It’s not all doom and gloom: what the pandemic has taught us about digitally inclusive practices that support people with learning disabilities to access and use technologies.

How to cite:

Seale, Jane (2022). It’s not all doom and gloom: what the pandemic has taught us about digitally inclusive practices that support people with learning disabilities to access and use technologies. British Journal of Learning Disabilities (Early access).

© 2022 Jane Seale

https://creativecommons.org/licenses/by-nc-nd/4.0/

Link(s) to article on publisher’s website:
http://dx.doi.org/doi:10.1111/bld.12497

Copyright and Moral Rights for the articles on this site are retained by the individual authors and/or other copyright owners. For more information on Open Research Online’s data policy on reuse of materials please consult the policies page.
It's not all doom and gloom: What the pandemic has taught us about digitally inclusive practices that support people with learning disabilities to access and use technologies

Jane Seale

Faculty of Wellness, Education and Language Studies, the Open University, Milton Keynes, UK

Correspondence
Jane Seale, Faculty of Wellness, Education and Language Studies, the Open University, Walton Hall, Milton Keynes MK7 6AA, UK. Email: jane.seale@open.ac.uk

Funding information
The Open University

Abstract

Background: The aim of this study was to examine whether and how people with learning disabilities were being supported to use technologies to keep connected and stay well during the pandemic.

Methods: Thirty-eight people in a range of support roles were interviewed about their experiences of trying to support people with learning disabilities to use technologies during the pandemic with a particular focus on the difficulties experienced by learning disabilities and the practices that supporters developed to try to overcome these difficulties.

Findings: Findings revealed examples of digital exclusion, where people with learning disabilities were not able to use technology. The three main barriers to digital inclusion were cost, access and environment. The findings also revealed examples of digital inclusion, where those in support roles worked to overcome these barriers. These digitally inclusive support practices can be characterised as 'possibility focused'. Possibility focused support has four key components: creativity, resilience, risk-management and shared decision-making.

Conclusion: The pandemic has shown us that it is important to support people with learning disabilities to use technologies. It is important that we learn from the experiences of those supporters who helped people with learning disabilities access and use technologies during the pandemic, so that digitally inclusive support practices is shared more widely and more people with learning disabilities are supported to be digitally included beyond the pandemic.

KEYWORDS
learning disabilities, pandemic, support, technology

Accessible summary
• During the pandemic when we had to stay at home, being able to use technology to keep connected with friends and family was very important.
I wanted to find out if people with learning disabilities were getting the support they needed to use technology during the pandemic.

I asked 38 ‘supporters’ about their experiences of trying to help people with learning disabilities use technology during the pandemic.

I found that there were three main barriers to using technology: cost, access and environment.

I also found examples where ‘supporters’ had been able to help people with learning disabilities overcome these barriers and use technologies.

1 | INTRODUCTION

There is a long and widely held view that technology has the potential to improve the lives of people with learning disabilities. Before 2000, this potential was mainly understood in the context of education. Education, health and social care professionals investigated using computers and associated games and software to teach basic literacy skills and to improve communication and social skills. Over time, with advances in technology and a move towards ‘Care in the Community’, professionals broadened their interest in the role of technologies to include supporting independent living skills such as shopping enabling independent travel and wayfiding offering vocational training and providing healthcare services (Seale, 2014, 2022) It is important to note however, that when people with learning disabilities talk about why technology is important to them, they tend to highlight other reasons for using technology such as engaging in leisure pursuits, making friends and finding partners (Lofgren-Martenson, 2008; Martin et al., 2021). Despite the differences in perspectives between professionals and people with learning disabilities, both groups appear to agree that technology can potentially be a good thing, that it can open up many possibilities and opportunities for people with learning disabilities to be digitally included and live the lives they want to live (Lussier-Desrochers et al., 2018).

Although technology has the potential to facilitate positive experiences and outcomes for people with learning disabilities, many people with learning disabilities are not experiencing these benefits, they are therefore digitally excluded (Normand et al., 2016; Seale & Chadwick, 2017). The aim of the study reported in this paper is to explore whether people with learning disabilities are experiencing these benefits, they are therefore digitally excluded (Normand et al., 2016; Seale & Chadwick, 2017). The aim of the study reported in this paper is to explore whether people with learning disabilities continue to be digitally excluded during the pandemic and whether and how they were supported to become digitally included.

2 | LITERATURE REVIEW

In this section I will provide an overview of what is currently known about the digital exclusion of people with learning disabilities both before and during the pandemic.

