



#SpeakUp - Sheffield Voices

What is #SpeakUp?

#SpeakUp is Healthwatch Sheffield's micro grants programme, offering funding of between £500-£1000 to not-for-profit, voluntary, and community groups. The purpose is to run a project which will reach out to people across Sheffield, and hear what matters to them in relation to health and social care.

By working with groups which are already trusted partners in their communities, we can make sure we're hearing from even more people, including those whose voices aren't often heard by decision makers.



Sheffield Voices

Sheffield voices is a self-advocacy service for adults in Sheffield and the surrounding areas whose voices are seldom heard. We are made up primarily of adults with a learning disability and autistic adults but we are also a welcoming and inclusive group.

We run sessions both face to face and online through zoom around self advocacy, issues affecting the learning disability community, healthy and active lifestyles and social groups. We also campaign and provide peer and experienced based training to do with the learning disability and autistic community.



Disability Sheffield
Centre for Independent Living

Healthwatch Sheffield

Healthwatch Sheffield helps adults, children and young people influence and improve how NHS and Social Care services are designed and run.

We're completely independent and not part of the NHS or Sheffield City Council. We want to understand your experiences, and help your views to influence decision-makers in the city.



Background

Why did we do this work?

People with learning disabilities have been disproportionately affected by Coronavirus. *'Unequal impact? Coronavirus, disability and access to services'*¹ published on 22 December 2020 found that the pandemic has had “profoundly adverse effects” on disabled people’s access to services. In addition to this, people in the learning disability community have been disproportionately affected by the illness. We know that they are more likely to die than any other group².

Throughout the Covid-19 pandemic, adults with Learning Disabilities and Autism have told us they felt pushed to the side. The issues are wide-ranging, from the constantly changing rules and restrictions not being available in Easy Read formats, to unclear advice about exceptions and exercise rules. Some people have been stuck in residential facilities and care homes without contact from family throughout the lockdowns.

It is important that these voices are heard. We talk a lot about these issues in our self-advocacy groups and often run out of time before everyone can talk openly. We wanted to give individuals who have a learning disability or autism a chance to speak more extensively about the issues affecting them currently and how things should change.

What did we do?

We originally planned to carry out more individual work with our group members, but as services began opening up again we lost some of our regular voices, and some others didn’t feel confident voicing their opinions alone.

Instead, we presented the questions to the whole group and discussed them together. We ran several Zoom sessions online where the group could talk about their issues together, work off each other, and prompt other members to make sure their voices were also being heard. Our wider group who couldn’t attend these meetings were also invited to contact us at different times, through email or similar, to add their opinions and ideas to the work.

¹ <https://committees.parliament.uk/work/320/unequal-impact-coronavirus-disability-and-access-to-services/publications/>

² Chapter 6 of the above review tells us that the death rate with coronavirus of people with learning disabilities is between 4.1 and 6.3 times higher than the general population. Among young people this is even higher; people with learning disabilities aged 18-34 are 30 times more likely to die from coronavirus than their peers.



We used a program called ‘Jamboard’ to capture the group's thoughts and feelings in real time. This is a programme that the group are familiar with from other sessions.

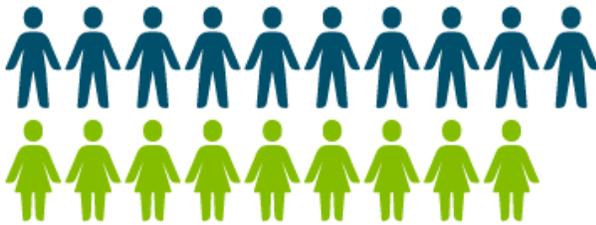


We shared our screen throughout the discussion so that the group could see their words being captured, add to points or correct them, and have a copy of the work sent to them if they requested it.

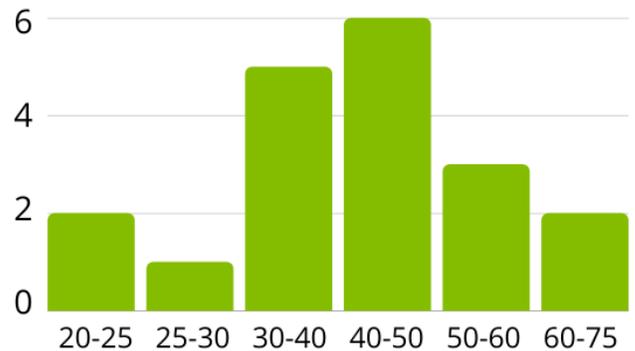
We made sure that the group understood why we were asking them these questions, as well as what was going to happen to the information they shared with us.



Who did we speak to?



We spoke to 19 members overall; 10 men and 9 women.



The people we spoke to were a wide range of ages - between 20 and 75 years old.

What questions did we ask?

We wanted to find out:

- How have you felt during lockdown?
- How has your health been during lockdown? (mental + physical + overall)
- What support have you had during the pandemic?
- Has there been any media or news stories you feel strongly about around lockdown?
- How do you feel about issues effecting the disabled community during lockdown?
- What questions do you feel are important to ask your community?

