



**“We have been completely
abandoned”:**

**Experiences of social care support
during the 2020 lockdown**



**Inclusion
Scotland**

Disabled People's Organisation

Our voices ■ Our choices

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Introduction

Between 3 and 24 July 2020 Inclusion Scotland surveyed disabled people and unpaid carers/ supporters to ask about their experiences of social care support during the COVID-19 pandemic. This report presents our key findings and builds on our two previous surveys carried out during the pandemic; a baseline survey¹ about the impact of COVID-19 asking a range of questions, and our short survey about the experiences of people who were shielding². It is no exaggeration to say the results of these three surveys have been shocking and stark. However, the social care support system was in crisis long before the pandemic struck. The pandemic has created new inequality “fault lines” and profoundly impacted on the human rights of people who use adult social care support.

No one can deny that we need change, and we need it now. Inclusion Scotland, along with other disabled people’s organisations and disabled people, have been campaigning for many years for transformative change; for an end to charging, for greater consistency, for accountability and for a National Care Service. Finally, with the recommendations of the Independent Review of Adult Social Care³, we have been listened to. Disabled people now demand the Scottish Government, all political parties in Scotland and COSLA, demonstrate

¹ Inclusion Scotland (2020) Rights At Risk -COVID 19, Disabled People and emergency planning in Scotland, a Baseline Report <https://inclusionScotland.org/rights-at-risk-covid-19-disabled-people-and-emergency-planning-in-scotland-a-baseline-report-from-inclusion-scotland/1>

² Inclusion Scotland (2020) Shielding Report <https://inclusionScotland.org/shielding-report/>

³ Scottish Government (2021) Independent Review of Adult Social Care <https://www.gov.scot/groups/independent-review-of-adult-social-care/>

the political will to make those recommendations a reality and to build a National Care Service worthy of the name. As Derek Feeley says, “if not us, who and if not now, when?” (Scottish Government, 2021, p 2). Disabled people in Scotland cannot be let down again.

Summary

Our findings showed that many people had their social care support packages cut, sometimes overnight as demonstrated in the quotes from survey respondents below. People were simply abandoned, without support to get out of bed or get essential food and medication. This violated many basic human rights, such as Articles 19 “living independently and being included in the community” and 28 “adequate standard of living and social protection” of the UN (United Nations) CRPD (Convention on the Rights of Disabled People).

People told us that across Scotland many had not had their care packages reinstated and some were still paying charges for care they were not receiving.

We asked if people had been involved in the decisions made about changing or stopping their Social Care Support because of COVID-19. Of those who said they had experienced a loss or reduction in their support/care during the crisis 51 responded (72%) that they were not involved in discussing the changes. This shows that there was limited (if any) involvement in decisions that could have significant negative impact on the lives of both disabled people and unpaid carers/supporters. Serious concerns were also raised around how people were informed of the changes to their Social Care Support. People described being informed by voicemail, text, or letter with no follow up to check these had been received

or to discuss the potential impact of this decision, and without regard to accessible communications/ information for individuals that may have required them.

The COVID-19 pandemic has highlighted concerns around how decisions are made about Social Care Support needs and how they will be met. There appeared to be an assumption that spouses or other family members would be able and willing to step in to fill the gap when Social Care Support was withdrawn or reduced. This has put additional pressure on both disabled people and family members and responses evidenced a worrying concern that this will be made to continue as people have been seen to have “coped”. Disabled people and their unpaid carers/supporters are also concerned that because they have been able to ‘survive’ with less support, any underspend on their individual budget this year will be clawed back by the local authority and/or that their individual budget for the next year will be cut.

Who responded?

115 people from across Scotland responded to the survey, 104 of whom were in receipt of social care support before the pandemic. Just under half (42%) were disabled people, the rest were supporters or unpaid carers. About half of those identifying as disabled were also providing care or support for another disabled person.

Over half of respondents (53%) said they were being supported by a council/local authority team, 28% employed personal assistants, 29% were supported by a voluntary organisation and 24% by a private company. Some people received support from several sources e.g.,

some provided by the local authority and some by a voluntary organisation.

This report presents the four main themes from the survey results and our recommendations in light of these.

1. Loss of Social Care Support during COVID 19

Our survey revealed that many people experienced a reduction or total loss of their social care support, often without any advance notice. This left people feeling abandoned, at breaking point and often unable to exercise even their most basic human rights.

