

Speak Out Council

Corona Virus consultation
June 2020

Who are we?

VoiceAbility's Speak Out Council (SOC) is made up of six employees with learning disabilities and/or autism, who work together to give people a say on the issues that are important to them. They do this by running consultations and drop ins with local people, and by talking to professionals and organisations who can make a difference. They are supported by a co-ordinator and a young person's project worker.



The Speak Out Council carries out 4 consultations a year. Each quarter it focusses on a subject that people with a learning disability and/or autism have told them is important in their lives.

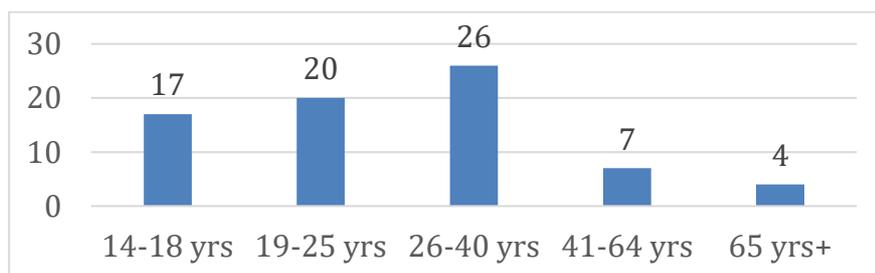
What did we do?

This time we choose to ask people about how they were managing during the Coronavirus lockdown.



During April-June 2020 we heard from:

- a) 40 students (aged between 16 and 24 years old) at Cambridge Regional College (CRC) during their online tutorial sessions
- b) 7 students, and 4 members of staff at Edmund Trust day service (Eddies) during an activity session on Zoom
- c) 8 people who joined our high support needs drop in
- d) 73 people who responded to our on-line survey. The ages here ranged from 14-65 yrs plus, breakdown as shown below.



This is a total of 132 people, but we are aware some people might have spoken to us in person and also completed the on-line survey.

The a), b) and c) sessions were carried out between 1 May and 20 May while Coronavirus lockdown restrictions meant people were only allowed to meet with one other person from outside their household.

The survey d) ran through April, May and early June during which time the Coronavirus lockdown restrictions changed.

What did we find?

Keeping in touch

Many people we spoke to, or who responded to our survey said they have a practical and cost-effective way of keeping in touch online. However:

- some students find using their college laptops expensive
- for two students the only way to get online at all is using their college laptop which can only be used for college work
- a lot of people who use services who do not have any access to the internet*, and
- some people in supported living do not have access to the internet at home



*for instance, we were told about a social club that usually has 30 plus attendees, but only 2 or 3 are able to join online. Lack of access to the internet might be caused by lack of equipment, lack of support to use the equipment, no Wi-Fi or a combination of these.



We have found that there might be a number of reasons that someone does not have access to the internet including:

- no Wi-Fi connection at home
- lack of equipment
- equipment is too difficult to use
- no support to use internet – family, carers, support staff may not have the skills required

During lockdown, when many day services have been shut, it has been particularly difficult for us to reach people who do not have internet access, so our data on the number of people affected is tricky to calculate and it has been difficult to get a true picture. The fact that many day services have been unable to run an online service for their students supports this theory that many people do not have access.