The most commonly talked about cause of digital exclusion for people with learning disabilities is a lack of access (Ågren et al., 2020; Owuor et al., 2017). This lack of access can be experienced by people with learning disabilities in a number of ways:

- COST: Not being able to afford to buy the technologies (Sallafranque-St-Louis & Normand, 2017)
- PROVISION: Not being assessed by education, health and social care services as requiring technology, so it is not provided (Tanis et al., 2012)
- INACCESSIBILITY: The technology is too difficult to use because it has not been designed with their needs in mind (Williams & Hennig, 2015).
- SUPPORT: Not being assisted to use technology by those in support roles such as parents and care workers (Ramsten et al., 2019).

During the pandemic, and in particular periods of government imposed ‘lock-downs’ Internet-enabled devices such as personal computers, laptops, tablets, and Smartphones have enabled us to use applications such as email, Zoom, Facebook and WhatsApp became essential tools to enable communication with others, access to information or services and opportunities to engage in leisure, educational and therapeutic activities. However, given that many people with learning disabilities were digitally excluded before the pandemic, an obvious assumption to make is that they would not be supported to access and use technologies during the pandemic. Indeed, some studies which were trying to understand the overall impact of the pandemic on people with learning disabilities did reveal useful insights regarding digital inclusion and exclusion. For example, in a Canadian study Lake et al. (2021) interviewed nine adults with learning disabilities about their well-being and mental healthcare experiences during the pandemic. The interviewees shared how they felt isolated from friends and family and how using technology helped them access support. Cost however was a significant barrier for some of the participants. Flynn et al. (2021) surveyed people with learning disabilities and family carers or paid support staff about their experiences and revealed some interesting findings relating to access. For example, results from cohort two (parents and carers of people with learning disabilities who were unable to be interviewed themselves, including those with profound and multiple learning disabilities)
revealed that just 37% had a device that they could access the Internet on, with or without support. Araten-Bergman and Shpigelman (2021) reported on how family caregivers in Israel relied on technologies to interact with and support their relatives with learning disabilities residing in supported accommodation during the pandemic. The caregivers expressed a desire for more support from ‘frontline staff’ to use technologies.

Whilst barriers to digital inclusion still existed during the pandemic, some people with learning disabilities were able to access and use technologies. For example, in 2020 a group of people with learning disabilities and their support workers wrote a book called Peter & Friends Talk About Covid-19 And Having a Learning Disability And/or Autism. The book was not just about technology, but Peter and his friends did share examples of how they had used technology to create and host a quiz on Zoom, hold trustee meetings online, film lock-down experiences and put them on YouTube.¹ Examples like this raise important questions around why some people with learning disabilities were able to access and use technology during the pandemic and some were not. This understanding is missing from other research studies that were conducted during the pandemic. In this paper I will report on a study that sought to explore this issue in more detail by examining whether people with learning disabilities were being supported to use technologies during the pandemic and if they were being supported, how those in support roles were helping to overcome access-related barriers.

3 | METHODS

The key questions that this study wanted to address were:

- What were the barriers to digital inclusion during the pandemic that people with learning disabilities and their supporters experienced?
- How were those in support roles helping people with learning disabilities to overcome these barriers?
- What are the key characteristics of these digitally inclusive support practices?

To answer these research questions two groups of people who supported people with learning disabilities were interviewed about their role and experiences during the pandemic. The first group were members of self-advocacy organisations, both staff and people with learning disabilities, who were trying to respond to the needs of their members during the pandemic, focusing particularly on their wellbeing. As many people with learning disabilities were shielding, it was anticipated that self-advocacy organisations would be delivering most of their services remotely, necessitating the use of technology.

The second group comprised of people who had informal or formal support roles and included parents, siblings, education, health and social care professionals, day service and supported living providers and advocacy organisations.

3.1 | Participant recruitment

The study used two strategies to recruit participants from the two target groups. First, members of self-advocacy groups who were known to the researchers through their networks were contacted directly via email and invited to participate in the study. For the second group, supporters who had responded to an online questionnaire were invited to take part in a follow up interview (the results of the questionnaire are reported in a separate study, see Seale, 2020). Overall, 38 participants agreed to be interviewed.

The largest groups of interviewees were members of self-advocacy organisations (see Table 1). The majority of participants were based in England. In reporting the results I will use extracted quotes from the interviews and use the codes noted in Table 1 to indicate the relevant stakeholder group. I will foreground in particular quotes from people with learning disabilities who were interviewed as members of self-advocacy groups.