Overall, 68% of respondents (71 people) receiving social care support at the start of lockdown said they had experienced a loss or reduction of care/support during the crisis. Of these respondents:

- 66% (47) still had not had their support reinstated at the time of the survey.
- Only 17 (24%) had had this fully reinstated by July. A further 7 (10%) have had some of their care/support reinstated.

The impact that this loss of support has had on people's mental and physical health, which we reported from our original COVID-19 survey in April, has continued and has increased.

“Shocking that we have become the forgotten sector. 24/7 care is breaking parents.”

“Even with Jeanne Freeman stating that care shouldn’t be stopped and should be reinstated it didn’t happen.”

“It’s a disgrace that we’ve had no support throughout this pandemic. I’m a single parent that’s shielding and have a 13-year-old with Cerebral Palsy that requires 24/7 care. We have been completely abandoned & our physical & mental health is suffering.”

This situation was made worse, both for the supported person and unpaid carers, because there was no clear end in sight.

“I am worried that because of the strain of caring I will need to place my 92-year-old with Alzheimer’s and dementia, in residential care and that the tax payers and council will have to fund this as he has no savings or property. I suspect that many other carers will be forced into the same situation.

“I’d like better communication about when my dad’s support will be increased.”

“We have coped without social care support but it is very tiring and my wife is not getting the same level of personal care”

“Disgusting and shocking. [COVID-19] used as an excuse to not assess me for the third time since January. Countless lies. I cannot access my kitchen in my wheelchair as it’s filled with rubbish bags. I have only managed two showers since March. This council doesn't want to support me and would rather I died to save money.”

“I don't know when it is going to go back to the normal hours”.

For some people there was enough flexibility available to change the service provider or self-directed support option for the way their social care support was delivered. For example, switching to a direct payment to allow a family member to be employed as a personal assistant. There was no clarity about whether this would be approved on a long-term basis or was to just be a temporary solution when social care support was withdrawn. Also this kind of flexibility was not universally experienced.

“I would like to continue to support my son [as a paid personal assistant] instead of employing agency, not sure my local authority will allow this after Covid19.”

“The new system is working well for us. I can give good support for my son, much better than him getting anxious all the time having to get used to new people all the time. Most support staff do not stay with their employers for long in my experience.”

For other people this wasn't an option, and it was unclear what alternatives, if any, were offered.

“I have been left with no support because of covid19 distancing rules. My private paid support stopped visiting and could not replace her due to social distancing rules.”

“As well as overnight respite provided by a third sector provider being cancelled by them, it appears me and my wife are not entitled to be employed as PAs using SDS because we are legal guardians. We are the only ones who can provide this care for our son when he is home with us. Other services he uses, such as Riding for Disabled, swimming pools etc. are also closed. Our son is reacting badly to this cancellation of provision.”

There were some examples where social care support, purchased with a direct payment, was reduced but permission was given to use some of the available funding for another purpose e.g., buying a tablet to make contact with friends or family easier and reduce isolation. Similarly, some people adapted their support to meet the changing needs and circumstances of disabled people and their households.

“PA [personal assistant] did contactless errands, shopping and video calls as alternative support while we were self-isolating.”

Several people reported having to fight to have the reduction in support overturned or cut by less than originally planned.

“We were told that some hours of my son's package would be suspended as nowhere was open for him to go. We successfully argued that although college was closed he still had coursework to complete for his HNC and therefore still needed support hours.”

In some instances, this involved approaching others for assistance.

“I tried to increase support when the virus was reducing. I had to go to higher management and negotiate one more visit.”

“Asked for more help and was refused until MSP stepped in. Got a little more but not much”

Even when services were reinstated, this was with less choice and control for the supported person in some cases.

Some disabled people and their unpaid carers reported feeling manipulated to accept a reduction and/or continue ‘bridging the gap’ in social care support and not to ‘rock the boat’.

“Council tried to get me reduce the care they provide, a bit [of] moral blackmail was what it felt like, I said still needed the care so it continued but with them saying timings would be erratic and only utter essential things”

Some people whose social care support was stopped or reduced turned to the Independent Living Fund⁴. They found this support really helpful, providing funding to fill some of the gaps left by reduced social care support.

A small number of respondents cancelled or reduced their support due to fear of contracting the virus or concern for the safety of their Personal Assistants.

⁴ The ILF in Scotland is currently only available to those already receiving it or to young people in transition. Please see <https://ilf.scot/>

“We stopped the care to self-isolate ... but they [the care company] aren't willing to restart without an assessment because it's longer than their 2 week break policy”

“I chose to reduce from a team of 4 to just 2 when the Pandemic was at its height to reduce risk for my son and ourselves which meant I was filling the gaps.”