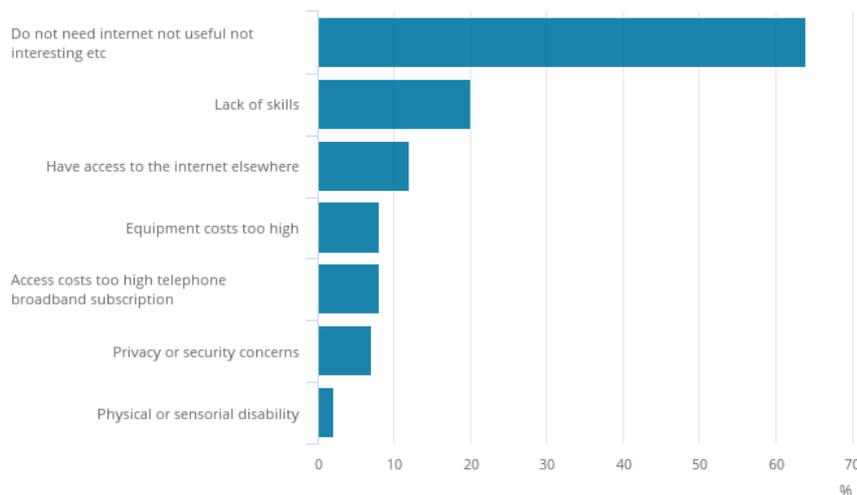
Information from the Office for National Statistics about disabled people and internet use also supports what we have found:

<https://www.ons.gov.uk/peoplepopulationandcommunity/householdcharacteristics/homeinternetandsocialmediausage/articles/exploringtheuksdigitaldivide/2019-03-04#what-is-the-pattern-of-internet-usage-among-disabled-people>

It says that although the proportion of disabled adults who are internet non-users has been declining since 2014 it remains higher than for non-disabled adults

- Among those of working age, the economically inactive are the most likely to be internet non-users, particularly those adults on long-term sick leave or disabled, as might be expected given the patterns among disabled people.
- Although the percentage of households without an internet connection has generally been declining, those who live alone are less likely to have an internet connection at home, than their peers.

Figure 17: The most common reason for not having internet access in the household is a perceived lack of need, followed by a lack of skills



Source: Office for National Statistics - Internet Access, Opinions and Lifestyle Survey (OPN)

- A lack of inclination is particularly prevalent among the older age groups. In 2018, 84% of those over the age of 60 years said that nothing could help them get online. Similarly, 38% of disabled people who are not using the internet reported that. These views may in part reflect a lack of understanding of the benefits, for example, that they may be paying more for some goods and services.
- A higher percentage of disabled people identified security or privacy concerns as a reason (28%) compared with non-disabled people. Almost double the percentage of disabled respondents identified a lack of skills or knowledge as a reason (29%) compared with non-disabled respondents (15%).
- In 2018, 5% of those not using the internet also reported that their disability prevented them from doing so.

The Foundation for People with Learning Disabilities is currently running a survey to find out how people with learning disabilities are using technology:
<https://www.surveymonkey.co.uk/r/TVTBYFQ>



How are you feeling?

How people are feeling

With the 3 groups a), b) and c), we talked through a range of feelings, these included happy, sad, worried, confused and lonely. Most people had experienced a wide range of feelings during the time, for instance:

- Two students said that this situation makes them feel happier as they don't have the stress of going out
- One member of staff in the Eddies group (b) told us that she has found a number of people in supporting living are enjoying a more relax day, and not having to rush out every morning
- One person was experiencing antisocial behaviour at home. She told us that she has found this more stressful as she had to be in her home more often. She told us she is being well supported with this

- When we asked if anyone felt lonely, everyone said they have someone they can talk to
- Where people express anxiety, or depression they also say that they are being well supported by their family, friends and college staff
- One person said that he has found it difficult to adapt, particularly to the change of routine, as he has autism

Of the people taking the online survey (d), most were given information about Covid 19 by their family or carers. A lot heard about it on the News, and some heard from social media, their school/college/day service, the Learning Disability Partnership and Cambridgeshire County Council, or from someone at their work or volunteering role.



Most of those people, 51 out of 71, said they understood the guidance. 17 were not really sure, 1 person didn't understand the rules, and 2 said they did understand the rules at the beginning but they were now confused as things kept changing.

Most of the students (a), many of those at Eddies (b) and people that joined us for our Speak Out Day felt that they had received too much information about Covid 19 and felt overloaded which led to confusion.