3.2 | Data collection and analysis

The interviews took place between July and September 2020 and were conducted remotely using a variety of video-conference technologies such as WhatsApp, Skype, and Microsoft Teams. All interviews were audio-recorded and transcribed.

For both groups the interviews were semi-structured in nature. The interview questions sought to find out about what technologies were being used, the different purposes that technologies were being

<table>
<thead>
<tr>
<th>Role</th>
<th>Frequency</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent</td>
<td>3</td>
<td>PAR</td>
</tr>
<tr>
<td>Service provider- day services, e.g., art and other activities</td>
<td>4</td>
<td>SP</td>
</tr>
<tr>
<td>Advocacy organisation</td>
<td>4</td>
<td>AD</td>
</tr>
<tr>
<td>Support organisation</td>
<td>4</td>
<td>SUPP</td>
</tr>
<tr>
<td>Self-advocacy organisation</td>
<td>13</td>
<td>SA</td>
</tr>
<tr>
<td>Sibling</td>
<td>2</td>
<td>SIB</td>
</tr>
<tr>
<td>Education professional</td>
<td>3</td>
<td>EP</td>
</tr>
<tr>
<td>Health professional</td>
<td>2</td>
<td>HCP</td>
</tr>
<tr>
<td>Social care professional</td>
<td>1</td>
<td>SCP</td>
</tr>
<tr>
<td>Learning disability charity</td>
<td>1</td>
<td>CHAR</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>Other</td>
</tr>
</tbody>
</table>
used for, the impact of this use on people with learning disabilities, perceptions regarding whether the use of technology had been successful and the factors that contributed to the success or failure of technology use.

A thematic analysis of the data was conducted. Four members of the research team individually identified potential core themes across all the interviews and then a set of four core themes was collectively agreed: Technology Use, Good Support, Problematic Support, Digital Exclusion and Digital Inclusion.

3.3 | Ethics

Ethical approval to conduct the study was obtained from the Human Research Ethics Committee of the Open University. Key ethical issues addressed in the protocol related to informed consent, anonymity and safeguarding. Easy read versions of the information sheets and consent forms were made available to participants with learning disabilities and, where appropriate, support workers facilitated the processing of the information and articulation of consent.

4 | FINDINGS

In this section I will draw on the analysis of interview data to examine what we can learn from the experiences of ‘supporters’ regarding the barriers to digital inclusion during the pandemic and the characteristics of emergent support practices that sought to overcome these barriers.

4.1 | What were the barriers to digital inclusion during the pandemic that people with learning disabilities and their supporters experienced?

Analysis of the interviews revealed that whilst some people with learning disabilities were able to use technologies during the early phase of the pandemic in 2020, others were not. Sometimes people with learning disabilities were digitally excluded because they did not know how to use technology or because they were not interested in using technology (see Seale, 2020, for more detail). I will not present examples of this kind of digital exclusion here because I wish to focus instead on the barriers to digital inclusion that are more related to what support workers and support organisations know or do rather than what people with learning disabilities know or do. With this in mind, three main systemic or structural barriers to the digital inclusion of people with learning disabilities were identified:

1. Cost related barriers
2. Access related barriers
3. Environment related barriers.

4.1.1 | Cost related barriers

The most common affordability issues reported by participants were related to Smartphone contracts, Internet and wi-fi service provision and the cost of affording the data required to use data-heavy Apps such as Zoom:

So if you're just using a normal phone plan, then doing a Zoom call like this probably is getting on for 1GB of data, which is a lot. So if you don't have Wi-Fi, it's a problem, and obviously having Wi-Fi is quite expensive as a monthly charge for people. So I go back to what I said before, it's brilliant for the people that have got it, but [there are] lots and lots of people who don't have it, that can't afford it (SA5).

Sometimes people refused to use technology because they were scared of getting into debt:

Some people that just won't do it, are not persuaded. Don't want to be paying for, what's the word, paying for the internet every month. I think that's an obstacle to some people. One person I know who rings most days won't go online. He's had problems with debt in the past, so I think he's scared of committing to something and ending up in debt again (SA1).

Interviewees felt strongly that not accessing technology because of cost issues was preventing some people with learning disabilities from participating in potentially beneficial activities or putting them at risk of being excluded from ‘digital by default’ public services:

For me the other issue is cost for people as well. A lot of them have smart phones but they don't necessarily have a good Internet package. There are lots of things like that, where people can't afford it [...] he just didn't have the Internet. He couldn't afford the Internet, so he immediately gets bounced out of services before he even gets a foot in the door (AD4).