“It flagged up that having a PA who relies on public transport and needs to use multiple modes [of transport] to get here was a huge barrier to accessing support. She doesn't feel confident to travel and I didn't really want her feeling at risk. Hard to know what is the 'right' thing to do, keeping her safe has a knock-on effect of disrupting progress of my children. And obviously reducing any respite I get whilst she provides support.”

“It felt important to follow guidance to keep our PA [personal assistant] safe yet it meant zero respite for me.”

2. Communication and involvement in decisions

Our survey asked if people had been involved in the decisions made about any changes to their social care support due to COVID-19.

Of those who said they had experienced a loss or reduction in their support/care during the crisis 51 responded (72%) said they had not been involved in discussing the changes. Only a third (33%) of people said they were involved in discussing any decisions about their social care support.

In addition to the limited (if any) involvement in decisions that could have a significant negative impact on the lives of both disabled people and unpaid carers, there were serious concerns raised around how people were informed of the changes to their social care support. In particular, some people were informed by voicemail, text or letter with no follow up to check these messages had been received or to discuss the potential impact of this decision.

“12 weeks on and a phone call from (the) Council to ask if support can continue to be stopped for another 12 weeks. It’s a very anxious experience and for my family member to be left a voicemail informing them was incredibly disappointing and completely inappropriate way to treat a vulnerable person.”

There appears to be an assumption that spouses or other family members would be able and willing to step in to fill the gap when social care support was withdrawn or reduced. This has put additional pressure on both disabled people and family members. It should also be noted again here that around half of respondents were disabled carers themselves.

“I’m really fearful for the future of social care. It has reduced me to just feeling like a burden. The emotional, financial and wellbeing cost of my family having to take over my care has

been huge. They feel they have no support either. It feels like we've been dumped and forgotten about."

"I have actually moved regions to be nearer to family and help. I felt very let down by my old company. I made myself very ill trying to cope. There is no guarantee I'll get back to my pre covid health level. I'm still very exhausted. My new council seem to be on the ball though with supplying help."

"I felt abandoned by the Care Company who were unwilling to discuss the decrease in hours offered to my 95-year-old mother who is registered blind, very deaf and suffering from dementia. No one lives with my mother but before the pandemic, myself and two sisters ensured that my mother had 24-hour care. I informed the care company at the start of lockdown that both of my sisters were involved in shielding as per government requirements, so I was very much relying on them for my mother's full care package. All to no avail. The total lack of social care from the care company has been enormously detrimental to my mother."

Communication from both social work and social care support providers was a clear area of concern.

"We have had about four emails from Social work checking we are OK. I missed one of their emails and they didn't follow it up anyway. Much happier without the hassle from SW."

"I have had one very brief call from the local authority in the very beginning."

“I’ve had no contact at all from my care management not even when I was rushed to hospital and my sister phoned my care manager saying so and asking for a call back. My sister or I still haven’t had a call back, I could be dead for all she knows.”

“We have received no information about when services will start again and we can't find out anything. No communication.”

Even when information was given it was not always accessible. An example was given of a local authority where there was a delay in a circular to employers of PAs. During the period of the delay two pay rolls had to be completed. When the circular did finally come out it was not in an easy read format.

A common theme was a lack of clarity about what social care support would be made available and when as lockdown was being relaxed, and whether the lost support could be carried over into the next month/year.

“To date have lost 16 days’ respite and hope these days are added on to next year’s dates.”

Lastly, there was evidence of confusion and concern about a lack of clarity around rules and restrictions, e.g., Personal Protective Equipment (PPE) use within the context of social care support. This pointed to issues around how this information was communicated and enforced.

“It didn't feel clear whether PPE should be worn - meeting new carers to do training but they didn't seem to know what precautions they should take other than washing hands.”

“Some care company staff didn't wash their hands entering or leaving. Travelled in cars in the front seats together and didn't wear gloves.”

3. Continued Charging for Social Care Support

We asked if the amount of money respondents pay for their social care support package had changed since the Covid-19 crisis started. Of the 71 respondents who said they had experienced a loss or reduction in their support/care during the crisis 34 respondents (48%) who had their support/care stopped or reduced had paid (or been invoiced) for support they were not receiving.

“SDS in place don't know if it was still being paid during time with no support.”

“No contingency plan for services for disabled people. I know one service which adapted quickly with full regard to Care Inspectorate guidance - had to pay to use of course on top of what I continued to pay to closed services.”

