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# “I would be lost without it but it's not the same” experiences of adults with intellectual disabilities of using information & communication technology during the COVID-19 global pandemic

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## Abstract

**Background:** COVID-19 is a life-threatening virus which has circulated the globe resulting in unprecedented effects on the daily lives of people across the world. Countries across the globe have advocated measures, including self-isolation and maintaining social distance to reduce the spread of COVID-19. The pandemic has seen an increase in the use of information and communication technology (ICT) for many aspects of life. This study aimed to find out from people with intellectual disabilities what it was like using ICT during COVID-19 and how this affected their lives.

**Method:** Interviews and focus groups were conducted with 19 people with learning disabilities throughout the COVID pandemic. The qualitative data gathered was analysed using longitudinal thematic framework analysis to identify the main ways technology use had impacted on people's lives and the challenges and facilitators of technology use during this time.

**Findings:** Technology played an important role in the lives of the people with learning disabilities who took part in the study. Technology facilitated continuation and maintenance of important daily activities and roles in people's lives (e.g., jobs, getting support and leisure), keeping people meaningfully occupied and maintaining social contact which reduced feelings of loneliness and isolation. People adapted and learned new skills, with help from friends, family and support staff, which boosted self-confidence. Despite some identified barriers, prior technology use, tenacity and a positive attitude towards ICT supported learning new skills and adaptation to increased ICT use.

**Conclusions:** Supporting the development of digital competence, confidence and persistence in people with learning disabilities was important during this international crisis and has had a fundamental positive effect on wellbeing.

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**KEYWORDS**

COVID-19, digital inclusion, information & communication technology, intellectual disabilities, support, wellbeing

**Accessible summary**

- COVID-19 restrictions means that things that used to happen face-to-face now happen using technology online.
- We talked to 19 people to find out their experiences of using technology during COVID-19.
- They told us that though they would be lost without it. It helped people to keep doing things but keeping in touch using technology was not the same.
- Experience, education, support from other people, being positive and not giving up helped people use technology during COVID-19.

**1 | INTRODUCTION**

COVID-19 is a life-threatening virus which has circulated the globe resulting in unprecedented effects on the daily lives of people across the world. It represents one of the greatest changes to human existence to have occurred in the past 50 years (Xu et al., 2020). People with intellectual disabilities have been disproportionately affected by COVID-19 with greater infection, severe infection, mortality and case fatality (Glover, 2020; Henderson et al., 2021). Countries across the world have advocated self-isolation, maintaining social distance, increased hand washing and the use of personal protective equipment to reduce the spread of COVID-19 (Wu & McGoogan, 2020). Social distancing and lockdown measures have led to increased use of information and communication technology (ICT), including the internet during the Pandemic, with many groups increasing their ICT utilisation (Hantrais et al., 2021).

Diagnostically, intellectual disability involves having below average intelligence based on an IQ test ( $IQ < 70$ ), significant impairment in one of more of conceptual, social and practical adaptive skills and occurrence before age 18 (Division of Clinical Psychology Faculty for Intellectual Disabilities, 2015). Societally, it refers to people who are disadvantaged because they differ from a culturally defined idea of 'normal' intellectual functioning (Manion & Bersani, 1987). People with intellectual disabilities often find reading, abstract thinking and processing new information challenging and require support to successfully negotiate everyday life (American Psychiatric Association, 2013; Emerson & Baines, 2010).

As people with intellectual disabilities were more likely than others without intellectual disabilities to require support to carry out everyday activities (e.g., Thompson et al., 2009), their ability to self-isolate during the COVID-19 pandemic was more complex to achieve and self-isolation itself led to reduced support for daily living. It has been shown that people with intellectual disabilities who struggled to comprehend the rapidly altering world during the pandemic and the changes to people's lifestyles by COVID-19 were adversely affected in their wellbeing (Holm et al., 2022).

In addition, despite positives being evident from engaging with ICT (Chadwick & Fullwood, 2018), access to it, its use and participation with it before the pandemic was lower for people with intellectual disabilities than other population groups (Alfredsson Ågren et al., 2020). ICTs defined broadly are products that can digitally receive, transmit, store, retrieve, or manipulate information, including telephones, televisions, personal computers, electronic mail systems, smart and robotic devices, and other internet-enabled systems, including both traditional and social media (Baranyi et al., 2015; Wilson & Jumbert, 2018; Ziamba, 2019). Being able to safely access, engage with, use and develop skills in ICT is so central to everyday functioning post pandemic, it is now included within human rights legislation (United Nations Human Rights and Digital Technology Resource Hub).

