

HEALTH AND SPORT COMMITTEE

SOCIAL CARE INQUIRY

SUBMISSION FROM INCLUSION SCOTLAND

Scottish Parliament Health and Sport Committee: How has Covid-19 impacted on care and support at home in Scotland?

Inclusion Scotland is a 'Disabled People's Organisation' (DPO) – led by disabled people ourselves. Inclusion Scotland works to achieve positive changes to policy and practice, so that we disabled people are fully included throughout all Scottish society as equal citizens.

Although we recognise that the Committee's call for views is directed at people who provide or receive care and support at home, we are concerned that the limited time for responding and lack of publicity to make people aware of the call could mean that many disabled people have been unable to get involved. It should also be acknowledged that some disabled people are still experiencing problems with their social care support and so may not be in position to provide their views at this time.

Since the start of the pandemic Inclusion Scotland has been asking disabled people about, amongst other things, their experiences of social care support. We would therefore like to take this opportunity to provide you with a short summary of what we have found.

Introduction

Many people need social care support, not just to stay alive but to have a life, to exercise choice and control, participate and contribute as equal citizens, and achieve even their most basic human rights. However, we already knew that social care support has been under increasing pressures over the last ten years in spite of good policy and co-produced reforms. The onset of Coronavirus pandemic served to expose the long-term fundamental flaws in the system, and resulted in devastating consequences for disabled people and unpaid carers when it struck.

Since March, Inclusion Scotland has conducted several surveys asking disabled people about their experiences during the pandemic. We received over 800 responses to our first survey from across Scotland. The impact of the crisis on social care support provided some of the starkest findings with disabled people telling us that provision of social care support, both formal and informal, has been seriously adversely affected since the start of the pandemic.

In the following section we set out some of the things disabled people have told us about their experiences of social care support during the Covid-19 crisis.

Disabled People's Experiences of Social Care Support

1. Loss of some or all social care support

Almost half of those who answered this question in our survey (45%) said that the Covid-19 crisis had impacted on the social care support that they receive. A further 12% of respondents said it may have an impact in the future. Around a third of respondents explicitly told us that the social care support that they received had either been stopped completely or had been limited.

We have heard some distressing stories about the situations disabled people have found themselves in as a result of this loss of social care, including people being left bedbound or unable to wash and dress themselves.

"Sleeping in wheelchair instead of bed, no help getting washed and dressed."

"I have gone from 20 hours of care (seven hours of which were personal care) to ZERO. I am now bedbound completely because of this."

People told us that withdrawal of, or reductions to, their support had also impacted on their physical and mental wellbeing. For example, for some people the loss of support also resulted in difficulties accessing food and medicine, prolonged isolation, inability to do any form of exercise and increased or new caring responsibilities.

"I can't go outdoors at all (I am blind). My support system is less than normal and I feel anxious a lot of the time."

"The 78 year old I care for is becoming increasingly disabled on a daily basis. He is now no longer able to get in/out of bath amongst many other things, and he is far too big for me to manage. His mental state is also becoming increasingly disturbed, (alternately sobbing and raging) to the extent that I fear for both our safety."

A separate but connected issue is the loss of health care appointments for disabled people. Although we did not ask a question on this in our survey, 7% of respondents told us that their medical appointments and/or routine health services had been cancelled or reduced since the start of the crisis. This included cancellations of physiotherapy, pain clinics, injections, neurology appointments and other vital services that many disabled people rely on to look after and maintain their physical and mental health.

Similarly, when we separately surveyed people who were shielding, respondents spoke about the loss of health care appointments and treatments and the loss of exercise opportunities. People said these factors have the potential to result in declining physical and mental health, and some people were already reporting negative impacts on their health as a consequence.

“No day service for me to go to. Not seeing family has been really hard but the worst has been not being able to see anyone from NHS to fix my broken wheelchair which has increased horrendous spasms for me.”

