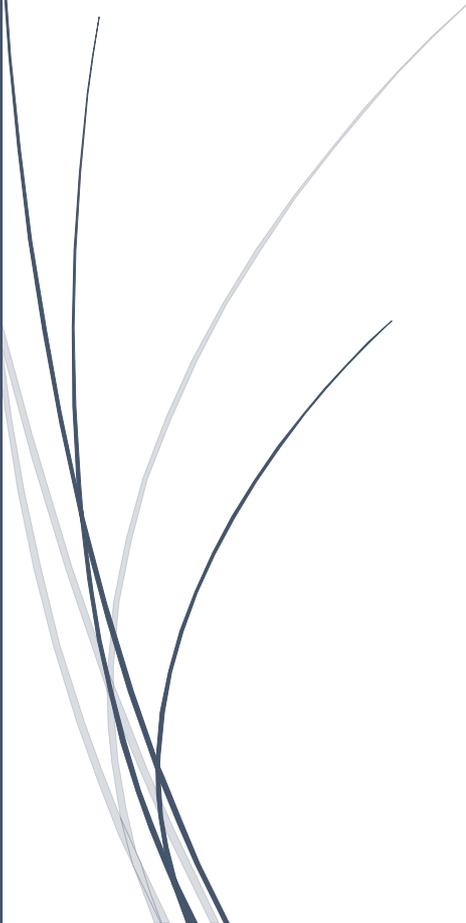


11/1/2020

Surrey Coalition Covid-19 Diaries



Surrey Coalition of Disabled People

Coalition Covid-19 Diaries

The pandemic has impacted on all our lives. We have been forced into embracing technology to keep in touch with others and the way we all work has been changed forever. Some of the changes have had a positive impact on our lives. Surrey Coalition decided to ask our members for feedback on their experiences during the lockdown.

We now know that the pandemic had a disproportionate impact on disabled people: around 60% of those who died during the first phase of the pandemic were disabled people ([ONS report](#)) and younger people with a learning disability in England were more than 30 times more likely to die from coronavirus than non-disabled people of the same age.

These stark figures underline the need to understand the experience of disabled people during the pandemic and to make rapid changes to future pandemic planning. Members were very honest about their experiences and the impact this has had on their lives, a number of themes emerged from the feedback including social isolation, communication and access to support.

Be under no illusion some of the feedback we were given was truly heartbreaking and will make for difficult reading. However, in order to learn from this and move forward we need to face the reality of what disabled people experienced during the lockdown.

March 2020 Lockdown

Access to support

I think we were all blown away by the way the community mobilised and lots of local groups were set up to help support those most in need. Our members described how this support worked for them. Everyone acknowledged this was an unprecedented situation with everyone learning as they went along. The feedback shows those things that worked well and those that could be improved.

‘As someone who lives on their own and has a hearing impairment, I was supported by my family during the lockdown with shopping etc. I was

lucky because the Salvation Army and Spelthorne Borough Council also offered assistance.'

'I joined a number of alliances to be part of the community. There was a lot of work going on, but I found that many people did not know about it. I found support from Action for Carers very helpful.'

'I received very good assistance from the Borough Council and my two Personal Assistants. Woking Borough Council also helped my elderly mother.'

'My husband was shielding; we were contacted by an alliance set up by councilors in Lightwater. These volunteers would go shopping or to the chemist etc. Eventually we managed to get an online supermarket slot. Surrey Heath Borough Council called to check the household had food and medication and we received one care package. Volunteers were great but I found it hard to ask people I did not know for help'.

'I had a call from the Borough Council because I have a community alarm'.

'The parish Council set up a helpline which is still running as far as I am aware'.

'I am fortunate to have friends living within 10 minutes' walk who could help'.

'I have not heard from anyone apart from the Coalition I have a neighbour who has not been able to get a tap that is constantly running, repaired.'

'I was left quite socially isolated as I have been unable to attend lunch clubs etc which stopped during the lockdown. I have been able to get lunch from a voluntary organisation in Cranleigh. The Coalition have been working with me to link me in with technology'.