I feel a bit worried about different rules for different people
"Lockdown is lockdown"

I feel stressed as I don't like change

I am feeling confused and bored. I am used to being very busy, active and out and about



National press reports from, for example Learning Disability England, reflect some of our findings:

7d ago
10:11

People in England with learning disabilities have called on the government to make its coronavirus guidelines easier to understand, with some “absolutely terrified” they may find themselves on the wrong side of the law.

Learning Disability England is aiming to tackle the problem by facilitating a campaign encouraging user-led activist organisations to pressure the Government into producing different formats of accessible and timely information.

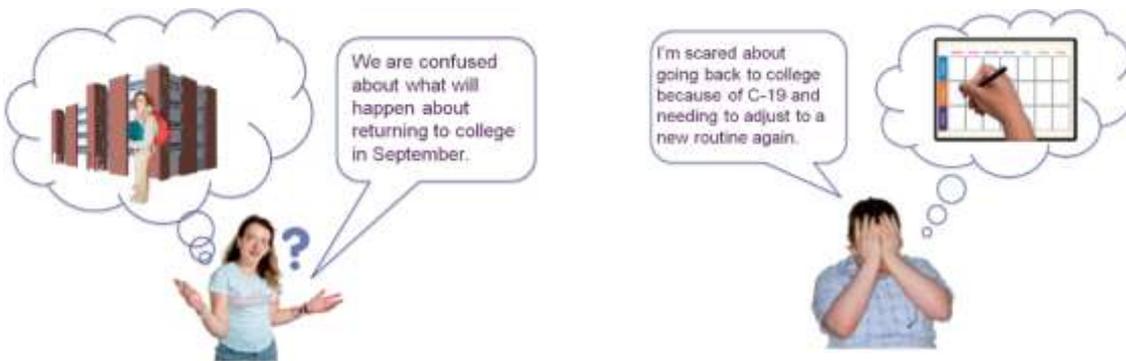
With lockdown restrictions being lifted week by week, clear and prompt guidance for the learning disability community is crucial now more than ever.

“The campaign becomes even more important as we go into a more flexible and nuanced situation,” said Ms Clark.

“When it was just ‘Stay at home’, manage and implement.”

“When it was just ‘Stay at home’, that was tough, but it’s somehow easier to manage and implement.”

The students (a) told us they are still confused about what may happen about returning to college in September. One person talked about being scared about going back to college because of C-19 and needing to adjust to a new routine again. Students also talked about the need for social distancing on buses including college buses when they do return to college.



Activities that people are doing

People across all groups have been doing a range of activities including watching tv, Netflix or YouTube, playing games and apps.



Many of the students in groups (a) and (b), talked about enjoying having more time with their parents and siblings. One person said, 'It feels like I'm on holiday.' 47 of those that responded online are living at home with family, and they were mainly enjoying that too.



Many of the activities students were doing related directly to their chosen course at college, for example the Horticulture tutorial group had been spending time painting fences or cutting grass and the Creative Industries group have been drawing, making films and one young person has been exploring how to advance his art career by working on some digital art for the first time.

41 of those that took the online survey (group d) said they had been contacted by their day service, school or college, although 8 were not sure. 30 of those who had been contacted said they were being given activities to do at home, although 6 were not being given things to do and 2 were not sure.

Do you feel the same as before lockdown? Or worse? Or better? Why is that?

Around half the student group (a) said they are feeling worse: they are missing college, finding it hard not seeing their extended family or going out to see their friends and feeling low and upset when they have nothing to do on non-college days.

Coronavirus makes me feel like I am trapped in a dark hole.



- some young people were feeling disappointed or frustrated by being stuck in a village, unable to do work experience and get a job
- for one young person told us that only having college sessions on one day each week and no work experience on the remaining days is frustrating
- a few people talked about feeling better being at home than college.

27 of 71 people who did the online survey (d), felt worse than before because of missing family and friends, stress caused by the change of routines and uncertainty about when and how things will return to normal. A few people were concerned that progress they had made before lockdown, particularly around mental health, will have been undone, and "the long-term effects of isolation, like severe social anxiety, started rapidly returning". One parent reported feeling "very depressed and worried about the future" for her autistic son.



