Take Ctrl South Lanarkshire for support with Personal Assistants, none of the information made any reference to the carer information, advice and support available. Many mentions of unpaid care being required to cover 'gaps' in Personal Assistants or day care services have been made by individuals who were or have had to become carers. An improved partnership approach and consideration of wider support network of the cared for person and their carers may have proved beneficial.

Whilst most survey respondents did not report positive experiences, there are a few examples of Self-directed Support packages having a positive impact. The practice, understanding and autonomy of individual social workers seems to be key to identifying how to get this right in future. Reported experiences seem dependent on the individual relationship with individual social workers and moving to a more collaborative/multi-disciplinary response to Self-directed support may improve the outcomes achieved. A 'trusted professional' relationship with open and ongoing communication is key to getting this right in the future.