'Although I am 75, I went out as much as I could during lockdown. I feel the authorities are taking advantage of covid to stop people from visiting relatives in care homes'.

'Having people at the end of a phone or zoom call has been a godsend. However, my daughter has not had a good time during lockdown and the Care Act has not been followed'.

'I have only been out five times on my own since the lockdown. I did manage to travel on my own last week, but the lack of support available on the train was even more evident because there were so few people on the train'.

'I am still scared to go out because of social distancing, and I have not been anywhere on my own as I feel very alone and insecure. Someone recommended that I wear lanyard when the lockdown first started but this did not help as everything had closed down. I do not feel like my old confident self anymore. I tried to access help thorough the church, but this was limited. I found the NHS volunteers to be a great help as they came every week and went to Waitrose and the chemist for me.'

'I found lockdown to be a mixed bag. The regular social features of the week disappeared but they were replaced with online activities and meetings which has led to a new social framework. I have been impressed with metro bus who have marked off which seats can be used on their bus services. I did make use of my local road ambassador through the Parish Council'.

'I don't receive care and haven't managed to successfully gain a care act assessment, despite asking, but probably wouldn't be able to afford it either as I'm working! The situation of splitting disabled people into Clinically vulnerable and Extremely clinically vulnerable, meant that there were a lot of people like myself who did not meet criteria for support, but still needed to follow similar actions i.e., shielding but without the letter to do so. There was very little information on where to go for help. Surrey's website and where to find information makes absolutely no sense to me (and I work for them!!) so how they expect people to find out is unknown'.

'During the first week of the 'lockdown' my hearing aids stopped working and consequently the world of sound vanished for me. It was impossible to get any help whatsoever as all organisations that could have helped me had reverted to telephone only. Even my hearing aid specialists were advertising saying that if you have difficulty with your hearing please call this number!!!!

My GP surgery had also cut off email contact and still has, but at the time I had an extremely bad bout with my left leg and had to beg someone to phone the surgery for me. They were advised to call 999. This entailed the services of an ambulance being diverted to me when some other person in greater need could have been waiting.

Even with my hearing aids I have great difficulty in hearing what people say and have to have subtitles on any recordings on my television. The internet for the last 18 years has been a lifeline for the likes of me living alone. Tesco and Morrison's were terrific having been advised by the

Government that I was a 'clinically at risk' person I was able to order my deliveries as normal.

If it had not been for Yasmin at Surrey Coalition, I would have been without my hearing aids even today. She managed to contact my hearing care people and a very obliging lady in Cardiff arranged for me to send my hearing aids to her and she had them repaired and returned to me having supplied me with a box in which to send them to her in the first place.

Living on your own and having communication with the outside world cut off so abruptly is quite alarming to say the least and I am not easily alarmed having been a Royal Marine for over twenty years and now crippled at the age of 81 years.

More planning has to be gone into as to how vulnerable people can obtain the services that they require in an emergency as this virus is and looks like going on for some time yet'.

'I have never felt so disabled, I used to manage OK but now everything is harder, and I feel trapped in my home with no support'

Information

Access to clear and accessible information is important at any time but is absolutely essential during a pandemic. Our members told us how they tried to process the information given during this time and the effect this had on them.

'I found it difficult to process all the guidelines for carers and the lack of PPE and carer shortages. There were different carers coming in each day and at different times this caused me anxiety and panic attacks. The stress lead to exhaustion'.

'Not being able to access help easily to fill out a DWP form also caused a lot of stress and anxiety'.

'Home covid test kits are quite complicated'

'Why do I have to wait days (and sometimes longer) to get the same information as everyone else in an accessible format? It's like my life isn't as important'

Isolation

One of the biggest impacts of the lockdown on our members is isolation. Members describe how it felt to have the activities that formed their day to day lives suddenly taken away from them and how they had to adapt to the 'new normal'. This is undoubtedly easier for some than others.