As a result of a combination of loss of social care support and health care, it is therefore likely that the social care support needs of a number of disabled people will have changed and/or increased since the start of the pandemic.

In a more recent survey we asked people about their experiences of social care support during the Covid-19 crisis. Over three quarters (79%) of respondents who were in receipt of social care support said they had experienced a loss or reduction of care/support during the crisis. Many of these respondents had not yet had their care packages reinstated and in some cases people said they are still paying charges for care they no longer receive.

2. New or increased caring responsibilities

Around 40% of survey respondents told us that they had experienced changes or challenges with caring for children or other family members at home since the start of the pandemic. In particular, a number of respondents noted that as a consequence of loss of support they had to act as carers to family members, or had to rely on family members to care for them. Although some people may have already provided care and support to their family member pre-Covid-19, the current situation placed a greater strain on carers, some of whom are disabled people themselves. Loss of social care support has also put pressure on families if a person has had to move in with a carer due to loss of their usual support.

Issues related to caring that people told us about included: the emotional impact of loss of independence and forced reliance on family and what this means for personal relationships; balancing new or increased caring responsibilities with work commitments; and managing conditions while also caring for others.

“My youngest child not being at school is proving difficult for my health as I'm now struggling to care for her 24 hours a day. I normally have 2 nights respite per week and one weekend daytime respite to rest in order to help me pace and cope. The stress and extra required activity is making my symptoms worse.”

Many parents spoke of their children losing vital services and support that would have been provided through the school, and the additional strain of having to educate children at home. A number of comments referred to an increase in violent outbursts and self-harm from disabled children and young people due to disruptions to their routine and services being suspended.

“Son has ASD and self-harms/has suicidal thoughts. He is also really volatile and can hit out. He has no support at all now, as his main support was a school

counsellor. I don't know how he will cope if this lasts much longer. I can't get out the house at all, as he won't come with me and can't be left alone."

3. Concerns around personal protective equipment (PPE)

Lack of information and availability of PPE made many disabled people, especially those at high risk of getting Covid-19, fearful of continuing to take support, in particular where this might involve personal support from PAs or support workers that have to work in other people's homes.

"I have no PPE to give to Personal Assistants. Therefore, I have cancelled the weekly 154 hours of support because I cannot have nine Personal Assistants coming into a vulnerable house and potentially being an asymptomatic carrier."

Our survey responses also showed that some disabled people and those that support them, were unable to follow social distancing rules when in or out of the home. For example, because they themselves need personal care, or provide such to another disabled person.

"I cannot follow these measures. I received the letter to tell me I was in the most vulnerable position medically and to use different towels, bathroom, eating alone etc... my wife brings me my food. I am bedbound. I cannot control who eats where. I have no access to running water for hand washing and I'm onto my last hand sanitiser bottle."

"My Local Authority is refusing to provide us with PPE even though I'm at risk and self-isolating, and I have open sores. I've literally been told that my PAs and I are not their problem!"

Conclusion

Social care support, such as it is, was already woefully under-resourced prior to the pandemic. This meant that disabled people were absent from the economy and our communities, and that our rights to independent living and many others which are closely connected, were negatively impacted.

Disabled people's experiences of social care support during the crisis has only served to highlight the inadequacies of the current system, many of which were not new and already experienced by disabled people.

A radical shake-up of social care support is therefore needed in order to create a national social care support system that works for everyone. As a starting point, this system should enable those with social care support needs to access the resources and support they need, with genuine choice and control over who provides it and how they use it to live their lives, to achieve independent living, equal citizenship and fulfil their human rights. It needs to be a system that is transparent and accountable to ensure that Scottish Government money designated for social care support is

spent on social care support throughout Scotland and so that it resilient in times of national emergency.

As with the NHS, which no one would see as a drain on resources, properly funded, good quality social care support is an asset. In this case it is an asset that prevents ill-health outcomes, both physical and mental health, frees up costly clinical services for clinical needs and supports disabled people's contributions and participation in society.