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Locked in or locked out

Redistributing power to d/Deaf and Disabled people when using remote technologies

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**Introduction**

The early months of the COVID-19 pandemic saw the world locked down. Unable to leave their homes for work, school, or doctor’s appointments, people flocked to remote technologies to keep in touch and keep on top of the meetings they were meant to have in person.

Zoom had 200 million daily users worldwide in March 2020, up from 10 million in December 2019 (Evans, 2020), including more than 100,000 schools across the globe (The Guardian, 2020). Google Meet’s user base grew by more than 30 times in the same period (Barrett, 2020). Primary care services in the UK, which prior to the pandemic fielded 1.2 million face-to-face consultations a day, swiftly moved to online and telephone appointments: by April 12, NHS GPs were seeing only seven in every 100 patients face-to-face (Lynch and Wainwright, 2020).

During this time, members of Shaping Our Lives (https://www.shapingourlives.org.uk/), our national organisation and network of user-led groups, service users, and Disabled people, began telling us that they were concerned about the sudden adoption of these remote technologies for a wide range of activities. These included social and leisure activities, peer groups, and support activities, community services, education, work activities, and, of particular relevance to this publication, the provision of health and social care services. Our members were particularly concerned about people they
worked with who could not use these technologies, or did not know how to do so.

In June, Shaping Our Lives was awarded a grant by the National Lottery Community Fund to carry out research into the impacts of COVID-19 on d/Deaf and Disabled people. With this support, we put together a survey investigating how d/Deaf and Disabled people in the United Kingdom were adjusting to the new ubiquity of these remote technologies, and what could be done to ensure they were supported and involved in decision-making when it came to this new way of working.

We surveyed people about three different types of remote technology: telephone calls, video calls, and video meeting solutions such as Zoom and Microsoft Teams. We received 90 responses. Those responses formed the backbone of our resulting report, *Locked In or Locked Out: d/Deaf and Disabled people’s experiences of using remote technologies during COVID-19.*

We found a lot of variety in the experiences with remote technologies that d/Deaf and Disabled people were reporting, for a variety of reasons. These reasons included the nature of each person’s impairments and long-term health conditions; their geographic location, and how that impacted the quality of their internet and telephone reception; their employment status, and their social and economic status; and the opportunities available to them to practise and receive training in these technologies.

Around one in ten survey participants (approximately 12 people in total) were more than comfortable with all three types of remote technology. A further one in ten participants felt that all three types were completely inaccessible to them. The remaining participants, around four fifths of those who responded, reported that they found some positives and some challenges in this new way of communicating and accessing services.
Using the telephone

Of the survey participants who had used telephone calls for social activities, meetings, or appointments, two fifths (36 people) were doing so for the first time during the first lockdown. Just under two thirds of participants (57 people) used the telephone to talk with a health or social care professional.

Participants indicated that there were a number of benefits to using the telephone for meetings and appointments, especially appointments with health or social care professionals:

- It saves me the effort of having to travel to meetings, etc. As a wheelchair user, getting in and out of my car and dealing with access issues is time-consuming and physically tiring.

- As an autistic person, not having the pressure of face-to-face meetings (including the issues of travel to get there, etc.) was a benefit in general.

- [It] reduced the need to travel for routine ‘check in’ appointments.

However, one in ten participants (11 people) told us that telephones were not accessible for them and that they needed assistance when using them:

- I like to keep in touch with people but need an assistant to help make the call.

- Not able to understand fully the conversation. Had to end a call and requested a call back at another time when help is in the house.

Others felt the telephone was inappropriate for meetings with health and social care professionals for other reasons, such as the lack of a visual connection or the risk of a poor connection:
It was better than having no contact with my mental health team but it was impossible to go into in-depth issues the way we might face-to-face.

It felt rushed, so I didn’t open up and tell the professional everything that I usually would have. I felt less connected to them, like the trust wasn’t there.

**Using video call technology**

Of the participants who used video call applications like WhatsApp and FaceTime, one third (28 people) used them for the first time during lockdown. A large number of those participants said they had positive experiences using them for their appointments and meetings. Several participants commented on the access benefits:

For friends and family video call is better than the phone as I can use lip reading to help … For work-related meetings the same applies re lip reading and it’s easier to see who is talking than on a group conference telephone call.

Professionally, it’s been a good experience and allowed me to stay home and reduce anxiety of infection. It’s also given more structure to meetings (enforced turn-taking, raising hands to speak, etc.), which is an autism-friendly way of conducting a meeting.

Fewer people used video calls for appointments with health and social care professionals than used the telephone. Those who did were, on balance, more likely to have a bad experience than those who used video calls to talk with other groups, such as community volunteers, or employers. That said, only a small number who used a video call to talk with a health or social care professional had a bad experience – four out of 21 people total.
Those people who had negative experiences often commented on the physical and technological barriers to access:

I find FaceTime and WhatsApp calls exhausting and anxiety-inducing and would always prefer just to talk on the phone.