'I locked down earlier than the national lockdown, but I have felt extremely isolated as prior to lockdown I led a busy life going out to lots of meetings and mixing with lots of other people.'

'I experienced feelings of isolation by not going out to my usual meetings.'

'I found the days tedious and was not able to do much, I also had medical issues that I was not able to resolve'.

'Routine trips out provided me with opportunities to talk to other people, I lost these during lockdown'

Health

It is widely acknowledged that the lockdown has had a huge impact on health and not just in terms of the virus. The disruption to treatment of other conditions and to normal physio appointments etc. has had a huge impact on people's lives.

'During lockdown I lost a considerable amount of weight, the GP didn't take into account mental health. I tried to get in contact with SABP only to find I have been removed from the system, so it was difficult for me to make contact.'

'Unfortunately, my mental health has suffered during the lockdown, and I have been trying to cope with anxiety and depression. I am now trying to get out as much as possible'.

'I am struggling with anxiety and I am worried that if I go out, I could bring back the virus to my husband and it could kill him. I am receiving some support around this. In the beginning I found the Coalition Virtual café to be a godsend'.

'I learnt a lot about myself, I found it very difficult in the beginning as I usually try to get out every day for exercise etc. My speech has declined during lockdown and I have fallen more. I visited A&E because I had broken her ribs, the journey was difficult and there was no social distancing in A&E. I was not told to shield despite the fact I have breathing problems'.

'I have been housebound because of medical issues and have not been able to get to medical appointments'

'The lack of face-to-face medical appointments has been difficult especially for my wife who needed an asthma check this is not something that should be done over the phone'

'The biggest problem was the majority of those things put in place for covid used phone numbers only. The 119 number to book a test cannot receive texts. I went for a covid test and those working at the test centre did not understand the need for lipreading. My GP and pharmacy still have not provided a two-way text number. There was a big failure to make sure accessibility was built into the process'

'Covid tests are also not accessible to those with a visual impairment as you are unable to read the instructions and you do not know which pot to put the test stick in'

'All medical support stopping has had massive impacts on many people's care needs. E.g., not being able to access physiotherapy etc. There is very little advice on accessing mental health support if you don't meet criteria for community mental health services'

'I lost all trust and faith in health services when I saw in the news that they will not give disabled people a ventilator if they need one. Even though the various NHS groups came back and clarified that doctors should not use the frailty triage tool for disabled people, the damage was already done, and I am scared that this is being used'

'I have trouble getting an appointment with my GP, when I phone, they say go online, when I go online, I can't work it out. I have given up'

'If my GP doesn't provide me with a text number and I can't use the phone or internet then how on earth do I get in touch?'

SCC Community Helpline and other services set up to support vulnerable people during lockdown

We asked members whether they had used the SCC Community helpline and if they did what their experience was. Most members had not used the helpline.

'I was not happy with my contact with the SCC community helpline'

'I did not know about the SCC Community Helpline but did contact Reigate and Banstead Borough Council'.

'I did contact the SCC Community Helpline, but they did not have much to offer in my area at the time'.

'I contacted them, and they gave me other numbers to call'

Shopping

It is widely acknowledged that there was an issue for many people trying to access online delivery slots during the pandemic. Although, this was a problem for those who had been told to shield, those people were sent a food box of essential items and were able to get on to the priority list for online slots (eventually). However, for the majority of disabled people who were not told to shield they experienced huge problems with trying to get a slot or food at all. Fry legal have launched various legal challenges on behalf of the disabled community and are keen to hear from any disabled person who is not given a priority delivery slot as a reasonable adjustment.

'I experienced some difficulty with online deliveries in the beginning.

'My husband was shielding but we found getting a supermarket delivery slot was the biggest struggle'.

'I managed to get food deliveries after a few weeks and before that survived by eating food left over from Christmas'.

'Disabled parking spaces have been cordoned off to enable queuing which means it is not possible to park near the shops'.

'I only ventured out early in the morning to local shops but was restricted on how far I could go because of a back problem. My parents brought me food in the beginning even though they are elderly themselves. I investigated where to get food and found Parsley box or Farm Foods'.