4.1.2 | Access related barriers

Experiences shared by participants revealed a complex picture of access to devices. Some people with learning disabilities had devices, but they were not the most up-to-date devices and therefore did not support current practices, such as using Zoom to communicate with friends and family:

Most of our members prefer to use a telephone [...] a lot of our members are older and I don't know whether it's an age thing, they're not that, they're quite resistant to it (SA3).
Others had devices but could not use them due to lack of Internet access or knowledgeable support:

We have had a range of barriers, some of them are like the fact that someone has got a tablet, but they haven't got Wi-fi. Sometimes they have got kit but the family don't know how to use it, so the customer can't access it. Some residential homes, staff aren't that familiar or they have only got kit that staff can use or they are anxious about using Zoom (SP2).

Others did not have any kind of access:

So we've got people who don't use Zoom or technology or digital (SA4).

Participants reported three kinds of problems with access to the Internet. The first related to problems with broadband speeds:

There are the normal problems, like maybe connectivity issues - broadband speeds or whatever [...] Yes, one of our members bless her. She plays the violin and she did a performance for us on Zoom, but the connection wasn't great. And I said to her: oh can I record it. And I recorded it. But it was distorting so much, I said Oh it's not any good I am afraid. So yes, she had problems (AD1).

The second problem related to a lack of reliable connection, particularly in rural areas:

My area in particular to be honest- nobody has the Internet, for some reason loads of people don't have the Internet (SA2).

The third problem related to situations where the whole home had not been connected to the Internet or the wi-fi signal did not reach to the space in the home that the person with a learning disability occupied:

Lots of our self-advocates don't have any internet in their homes, residential homes or care homes, which can mean those people could be isolated (SA8).

They've got internet in her house but she can't get internet access in her room [...] it's a bungalow, it's got quite a large floor area. It doesn't extend. They've been asked to look into doing it but none of the bedrooms seem to be able to get reliable internet connection which isn't a good thing (SIB1).

Participants reported three kinds of accessibility issues. First, some people with learning disabilities found mobile phones difficult to use because the screen was too small for them to see or because they were unable to hold it:

For the chap who had the mental health problems all of the referrals that we made came back to an online application, which he couldn't do. He had a small mobile phone, but his literacy isn't great. He is trying to fill in forms on a small [screen]. It just didn't work (AD4).

Second, some participants reported difficulties with logging onto accounts for Apps such as Facebook, Google, Play Store or Zoom:

I tell you another big one is, what I have found, when people have got Smartphones or tablets but then they don't have the passwords for the device. So they might have a Smartphone and you say can you download the Zoom App or the WhatsApp app and then they come into problems because they don't have the password for the Play Store where they download the App from. I think sometimes they get set up by organisations that support them. But it's like, who has that information, where is that information held? And is it accessible for them? Can they get hold of it if they want to? (SA2).

Third, participants reported that some people with learning disabilities became quite stressed or anxious when the technology did not work as they expected, which resulted in them refusing to use technology again:

You've had that knock-on effect of people getting very anxious and stressed about the technology not working and then feeling like they're missing out, or that they're letting us down. And we're like that's not your fault, that's technology's fault. But then obviously you can understand that it's had a knock-on effect in that it's then made them anxious, stressed, and then not wanting to do the next one (SA13).

4.1.3 Environment related barriers

Many people with learning disabilities do not reside in family homes. Instead they live in homes provided by local authorities or private health and social care companies. Participants identified two specific issues relating to the home environment provided for adults with learning disabilities by these service providers: (1) access to technology is not provided or prioritised by service providers; (2) access to support staff with the skills and attitudes required to support technology use is not provided or prioritised by service providers.
One issue that participants frequently mentioned was that many care and residential homes did not have technology or all the components required to enable residents to get online and stay reliably connected:

There is one home where they were trying to sort out Wi-fi and they have got the maintenance team coming in but they have not worked out how to cure all the bits that don’t work and they haven’t got the booster (SP2).

Right, so there are two people in the group who have not been able to [...] And the other person lives in a residential care home and they used to have a computer and then they got rid of it because nobody used it (SA11).

Perversely, some participants shared examples of how, in some homes, whilst technology was present, it had been provided for staff use only, to enable them to undertake their administrative tasks:

I think in some places people just don’t have access to the internet. It’s there for the staff and nobody else (SA1).

Examples were also shared of how people with learning disabilities needed to seek permission to use these staff computers or computers in communal areas:

So all the communal computers, they have to get permission and they have to get help to set it up. And sometimes that is quite difficult, because the staff aren’t always about. So that’s really difficult for lots of people because staff could be busy or not got time or whatever and so they lose out because of not connecting to a computer, which is really sad. It is really sad (SA8).