“Support was stopped and agency haven't been charging for support we used to get but City Council have still insisted contribution towards this is paid.”

Some people reported being pressurised to pay for services they had not received.

“Still sent bill for care (same charge despite not getting any). Have refused to pay it until my care is reinstated. Now been

told in debt and debt team investigating and may be charged extra.”

Many people are not clear how much money has or has not been spent on their social care support as their budget is controlled by the Council.

“We do not pay for mum’s support from the local authority although she still has approximately £10,000 SDS money sitting with the council unused as the services we wanted were unavailable. SDS was a huge disappointment.”

“Allocated budget for my husband is only having a small amount used”

Specific concerns were raised around paying Personal Assistants (PAs) who were not working as a result of COVID-19.

“Have had to pay PA who is shielding full wages.”

“Family were able to help in the end but we couldn’t apply for funding to help them as we were strongly encouraged to keep paying PAs full rate. Only recently discovered that we could have applied for extra funding.”

Whilst not specifically related to COVID-19 some respondents commented that they had not been able to afford to pay their Personal Assistants the real living wage and were concerned that they may not be complying with Scottish Government regulations. They were particularly concerned that if their individual budgets are not increased they may

need to reduce the number of hours of support they receive or risk losing skilled staff to higher paid posts e.g. for the Local Authority.

“My personal assistants need to be incredibly skilled and capable - this is not reflected in the level of pay the council expect me to give them. I have tried to increase their pay slightly, at detriment to me because it means I have less hours, but it's still way off what my staff should be earning.”

Some respondents reported that their direct payment budgets have not changed in years even though costs such as salaries, pension schemes, employer insurance etc., have gone up.

One respondent raised a concern about the potential impact of BREXIT on their ability to recruit and retain PAs in the future.

There were also concerns raised that reduced social care support was putting additional financial pressure on disabled people.

“I no longer pay for support I used to receive, but other costs have gone up, food costs 4 times as much to access and have delivered, no one to help prepare food, so rely on expensive frozen meals which cost £50-70 per week.”

4. Positive Experiences

Whilst the survey responses have highlighted a significant number of concerns there were also examples of things that were going well and had a positive impact on disabled people and their family carers. From this there is emerging evidence from this survey that being on SDS option 1 had led to positive outcomes during this time. People also

reported benefitting from local community-based responses, such as food delivery services. The following quotes illustrate some of the positive experiences people reported:

“I receive SDS option 1 and I think this is the difference. I am paid directly and therefore carried out all checks on my PA myself. Local Authorities cannot withdraw care and send the staff elsewhere, e.g. care homes.”

“I have a very good working relationship with our Social Work team and I think that may have been one of the reasons why they didn't attempt to reduce my son's care package. “

“My guardian and social worker applied for additional hours of support to enable me to continue to live independently in the community. This application was successful, thank goodness.”

“Staff have been incredible and deserve a massive pay rise.”

“Community Council have been great and bring meals 2 times weekly. This has been a huge help and morale boost.”

Conclusion and recommendations

“The impact on those with social care needs and their carers has been huge. The focus has been on education - but the same effort and resources need to be applied to resuming social care to previous levels. Social care needs the same priority!”

It is painfully clear that the real-life experiences of disabled people and their unpaid carers/supporters does not fit well with the expectations contained in the Scottish Government and COSLA guidance issued in May 2020 to local authorities, health and social care partnerships and care providers delivering self-directed support Option 2.⁵ This guidance stated that:

It is critical that Social Care Support is maintained with minimal interruption during this period to ensure the safety, dignity and human rights of people who already have support in place and for those who will need it, taking into account their strengths, family and community assets at this time. Scottish Government and COSLA expect that local systems will act to do what is right to deal with the virus and to protect people's health and wellbeing, recognising that funding is available to meet both existing and new demand in social care during this period of unprecedented pressures.

Scottish Government (2020) Coronavirus Covid 19 Guidance on Self Directed Support.

As argued by the Scottish Independent Living Coalition of Disabled People's Organisations⁶ (SILC) human rights do not cease in times of crisis, they are even more important. **We must learn from disabled people's experiences during the pandemic to create more robust**

⁵ Scottish Government (2020) Coronavirus COVID 19 Guidance on Self Directed Support <https://www.gov.scot/publications/coronavirus-covid-19-guidance-on-self-directed-support/>

⁶ SILC (2020) Call for Immediate Action: Disabled people's human rights to life and health under threat https://inclusionScotland.org/wp-content/uploads/2020/04/SILC-Statement-on-NHS-and-rights-of-Disabled-People_17.04.20.pdf

systems and to ensure what happened to disabled people and their carers/ supporters never happens again.