Empirical data about the access and use of digital technology by the population of people with intellectual disabilities, before the COVID-19 pandemic, is lacking. However, there were sources of evidence that suggest that before COVID-19 some groups of people with intellectual disabilities were more likely to use ICT than others, namely those with mild to moderate cognitive impairments (rather than people with severe impairments), those who were younger, and who lived outside of supported accommodation (Alfredsson Ågren et al., 2020; Anrijs et al., 2022). Moreover, the literature suggests that people with intellectual disabilities had both lower and different patterns of ICT use when compared with the typically developing majority. For example, Alfredsson Ågren et al. (2020) found that younger people with intellectual disabilities were more likely to use ICT for playing videogames but much less likely to use it for gathering information than their typically developing counterparts.

Societal and individual factors interact in particular ways which introduce challenges in accessing ICT for people with intellectual disabilities. ICT is generally developed for the typically developing majority living in the affluent global north and not people with disabilities. In addition, people with disabilities are heterogeneous in their impairments and associated support needs (Chadwick et al., 2013; Chadwick & Wesson, 2016). These circumstances coalesce leading to lower uptake

and use of ICT by people with (intellectual) disabilities. This has been termed a 'disability digital divide' (Gorski & Clarke, 2002).

During the global pandemic, there was a population increase in the use of ICT (Sarault, 2020; Twigby.com, 2020). Many face-to-face services and support systems for people with intellectual disabilities were reduced, with some rapidly adopting various technologies to enable them to continue in adapted forms with varying degrees of success (Amor et al., 2021; Araten-Bergman & Shpigelman, 2021; Datlen & Pandolfi, 2020; Jeste et al., 2020; McCausland et al., Early View; Navas et al., 2021; Power et al., 2021; Rawlings et al., 2021; Rothman, 2021; Scheffers et al., 2021; Spencer et al., 2021). Moreover, much of the information disseminated by the UK Government along with rapid changes in guidance and societal rules have been disseminated via ICT mediated means (Lake et al., 2021; Navas et al., 2021).

The introduction of ICT has created a digital aspect to inequality likely to interact with existing risk factors for deprivation (e.g., socio-economic status, global geographical location, age, disability status, ethnicity etc.) (Seah, 2020). This has been referred to as 'digital poverty' a concept originally defined as 'lack of goods and services relating to ICT' (Barrantes, 2007). There are two aspects to the lack of goods and services characterising digital poverty; the first links to marginalised sections of society. The second links to the lack of digital skills and the consideration of people who, for differing reasons, do not access, use or demand ICT (Barrantes, 2007). Concerns have also been raised about the extent to which people with intellectual disabilities face digital poverty. They are being digitally left behind during the Pandemic, which may further isolate them and leave them with more impoverished lives in the aftermath (Chadwick et al., 2022). Emerging evidence has revealed that ICT use has increased during the pandemic amongst people with intellectual disabilities (Caton et al., 2022) although a disability digital divide is still present for some (Chadwick et al., 2022).

Investigations tangentially addressing the use of technology by people with intellectual disabilities during the COVID-19 pandemic are beginning to be published. These highlight increased awareness of the need for digital inclusion, digital amelioration of negative aspects of COVID-19, but persistence of digital disadvantage (Chadwick et al., 2022). This investigation contributes to this small existing body of knowledge by giving a more detailed insight into individual experiences, focusing specifically on the personal accounts of people with intellectual disabilities of their use of ICT throughout the pandemic. This contrasts with the broader overview provided in recent literature, which, unlike the present study, did not always have ICT use as the primary focus of the research.

## 2 | AIMS OF THIS STUDY

It is important that research explores and better understands the ways in which ICT has been introduced, maintained and embedded within the everyday lives of people with intellectual disabilities. Possible facilitative and hindering factors and the impact that digital

technology use has on the wellbeing of people with intellectual disabilities need further exploration to inform practice. This study gathered qualitative data about the lived experiences of people with intellectual disabilities of incorporating ICT into their daily lives during the COVID-19 global pandemic. Research questions addressed in this investigation are:

1. What are the lived experiences of people with intellectual disabilities of integrating ICT into their everyday lives during COVID-19?
2. What factors have facilitated and hindered the digital participation of people with intellectual disabilities during the pandemic?
3. How has digital inclusion influenced the wellbeing of people with intellectual disabilities during the COVID-19 Global Pandemic?