In some organisations, information security and safeguarding policies prevented staff from using their work or personal technologies with people with learning disabilities:

It's been really, really challenging, because we probably have oh, a handful of people who don't have access to any sort of technology. So we are reliant on parents and carers. Then there are lots of issues around some carers. Their organisations issue them with work phones and then there is issues around what apps they are allowed on their work phones. There are some carers who don't have work phones, some have got personal laptops or tablets; others won't do that because there are privacy issues around that. It has just been really complicated (SP3).

4.2 | How were those in support roles helping people with learning disabilities to overcome barriers to digital inclusion?

In the previous section, examples of how people with learning disabilities experienced digital exclusion during the early phase of the pandemic were shared. In some ways this picture of ‘doom of gloom’ is not surprising because we know that many people with learning disabilities were digitally excluded before the pandemic. However, analysis of the interviews did also reveal a more positive picture. Many interviewees shared their experiences of how they tried to overcome the barriers to digital inclusion. In this section, I will present examples of how support workers and organisations worked to overcome cost-related, access-related and environment related barriers.

4.2.1 | Examples of how support workers and organisations worked to overcome cost-related barriers

Many of the participants shared examples of how they had tried to overcome cost-related barriers. Parents and siblings would either purchase the technology for the person with a learning disability or support them to source and fund the purchase from their own money (e.g., benefits). Many support organisations began systematically identifying sources of external funding and writing grant applications for the funds to purchase technologies such as tablets and smartphones to people with learning disabilities. The sources of funding were varied and included charities, and local authorities. The experience of bidding for funds to provide technology to people with learning disabilities during the pandemic prompted many of these organisations to commit to try to sustain funding sources beyond the pandemic:

[.] our director's making a bid for funding to look into digital access for people with learning disabilities as a result of doing this whole lockdown thing, because it's something that we see as a big problem. So even if we're coming out of COVID moving forwards, we're going to be looking at this issue and trying to work out how we can get more people online [...]. (SA5)

4.2.2 | Examples of how support workers and organisations worked to overcome access-related barriers

Many of the participants that I interviewed were providing remote support to people with learning disabilities which often meant having to contact care providers or technology providers on behalf of the person with a learning disability to try and negotiate access to technology. Sometimes this was successful, sometimes it was not:
And I phoned up one care home company a couple of months ago now [...] And that was an eye opener because we’d had so much success with some supporters and I phoned up and spoke to some young guy who said, ‘Well I can’t really get them online because our computer’s really old, it’s got no webcam and they wouldn’t understand anyway, because they’re from a different time.’ And I was like ‘oh come on!’ [...] but I just said, ‘well really, surely it would make your job far more satisfying if you could do it and you could support somebody to do it, it’ll be good for all’. But we didn’t get anywhere (SA6).

Sometimes the support worker or organisation were able to provide direct help by donating old technologies that had been refurbished and creating easy- to-follow- instructions on how to use the technology:

One of the things, one of the massive barriers that we know affects people with a learning disability [...] is the lack of, not everyone has access to a smartphone or a computer or wi-fi. So one of the things that [name of organisation] are involved in is a project to refurbish and donate laptops and smartphones to people who don’t necessarily have that technology. There’ll be some joining instructions, there’ll be how to set it up, how to do, they come with a dongle, whatever that means (SA13).

4.2.3 | Examples of how support workers and organisations worked to overcome home or environment -related barriers:

In the United Kingdom there is no law or policy that mandates that care and residential settings provide access to technology for adults with learning disabilities over the age of 25. It is significant therefore that some parents, siblings and support workers did share in their interviews examples where supported living homes had put in place policies, practices and procedures that enabled people with learning disabilities to access technologies. For example, one support worker in a supported living home shared how the organisation they worked for provided a laptop, a mobile phone and access to an online chat facility called Yammer to every home. Staff in the home were permitted to enable the residents with learning disabilities to use these technologies if they needed to:

[...] every team had a netbook or a laptop and a team phone [...] The reason it started was because some people don’t have their own smartphones or laptops at home to access their emails and things like that. So it was about keeping people connected. And if there were team meetings, they could be minuted. […]

Basiclly, it is for the people that we work for to use. [...] Most people would prefer to have their own if they can afford it, but if they can't, then it’s there to use as long as they use it appropriately. At (name of the organisation) people are encouraged (to use technology) because it is a skill, and it shouldn’t just be for people who are employed to have. It should be for everyone to have that skill if its available (SUPP1).

4.3 | What are the key characteristics of digitally inclusive support practices?