It was really bad. I was sent the link ten minutes before meeting started. Then call started, picture froze, the internet dropped, it took 30 minutes the appointment was only due to last 60 minutes. By the time all the technical issues was sorted out. I was so upset as during my appointment different people were on my video call talking to the doctor.

For meetings with NHS workers I would much prefer video to phone but the technology never worked at their end.

**Using video meeting technology**

Of the participants who used video meeting solutions such as Zoom, Google Meet, and Microsoft Teams, just over half (42 people) told us that they used those solutions for the first time during the first lockdown. Many found this technology to be a great way to communicate remotely:

Ability to see faces, interact on a more personal level, and include more than one other person. If an in-person appointment is not feasible, I find this the next best option for meetings and consultations.

With a speech impairment it is much easier than phone calls.

Using video meeting technology to talk with health and social care professionals, participants reported more positive experiences than negative. However, more participants still used the telephone for those appointments.
A small number of participants (12 people) said that video meetings were not accessible for them. The physical and technological barriers they experienced were quite similar to the barriers that participants reported with video calls:

Subtitles slow and often incorrect.

I find video calls extremely difficult – exhausting, anxiety-inducing, confusing, and not very useful as I am rarely able to say what I need to say and I rarely fully grasp what is going on during the meeting or remember afterwards what has been said.

It was great providing the connection was stable – I pay extra for fibre optic – but even then there were issues with the screen freezing or the connection dropping – it meant that conversations had to be repeated and that was tiring.

We asked participants about the additional functions available in video meeting solutions, including text chat, breakout rooms, and on-screen document sharing. Of those who answered, one in three (17 people) said they had experienced difficulties or had only found these functions accessible once they had learned how to use them:

It was difficult to read shared presentations at a focus group I attended on Zoom. They were small and apparently screen readers don’t read them either as they see them as images.

I found these facilities accessible but I was aware that they were not accessible to everyone participating in the online workshop I facilitated and I know that other people I have worked alongside regularly have been unable to participate in meetings because support around accessibility has not been available to them.
Redistributing power

Our research found that for d/Deaf and Disabled people there were a number of positives in the sudden popularity of remote technologies. They saved time and energy, helped people avoid the stress of travel, and enabled them to meet others and safely attend appointments. For many, these technologies provided greater access to activities and opportunities and helped them keep in touch with friends and family during a difficult period of social isolation.

However, these technologies do not provide a like-for-like replacement for face-to-face contact, and more needs to be done to reduce the barriers to access. There are a number of steps that health and social care professionals in particular can take to redistribute power to d/Deaf and Disabled people when using these remote technologies.

Health and social care professionals should establish the preferred method of communication in advance, and be prepared to offer service users a choice of different communication options. Some Disabled people may have equipment for a video meeting but not for a phone call; others may not have access to a reliable internet connection, making video calls or meetings inappropriate.

Health and social care professionals should check with the service user about their access requirements well in advance of their appointment. Once those requirements have been ascertained, make the adjustments required to meet them. For example, provide subtitles for video meetings, include a free or standard-cost dial-in number if the service user doesn’t have a reliable internet connection, and allow for breaks if a meeting is going to run long.

If contact can only be made through a specific technology, health and social care professionals should make sure the service user has the equipment they need for access: up-to-date headsets, iPad stands, reliable internet connections, and so forth. If they don’t, the professional should research what support is available to the service user through community and voluntary sector services.

If the service user needs training to use the technology, they should be provided with accessible information and
offered separate practice sessions. If the service user needs a support worker to help them, the appointment should be scheduled for when the support worker is available.

Health and social care professionals should maintain guidelines on accessible use and inclusive practice, and these should include the use of remote technologies. Professionals should also maintain standards for use of those technologies that can be applied to all appointments and interactions. These guidelines should include information about consulting with participants in advance and redistributing power to the service user.

Remote technologies cannot wholly replace face-to-face interactions. They can be good for some kinds of meeting and wholly inadequate for others. With that in mind, it is vital that health and social care professionals use these technologies in a mindful and accessible way, prioritising the full and equal participation of all parties. If you plan on replacing a face-to-face activity or service with one that uses remote technology, first consult with the Disabled people who are affected, and redistribute the decision-making power to them.

What needs to be done

• Treat remote meetings in the same way you would face-to-face meetings: establish clear guidelines and standards for the accessible use of remote technologies.
• Patient/user choice must be prioritised: establish the preferred mode of communication in advance, and make adjustments based on the service user’s accessibility needs.
• Plan appointments well in advance and provide service users with training in the relevant technology.
• Ensure that the patient has the equipment they need in order to use the remote technology in question.

resources/our-resources/research-reports/locked-in-or-locked-out-report-from-our-covid-19-remote-technology-research-project

References