'I have received help with shopping from friends, but it has taken a long time to get help and support'.

'Changes to parking has meant I have been unable to access local shops. I have not been able to get my shopping delivered so have had to go out the shops'.

'I have been doing the shopping for elderly neighbours that are unable to get to the shops'.

'I had difficulty in obtaining a slot for online shopping so instead purchased my shopping from the corner shop ordering by phone and paying with contactless'.

'It was incredibly stressful to try and arrange a delivery (something I have been doing for years)'.

Employment

'Working for SCC has been horrendous! As an employee I can say that SCC have provided no support around mental health or change in work patterns. Reasonable adjustments no longer being upheld. Managers do not know about the equality act. The IT department refuse to make adjustments based on what I tell them and access to work report. They now want an OH report as well, which seems like a huge waste of time.

There has been no support for isolation. No support for people who are not living in suitable accommodation. For example, we have two of us now working from home and only one desk. I've had to set up in the lounge as there's nowhere else I can work; this means never being away from my work stuff which is really bad. Managers openly talk about sitting in their gardens and how lovely it is, but forget the majority of staff cannot afford that, with many people living in flats. No assistance with internet issues. We pay for the most expensive broadband, but Leatherhead is notoriously bad. I've lost days of work to internet issues, yet they don't seem to be able to assist with that. They then made return to work plans and 'covid compliant' offices which completely ignored the needs of disabled staff. They have made it really difficult for disabled staff to access training that has been running over lockdown on new software etc. Commissioned training on unconscious bias that isn't accessible to disabled staff and the people running this training had not even considered accessibility in their training!

Positives

Although it may not seem like it there were some positives to come out of the lockdown. Our members were pleased to be able to feedback on these.

'The positive has been that all chats and meetings have been available on zoom. I am not able to come out of the house but through lockdown I have been able to attend prayer services, knitting groups and choir. This helped to put back some of the structure that had been taken away me. I have also been able to access other groups I previously could not attend because of having to travel. GP services have also opened to me because I can have a consultation over the phone or a home visit.

'I have connected well to the zoom meetings that have taken place daily. This has brought a lot of people together and enabled them to make contact more easily'.

'Zoom meetings have been beneficial as it has meant I have been able to stay in contact'.

'Zoom meetings have been beneficial'.

'I have been able to attend more meetings now they are available online.'

'I have been talking to everyone via the computer or WhatsApp groups'.

'I joined the Surrey Coalition Virtual cafe every week and this is the highlight of the week for me'.

'I've finally got online, and it feels like I will have much more freedom and independence'

'I've met many more people than I would usually through attending social activities online, I just hope they continue'

'Daily activities have helped me to cope mentally'

'We have seen thousands of people do their jobs at home. Disabled people have argued for many years that they could do a job from home but been told it wasn't possible. If any positive comes from Covid-19, I think it is that people have proved that employers can be more flexible and that almost anyone can work from home. This will open up employment opportunities for the disabled community'.

January 2021 lockdown

Add in most recent

The future

It is clear that the disabled community have been disproportionately impacted, as have other groups of people with protected characteristics. In response, [in its new COVID-19 Winter Plan](#) – the government describes how ministers will manage the end of the national lockdown on 2 December, the government has revealed that it is “considering what further action is needed to protect disabled people”.

“It is especially important that the needs of people with characteristics that could put them at greater risk are fully considered and that the fullest efforts are made to engage them in the roll-out of rapid testing and vaccines.”

The Joint Committee on Human Rights (JCHR), an influential parliamentary committee made up of members of both the House of Commons and the House of Lords, has published a detailed and hard-hitting [report on the coronavirus pandemic](#).

The committee looked at the human rights implications of the measures introduced by the Government to tackle the pandemic. They concluded that some groups of people, including disabled people, have been especially severely affected, and that urgent action is needed. This echoes the findings of the National Autistic Society’s [Left Stranded](#) report.