Findings

Key findings

A few points came across strongly from the group. These were:

- How confusing lockdown was, particularly around conflicting messaging, lack of Easy Read information, and constantly changing rules
- Feeling that both their physical and mental health deteriorated and that some things have not 'returned to normal'
- The range of support offered varied and often people felt it wasn't enough
- Feeling like there was a lot of conflicting information in the media
- People with learning disabilities were not being respected and cared for properly at best, and at worst there have been cases of abuse

How have you felt during lockdown?

Most people told us about negative feelings they had gone through during lockdown. Some people mentioned experiencing low mood, loneliness, and poor mental health:

"Feeling very low and crying because of lockdown"

"Lonely, missing my family"

Others told us they were worried about themselves or others:

"Worried about people not taking things seriously now lockdown is ended"

"Not seeing your parents for long time affects Mental Health, not seeing again is big worry"

Confusing or mixed messaging had also felt significant to some people:

"Confused with the rules, with everything changing, and what I am/am not allowed to do"



However, some people felt more positive, saying that they had kept busy during lockdown or had been able to focus on other interests:

“Enjoyed having more work to do”

“One good thing was learning a new hobby in my supported living”

“Quite good [...] I have everything I need around me and I enjoy being alone”

How has your health been during lockdown? (Mental + Physical + Overall)

The responses to this question were stark - everyone felt that their mental and/or physical health had been negatively impacted by lockdown. People’s mental health had been impacted by issues like having to stay indoors, and bereavement:

“Feel like my mental health plummeted [...] It’s been a year later and I haven’t had as much support as I need”

“I feel very depressed by lockdown”



Two people shared that they had needed to reach out to The Samaritans for support when they felt especially unwell - fortunately, they found this service helpful:

“I was spiralling, I’ve found support with online services like the Samaritans, really helped knowing somebody was there”

Some people’s physical health has also gotten worse because of staying indoors:

“Scared for my physical health when essential appointments were cancelled. I’ve been left in pain when things were delayed”

“Not being able to go out as often made my mobility much worse”

“Eating too much effected my weight, been stress eating and lack of physical activity has impacted this”

For some people, having to stay indoors impacted them for longer than others:

“Feeling angry and confused when the rest of the world got to come out of lockdown but we didn’t in supported living”

What support have you had during the pandemic?

Most people spoke about support they have received from people in their personal lives - their families, partners, colleagues, neighbours, etc:

“Had to stay at my mom’s for 6 months in the first lockdown for extra support”

“Neighbours helping with walking dog”

Lots of people also mentioned online support - Zoom groups, online communities, or just using the internet to access entertainment:

“Good Zoom community - being able to talk to other people when needed”

“Youtube, Netflix, streaming service helping to keep calm etc”



One member in supported living did say that staff their continued to help them:

“Staff at home helping me with what I needed, cooking meals and shopping etc”

However, for the most part when people referred to more formal support, it was to say this had fallen away or wasn't enough:

“Had support before lockdown and had this cancelled without my knowledge during lockdown, and it’s been hard to get through without it. Even now the department who offered the support is claiming I cannot be”

“Before lockdown I had support from the Blind Centre and this has dissolved over lockdown through poor communication”

“I needed more support sooner than I got it. Felt my help suffered”

“I don’t have support”

Have there been any media or news stories you feel strongly about around lockdown?

We asked this question due to conversations in our previous meetings, where people had expressed frustration with media coverage. We wanted to give them an opportunity to discuss this in more detail.

A lot of the discussion focused on face coverings/face masks - people felt there was unclear messaging in the media around their use, and not enough information about exemptions (which are more likely to be needed by people with disabilities):

“Different opinions on masks and where they should be worn is not helpful”

“People are being questioned why they’re not wearing them and it’s not fair”

“Not clear information/discrimination of when people need to take them off when necessary for things like lip reading - and rules around exemption”

One person raised this issue in response to an earlier question too:

“Still confused about the rules and getting frustrated when I’m not being listened to when I say I can’t wear masks. I’ve been forced by people who don’t understand my disabilities”

A lack of accessible information throughout the pandemic has been a concern for some:

“Finding media/gov information not accessible, no signers on the news compared to Scotland on the news who always had signers. Felt like people who use sign language were not being cared about”

People were concerned about some of the news they saw relating to disabled people:

“Hearing about neglect in social care settings in the media during lockdown as a big news story. Covid restrictions have stopped providers from inspecting things properly”



However, they were also concerned that news about disabled people was sparse. Not hearing regularly about issues affecting disabled people gave them the sense that they were being forgotten about in the mainstream dialogue about Covid-19:

“Autism Strategy funding is on the news, but not hearing about what it actually is and how it’s going to be helping people”

“Not hearing enough about the disabled community during lockdown on the main news, hearing it more from disabilities groups”

How do you feel about issues effecting the disabled community during lockdown?

People had strong views on the way that disabled people had been treated during lockdown, and the lack of support they had received.