Before the pandemic, several research studies had tried to understand why those in support roles were not helping people with learning disabilities to access and use technologies. Findings indicated that the most common reason is that they perceive people with learning disabilities to be vulnerable and in need of protecting particularly in relation to the risks of using the Internet. They therefore take-on a protective or gate-keeping role (Chiner et al., 2017; Ramsten et al., 2019; Sorbring et al., 2017). Sometimes this role leads them to restrict access to technology and undermine the skill development and agency of people with learning disabilities (D. D. Chadwick, 2019). The tendency towards an over-protective and risk averse approach to support led me to argue that support workers need to adopt a positive risk-taking approach to supporting people with learning disabilities to access and use technologies (Seale, 2014). In later work, I renamed this approach ‘possibility-focused’ support and proposed that the key components of possibility-focused support are creativity, risk management, shared decision-making and resilience (Seale, 2022). In examining how supporters have tried to overcome barriers to digital inclusion during the pandemic, I found many examples of creativity, risk management, shared decision-making and resilience. In this section I will define each component and illustrate with examples drawn from the interviews.

4.3.1 | Examples of creativity in digitally inclusive support practices

In the context of supporting access to technology, creative ‘possibility-focused’ support practice involves identifying possibilities for positive outcomes as a result of technology use; refusing to give up when circumstances seem impossible or using imagination to solve the ‘problem’ of how the risks related to using a particular technology can be managed to maximise the possibilities for a positive outcome. From the interviews it was clear that many supporters who were trying to enable people with learning disabilities to access technologies during the pandemic refused to be deterred by resistance or obstacles:
Some people it’s taken weeks and weeks of just persevering (SA6).
So it’s a bit of a slow painful process, so I’m going there and I’m meeting them in their gardens or out the front, so I keep the social distancing, wearing masks, trying to explain what buttons to press, so they can access, so we can get more and more people online, talking to us on Zoom, being with the outside world. And socialising! So um, and it was really good, we have regular meetings now, on a Tuesday afternoon, and a Thursday afternoon (AD3).

In refusing to give up, many explored the possibility of doing something new, even though it appeared to be impossible:

We actually went out and we got some funding to actually go and buy some tablets as well for members. And a member of staff actually guided them through the help to set it all up there and use it. Which is good, so they can take part in all the activities. Because we thought it would be good for them to learn new technology, and we will continue using this once the pandemic is finished. We thought it was a good investment (SA7).

[x] was completely isolated because she didn’t have any internet or anything. So in the end we just, we asked, we talked to her support and said can you sort out an iPad or a phone even, or anything? Didn’t really get too far with that, so in the end we found an old one in the office and [...] went up, drove outside and set it up for her and left that with her. Got her some mobile data on it or whatever that could be used. And yes, but now she can join meetings (SA6).

4.3.2 | Examples of risk management in digitally inclusive support practices

Risk management involves putting in place strategies that attempt to mitigate the risks of technology use, in the hope that there will be positive outcomes. Risk is understood broadly as the possibility of digital exclusion, the possibility of failing to achieve a goal, or the possibility of a negative experience (e.g., online abuse, or technical difficulties). Data from this study suggests that digitally inclusive support practices during the pandemic were focused on adopting ‘protective strategies’ that attempted to balance both the risks and opportunities of accessing technologies:

But like I say when it came to it, it was about weighing up the benefits of, the risk of actually, we put all the security things in place we could with Zoom and thought we’re not, we can shut a meeting down if somebody Zoom bombs us and stuff like that. We have all that in place, all that sort of stuff. And we just figured that it actually was, it was better worth the risk than excluding people again because they couldn’t fathom a different platform (SA11).

The issue being about if you’re then sending a piece of equipment to a residential home, and how safe and secure is that? If it’s in someone’s home, their own home with their family it’s more secure, isn’t it? [...] you’ve got to balance up haven’t you, about how do you manage that [...] So it’s about prioritising where we go, so it’s not simple is it, technology (SA8).

4.3.3 | Examples of shared decision-making in digitally inclusive support practice

Shared decision-making is a process that takes place between people with learning disabilities and their support workers in which both the potential positive and negative outcomes of technology use are considered. Participants in this study shared how sometimes a ‘supporter’ made a suggestion regarding technology use and then built-in time for the person with a learning disability to consider the suggestion and agree or disagree with it.