The evidence of Local Authorities' long-term failures to deliver social care support that respects disabled people's human rights is overwhelming. Since COVID-19 struck, it has been catastrophic for many people who rely on social care support even just to survive. Our surveys⁷, the surveys of other DPO's⁸ and the Scottish Human Rights Commission's research⁹, revealed the shocking reality that disabled people had care packages stopped sometimes overnight. This left some people without support to get out of bed or get essential food and medication and violated many basic human rights.

There is therefore overwhelming evidence of the absence of any meaningful way to hold Local Authorities to account or seek redress, whether it concerns questions about the overall system, or for the cuts to the care packages of individuals. Local democratic accountability is a myth. It does not exist. Local authorities have had years to demonstrate they can deliver on social care support. They have unequivocally failed.

We therefore support the recommendation of the Independent Review to shift accountability for social care support from local authorities to the Scottish Government and the creation of a new Minister for Social Care Support.

⁷ Inclusion Scotland (2020) COVID-19 Experience Survey: <https://inclusionScotland.org/covid-19-evidence-survey/>

⁸ Glasgow Disability Alliance (2020) Supercharged - A Human Catastrophe: <https://gda.scot/what-we-do-at-gda/resources/publications/supercharged-a-human-catastrophe-inequalities-participation-and-human-rights-before-during-and-beyond-covid19>

⁹ Scottish Human Rights Commission (2020) Covid 19, Social Care and Human Rights: Impact Monitoring Report <https://www.scottishhumanrights.com/media/2102/covid-19-social-care-monitoring-report-vfinal.pdf>

That is not to say that there is not an integral role for local authorities within a National Care Service, especially for social workers if they are given autonomy to support people in assessment of their rights and needs without having to return recommendations based on limited Council budgets and strict eligibility criteria.

The Independent Review supports calls for the incorporation of human rights conventions, such as the UN Convention on the Rights of Persons with Disabilities (UNCRDP) into Scots Law and the rights to independent living this would enshrine. **To make these rights real, mechanisms must be established to hold all responsible for delivering Social Care Support accountable, with redress where rights are shown to have been breached. These mechanisms should also include an independent complaints system as well as investing in Independent Advocacy, particularly collective, peer advocacy.**

The report of the Independent Review of Adult Social Care must now accelerate positive progress on the good work already done, not represent another interruption to it. No one will tolerate any more good initiatives that fail to deliver. As we all know an excellent report is never enough. **The true test is what happens next; how these positive recommendations will be implemented and financed and that there are transparent mechanisms for ensuring disabled people and our organisations are at the centre of the process.**

Given the impacts of the pandemic on an already broken social care system and the resulting devastating human impacts disproportionately

faced by disabled people, the time for change is now. Just as the NHS was set up after the devastation of World War Two, we too see the establishment of a National Care Service as our post COVID-19 legacy. The creation of a National Care Service for Scotland can play a crucial role, not just in recovering socially and economically, but in how we recover our humanity after the COVID-19 crisis.

Our recommendations

- Urgently reinstate social care support that was reduced or taken away because of Covid-19;
- Urgently complete social care support assessments that were postponed as a result of Covid-19;
- Re-open the Independent Living Fund to new applications or consider what lessons could be learned from it to improve the way social care support is funded;
- All four SDS options must be promoted and communicated effectively, with disabled people informed and empowered to have meaningful choice and control over their care and support;
- If there are other national or local lockdowns provide accessible information about what this will mean for disabled people and their unpaid carers including the changes to social care support services and any alternatives available;

- Keep disabled people and our unpaid carers/supporters informed about when respite centres and supported short breaks will resume and take steps to prioritise the re-opening of these and have interim steps that provide alternatives to respite breaks;
- Involve disabled people and our organisations in contingency plans for any subsequent waves (and other potential future disasters and emergencies);
- Take urgent action to reimburse any payments made for social care support that has not been received;
- Stop debt collection action against disabled people for social care support they've not received;
- Ensure that, disabled people are aware of their options around paying their personal assistants or other social care support charges if future COVID-19 restrictions lead to a loss or reduction in the support provided;
- Cross-party support for implementation of all 53 recommendations of the Independent Review of Adult Social Care Support. This includes the creation of a National Care Service with ultimate accountability for social care support sitting at Scottish Government level.