Some people mentioned that they were unable to access their regular health services and therefore couldn’t always receive the right care:

“Essential appointments getting cancelled, both making health worse and hard to deal with (for example for people with autism)”



Some said that other support they received - from statutory or community services - were cut back or had to close during lockdown. They felt that this was an oversight as these services are essential to them:

“Some groups that support disabled communities were shut completely when they should have been listed as essential”

People mentioned that even where accommodations had been made for disabled people in the regulations, these weren’t always followed:

“Rules/exceptions for disabled people in place (like extra time outside for Autistic people) but supported living not following this”

Other issues raised include a worry about ending the uplift to Universal Credit, likely to disproportionately impact on disabled people.

Disabled people's voices are not being listened to

The most significant message arising from this discussion - about the issues affecting disabled people during lockdown - is that disabled people's voices are not being listened to.

People felt that disabled communities had been forgotten about, and hadn't had a voice throughout lockdown, which had led to them becoming further sidelined:

"Feels like people were being discriminated against because of their disabilities and their voices not being heard"

The group felt that in some instances, not listening to the voices of disabled people had led to serious consequences:

"People being left in care homes especially at the start of lockdown and dying there because of Covid spreading"

People were specifically concerned about Firshill Rise, a Sheffield Health and Social Care Trust service for people with a learning disability and autism. Disabled people had been raising serious concerns about the ward for some time, and the Care Quality Commission rated it 'inadequate'³ in July 2021. The group felt that harm could have been prevented if people had listened to disabled people's voices earlier:

"It's really bad what's happened in places like Firshill, people haven't had their voice heard and things have gone unnoticed. People should have been asking more what lockdown was like for them"

"Has exposed that there is not a good vetting system for people who work with people with disabilities and abusers have been allowed to work with people when they shouldn't have"

³ <https://api.cqc.org.uk/public/v1/reports/2ad62230-2c52-44cc-b195-bb7695185eda?20210715070221>
Published July 2021. The report flags serious issues eg that "people experienced harm because of a lack of protection, they experienced abusive incidents, restraint and seclusion"

What questions do you feel are important to ask your community?

We hope to build on the findings in this report, using the questions we asked above as a starting point when approaching new members in the future. Hopefully we will be able to speak to those in care homes and in communities not digitally included, so we can capture their ongoing ideas and ensure that disabled people do have a voice and they are listened to.

To do this, we also asked existing members what other questions they thought would be important. Their proposals were:

- Do you think masks should be kept on public transport?
- What can the government do to make us feel safe?
- I want to ask them about their experiences and make sure everyone has a voice
- What training should all care staff have?
- What they feel about the need for easy read materials
- What can we put in place to make sure discrimination doesn't happen?
- Do you think we should protest about the treatment of adults with learning disabilities?



Conclusion and recommendations

Conclusion

Group members shared a range of views with us based on their own experiences of lockdown. Some common themes ran throughout:

- Every member felt their mental and/or physical health had been negatively impacted by lockdown, with some even needing to access crisis support
- Most people have relied on their personal relationships for support; health services and organisations who support disabled people have been closed or difficult to access, with some people very impacted by this drop in support
- People felt that mixed messaging and constantly changing restrictions were unhelpful, and there was not enough news or explanation of issues that disproportionately impacted on disabled people
- The voices of disabled people were not adequately sought out or listened to throughout the pandemic - this has had consequences such as discrimination against those who couldn't follow the restrictions or didn't understand them. At its most serious, the group believe this has led to real harm.

Through Covid-19 we have found it very difficult to connect to more adults with learning disabilities, especially those who live in care homes and/or aren't digitally included. We understand why there are extra restrictions still in place but we feel that there are voices still not being heard, and additional work needs to be done to address this.

Recommendations

The recommendations below are based on the findings in this report. These recommendations are aimed at commissioners and providers of health and social care services working with adults with a learning disability:

- When commissioning, reviewing, or inspecting services for disabled people, the views of disabled people (including those with learning disabilities) should be proactively sought and involved in decision-making. When disabled people raise concerns about service providers, these should be thoroughly reviewed
- Support packages should be reviewed to assess whether additional support is needed to help people with a learning disability move forward out of the



pandemic - especially where their mental and/or physical health has deteriorated during lockdown

- Keeping services for disabled people open should be prioritised in any future lockdowns
- Ensure that information about services and changing regulations is available in Easy Read format, especially where this has not been provided at a national level

Next steps for Sheffield Voices

We are thankful to have the opportunity to capture the voices of our group to use in future work. We want to work with organisations like Healthwatch to make sure these voices are being heard, that the issues the report has found are being addressed through campaigning and/or investigating where appropriate.

We are regularly approached by organisations wishing to ask similar questions to the group. This is often a fleeting visit, with some voices in the group not heard or rushed over. We hope that we can use this piece of work to present in future, in order to ensure that our members' voices are heard.

We have also set up a self-advocacy drama group with funding from the Arts Council and our first play will be about lockdown. We will take the findings from this project as a starting point to present those voices in a creative way. We want to give our group and others from the community a way to express or see their unique experiences on stage.

You can view the original Google Jamboard, where responses from the group are presented in full, online [here](#).