I have actually been running a couple of Zoom meetings- self-advocacy meetings. That has been with one group [...] They have been really on-board with interacting over technology, which has been fantastic. [...] I think it was do with, they are kind of isolated. So they are in a community, a residential home. They are quite isolated, and they have been finding being part of self-advocacy group really, really good in lots of ways. So when we suggested meeting up on Zoom, I think straight away they were on the ball with it. They have got somebody there as well, someone from a community-based charity who works within their village and she was really on-board with it, so I think that really helped (SA2).

Other times, a person with a learning disability made a suggestion or a request which prompted a discussion or response from the support worker:

What we started to do, we thought about how we could contact people [...] So I rang up everybody and asked them if they would like me to ring them on a regular basis or if they wanted me to write to them. So I asked them, what they would want. A few of them said: could we not have chats via WhatsApp?
They wanted to see each other as well. So those who wanted me to, I still do, I ring around every week. Those who didn’t, we started a WhatsApp group (AD2).

We discussed this last week as to what to do after lockdown, and those that were in that meeting think it’s a brilliant idea. That we use the two together and combine. So should any of them start coughing or sneezing, they won’t come but they’re not going to miss out. So they’ll know what’s going on, they’ll want to do this as well, it was actually one of them who gave me the idea. It wasn’t my idea; it was one of theirs (AD3).

4.3.4 | Examples of resilience in digitally inclusive support practice

In the context of supporting access to technology, resilient ‘possibility-focused’ support practice is underpinned by two beliefs: (1) People with learning difficulties have the potential to be resilient or to live resilient lives (2) Support workers have the potential professional skills and experience to be resilient. The interviews provided interesting insight into how the resilience of those in support roles appeared to be influenced by a willingness to embrace change, try something new and learn from the experiences.

Sometimes a willingness to try something new was characterized by a ‘give it a go’ attitude.

So to not be afraid of looking into it and take every step you can to help people to move forward in learning to use technology (SA2).

When many of the practitioners talked to me about their willingness to try something new, it was clear that they were not scared to fail:

I think people feel that the computer is going to crash, and I just say, well if it crashes, we’ll just re-boot it. We’ll set it back again, we’ll get another computer. There are always ways around it. It’s that old thing: you learn from your mistakes. I don’t know how many times that I say that to people. It’s great that you are making these mistakes because we can learn from them. We won’t be pressing that button again will we! [laughs]. Bring a bit of fun to it - really. Because learning should be fun (SUPP4).

In talking about their support practices, particularly when they were adopting a new practice, several participants talked about ‘learning curves’ or ‘learning on their feet’. In doing so, they appeared to embrace the learning journey and were willing to learn from the experience:

We were learning on our feet. So things that we did within the first two weeks of the pandemic - with technology - we do totally different now - because we have learnt by developing - by our learning we have learnt different ways (DAY2).

5 | DISCUSSION

The study reported in this paper has provided three important insights into the digital exclusion experienced by people with learning disabilities during the pandemic. First, it has revealed the impact of environment-related barriers to digital inclusion. This is something that was not highlighted in other pandemic-focused studies (Araten-Bergman & Shpigelman, 2021; Flynn et al., 2021; Lake et al., 2021). Second it has provided a more in-depth understanding of not just the barriers to digital inclusion, but also how some ‘supporters’ have sought to overcome these barriers. Third, it has provided evidence to suggest that it may be helpful to use a framework of ‘possibility-focused’ support to characterise digitally inclusive practices. One limitation of the study is that the majority of interviewees were based in England. It would be helpful to interview ‘supporters’ in other countries to explore whether ‘possibility-focused support’ to use technologies are being developed beyond England.

Overall, this study has highlighted how, even in seemingly impossible circumstances such as a global pandemic it is possible to develop practices that enable people with learning disabilities to be digitally included. The results of this study do however raise important questions:

- Why was it not possible before the pandemic to develop digitally inclusive practices?
- How do we sustain these digitally inclusive practices beyond the pandemic?

Digital inclusion is a complex issue and as a result there are many possible answers to the first question. However, based on my 30 years of experience as a practitioner and researcher in the field of learning disabilities and technology one answer that I would like to suggest is that before the pandemic many of those in support roles, particularly formal support roles such as day care providers, did not understand why people with learning disabilities would need to use technology or assumed people would be incapable or not interested in using technologies. During the pandemic, the need to be able to use technology became crystal clear. This need was understood on both a personal level and professional level. On a personal level, during the many lockdowns, support workers, like people with learning disabilities were ‘stuck’ at home, not being able to see friends and family and not being able to engage in the everyday activities that kept them engaged and interested in life. Many support workers turned to technology to enable them to keep connected and stay
well. Some of these probably needed to gain new digital skills and confidence to do this. On a professional level, I would suggest that this experience may have given support workers insights that they might not have had before the pandemic as to why it was important for people with learning disabilities to be able to use technologies and also how relatively easy it is to learn the digital skills needed to use technologies.