33 people in this group (d) told us they feel better than before, particularly where they were able to spend more time with their families.



We like spending more time at home and with family



What support and help do you have now?

Most people we spoke to in person (groups a and b) and online (d) did not refer to having paid support but talked about the support they have from their friends and family, and staff at college or their day service. Everyone felt this support is helpful. Several people living with their families said that their support is good or better than before.

One young person lives in supported living and felt they didn't get much support, but it did not seem that this was worse now. We asked what support would be useful, but they didn't know.

It appears those in the high support needs group (d) were getting good support at Aurora Meldreth Manor and/or from their families. But we were surprised that some people in supported living did not have access to the internet and other resources until a family member purchased an Amazon Firestick for those living there to enjoy streaming films etc.

What has been really helpful to you during lockdown?

The students (a) and those at Eddies (b) all talked about their friends and family, college/day service online groups and being able to spend time chatting online.

The high support needs group (d) also really benefitted from a variety of online activities such as playing games, "visiting" exciting places across the world, and experiencing new things such as roller coaster rides! They also enjoyed using the large outdoor space at Meldreth Manor when that was permitted again.

College work and being online with other students has been my lifeline!



Please can you tell us what would make staying home during lockdown feel better for you?

For the students (a), the Eddies group (b) and those who completed our on line survey (d), the main theme was around having clear communication about how and when people would be able to return to normal (college, day services, volunteering etc) along with having more space at home. Many people felt that there wasn't anything else that could help.

The feedback on behalf of those with no online access at the moment (which might be people in day services with no access, or those living at home) is that this would make a big difference because they are missing out on a huge amount of activities and social opportunities on the internet.

One person told us that what is needed is:

“One piece of technology which has all you need on it. But not loads of stuff. It needs to be easy to use – it could for example just have the next 7 days activities at Eddies”.

We completely understand that it would not be as simple as giving someone a device and a Wi-Fi connection as ongoing training and support would be needed to use it. For example, one person we spoke to would need someone to regularly spend time with her and her carer talking through how to use it because her carer does not use the internet or even have a tv!

What do we think this means, and what should change?



Internet access

Some people have been really cut off during isolation

- We think many of them would benefit from having access to the internet
- Staff should have training about using technology and e-safety

What would we like to see?

- We think more people should have the opportunity to use the internet.
- We would like to see cheaper and simpler technology available from a reliable local source
 - We have been talking to local providers who could provide a Raspberry Pi computer for as little as about £50 – 55 with keyboard and mouse etc which would allow someone to use the internet. This particular solution is being taken up by East Cambs District Council predominantly for older people who are isolated.
- People in residential settings should have access to Wi-Fi and have the support to use it
- Support staff should be upskilled where needed
- Day services should provide training and support to help people get online and to help people appreciate what opportunities are available to them
- Other services such as Cambridge Online could be explored to help people with a learning disability get on line

Messages and communication

- People have said they are really confused by Covid-19 messages

What would we like to see?

- We think having clear communication about how and when people can return to normal (school, college, day service, volunteering) would help

We plan to do more work around this between now and September.

Reaching people

- Some people are really hard to reach when they are not at school, college or their day service:
- We would like to be able to hear their view and help them to Speak Up too

Appendix

Here are some useful sources of information if you'd like to find out more.

- Foundation for People with Learning Disabilities www.mentalhealth.org.uk/learning-disabilities
- Joseph Rowntree Foundation www.jrf.org.uk/
- Mencap www.mencap.org.uk/
- National Autistic Society www.ndti.org.uk/resources
- Office of National Statistics www.ons.gov.uk/

To find out more or get in touch

Email: Speakoutcouncil@voiceability.org

Call or text: 0786 700 2124

Visit: www.voiceability.org

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