In a review of digital inclusion and participation of people with learning disabilities during the pandemic, D. Chadwick et al. (2022) concluded that although the pandemic has raised awareness of digital exclusion, it is not clear how this increased awareness might lead to action and change. Therefore finding answers to the second question relating to sustaining digitally inclusive practices beyond the pandemic is really important.2 My response to this question is one of both concern and hope. My concern is that many support organisations may revert back to their old non-digital practices. The excuse for this is likely to be that people with learning disabilities have missed the face-to-face contact with support workers and others and therefore there is less of a need to provide support for people with learning disabilities to go online. Whilst it is true that many people with learning disabilities have missed face-to-face contact and therefore do not want a solely digital life; comments interviewees made during this study suggests that they would like a mix of both face-to-face and digital activities, suggesting a hybrid model of support may be appropriate. The challenge, therefore, for people like me is to convince support workers that the need to ‘stay connected and keep well’ is a lifelong need, not just a pandemic-related need. As Learning Disability Wales argued:

Technology needs to be a part of life for people, not just a stop gap during the pandemic.3

Although I am concerned for the sustainability of digitally inclusive support practices after the pandemic, I do also see cause for hope. One particular cause for hope is the work that a number of support related organisations are doing to build capacity and enable support workers to develop their digitally inclusive support practices. One example of such a capacity-building initiative is the set of toolkits that I have co-produced with SeeAbility and other learning disability organisations who were part of a digital inclusion project called Creating Connections.4 The Creating Connections Project was a partnership between SeeAbility and 23 self-advocacy groups who were members of Learning Disability England. The project had been funded by the UK National Lottery Coronavirus Community Support Fund to implement a 6-month rapid response programme designed to help increase the network of support and social connections for disabled people, including people with learning disabilities. One key aspect of this study involved using technology to help people build and keep connections within their communities. Drawing on the research reported in this paper and the experiences of support workers and people with learning disabilities in the partner organisations we developed three toolkits: one for people with learning disabilities one for support workers and one for managers and funders.5 The content of all three toolkits is underpinned by a framework of core beliefs and knowledge that reflect the four characteristics of creativity, risk-management, shared-decision-making and resilience. Other ways in which the community might build capacity to deliver digitally inclusive support include:

- Offering networking and knowledge-exchange opportunities: For example, during the pandemic, Learning Disability England recognised the importance of technology in enabling people with learning disabilities to keep connected and ran a series of webinars where people with learning disabilities and support organisations shared their experiences of support.

- Sharing resources such as toolkits, videos and easy read guides: For example, in 2019, LDW established the All-Wales Personal Technology Community of Practice to promote the use of technologies through collaboration and the sharing of good practice. The Community publishes ‘good practice stories’ and holds events where members describe their experience and share resources.

6 | CONCLUSION

The study reported in this paper examined whether and how people with learning disabilities were being supported to use technologies to keep connected and stay well during the pandemic. Whilst the results revealed stories of how people with learning disabilities did not have access to technology during the pandemic and were not being supported to use it, they also highlighted positive stories of access and support. The stories of digital exclusion are not surprising given that previous research has already identified the persistent digital exclusion for people with learning disabilities. The stories of digital inclusion however have revealed how possibility-focused support can bring about change.

ACKNOWLEDGEMENTS

The research was funded by The Open University, UK, as part of its 2020 covid-19 research initiative.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

ORCID

Jane Seale http://orcid.org/0000-0002-4279-7463

5Toolkits for supporting people with learning disabilities to use technology: https://ordo.open.ac.uk/authors/Jane_Seale/9551018
REFERENCES


Disabilities

Tizard Learning Disability Review

Policy and Practice in Intellectual Disabilities

Advance online publication. https://doi.org/10.1111/jppi.12410


Sorbring, E., Molin, M., & Löfgren-Martenson, L. (2017). "I'm a mother, but I'm also a facilitator in her every-day life": Parents' voices about barriers and support for Internet participation among young people with intellectual disabilities. Cyberpsychology: Journal of Psychosocial Research on Cyberspace, 11(1), Article 3.


How to cite this article: Seale, J. (2022). It's not all doom and gloom: What the pandemic has taught us about digitally inclusive practices that support people with learning disabilities to access and use technologies. British Journal of Learning Disabilities, 1–11. https://doi.org/10.1111/bld.12497