## 3 | METHOD

### 3.1 | Approach and reflexivity

The qualitative approach taken was exploratory but adopted a phenomenological post-positivist epistemological stance (Racher & Robinson, 2003). From this epistemological stance, the researchers aimed to understand the complex world of lived experience from the perspective of those living it. Hence, the study prized the lived experiences of participants with intellectual disabilities and their 'reality' relating to the use of ICT throughout the COVID-19 pandemic. In addition, this approach acknowledges that the researchers are not detached and contribute to the shaping of the research process, hence reflexivity is required. Thematic framework analysis (Gale et al., 2013) was employed with an initial descriptive and latent coding framework informed by existing theoretical lenses used and adapted inductively. Various theoretical lenses underpinned the initial deductive framework informed by the experience and knowledge of the authors. Phenomenology served as an overarching framework prizing the voices of participants, the meanings ICT had had in their lives during COVID-19 and their accounts of their lived experiences. A number of theoretical lenses were pragmatically applied to interrogate the preliminary data gathered, used to develop the initial framework alongside inductively derived aspects of the framework. Uses and gratifications theory of social media (which posits that individuals will actively seek out social media, amongst competitors, that fulfils their needs and leads to gratification) was used to help identify what everyday needs differing ICT had supported during the pandemic (Katz et al., 1973; Raacke & Bonds-Raacke, 2008; Stafford et al., 2004). Social support theory allowed reflection on and types (Emotional, tangible, informational, esteem) and sources of support provided via ICT during COVID-19 (Asmar et al., 2020; Barrera & Ainlay, 1983; Liu et al., 2018). Social capital, in particular, how ICT facilitated maintenance of bonding capital and processes of structural, cognitive and relational social capital (Morrow, 1999; Bhandari & Yasunobu, 2009), were utilised in relation to social online contact. Self-determination theory was used

to consider the factors (Autonomy, relatedness and competence) influencing motivation to use ICT (Wehmeyer, 2020). The nested ecological model (Bronfenbrenner, 1979) underpinned consideration of the facilitators and barriers to ICT use. A strengths-based approach and quality of life domains (Dodge et al., 2012; Felce, 1997; Schalock & Felce, 2004) served as a framework to explore effects of ICT use on wellbeing. Finally, a longitudinal lens was employed to consider any changes in ICT use throughout the course of pandemic in participant accounts. Ethical approval for the study was granted by [Removed for Blind Review] ethics committee.

### 3.2 | Participants

This investigation recruited a self-selected opportunity sample from the general population of people with intellectual disabilities (Table 1). Participants ( $N = 19$ , mean age = 37.1 years [ $SD = 13.0$ ], 11 male and 8 female) were recruited using purposive opportunity and snowball sampling via social media, existing partnerships,

personal networks and identified digital networks. Participants with intellectual disability involved in this study had borderline to moderate levels of cognitive impairment, such that they were able to engage meaningfully with an interview format of data collection and had used ICT during the COVID-19 pandemic. As interviews and focus groups were used to collect data people with severe and profound cognitive impairment did not take part in the study. Participants lived in the West Midlands ( $N = 12$ ), Worcestershire ( $N = 2$ ), Herefordshire ( $N = 1$ ) in the United Kingdom and Dublin in Ireland ( $N = 3$ ).

### 3.3 | Procedure

Easy read information sheets and consent forms were circulated to participants at least 1 week before conducting the interviews and a preliminary online meeting was offered. Two of the participants and two of the focus groups took up this offer to further discuss what was involved in the study.

**TABLE 1** Participant background information.

No.	Pseudonym	Interview/focus group	Sex	Age (years)	Ethnicity & nationality	Residence	Self reported diagnoses
1	Steve	I1	Male	35	White, British	24 h Supported living residence	Mild ID; Autism; Visual Impairment; Left hemiplegia; Epilepsy
2	Ursula	I2	Female	31	White, Irish	Family home	Mild ID; Down Syndrome
3	Sally	I3, FG2, FG3	Female	23	White, British	Family home	Mild ID
4	Timothy	I4	Male	29	White, Irish	Family home	Mild ID
5	Yin	I5	Female	30	Asian, Irish	Family home	Mild ID; Down Syndrome
6	Sameer	I6	Male	49	Indian, British	Independent living residence	Mild ID; Hearing impairment
7	Victor	FG1, FG2, FG3, FG4	Male	32	White, British	Independent living residence	Mild ID; Autism
8	Mike	FG1, FG2	Male	29	White, British	Independent living residence	Mild ID; Autism
9	Carl	FG1	Male	32	White, British	Family home, pre-COVID-19 in Independent living residence during COVID-19	Mild ID; Autism; Global Developmental Delay; Sensory processing disorder and Mental health problem.
10	Jois	FG2	Female	37	White, British	Family home	Moderate ID
11	Tony	FG2	Male	27	White, British	Family home	Mild ID; Autism
12	Amy	FG4	Female	28	White, British	Independent living residence	Mild ID; Autism
13	Rachel-	FG4	Female	36	White, British	Family home	Mild ID; Autism
14	Colin	FG4	Male	21	White, British	Family home	Borderline/Mild ID; Autism; ADHD
15	Bea	FG4	Female	51	White, British	24 h Supported living residence	Mild-Moderate ID
16	Robert	FG4	Male	48	White, British	Family home	Mild ID; Autism
17	Rose	FG4	Female	64	White, British	Independent living residence	Mild-Moderate ID; Dyslexia
18	Geoff	FG4	Male	68	White, British	Family home	Mild ID
19	Mark	FG4	Male	34	White, British	Family home	Mild ID; Autism

Abbreviations: ADHD, attention deficit hyperactivity disorder; FG, focus groups; I, interview; ID, intellectual disability.

Before data collection, the interviewer or group facilitator went through the information sheet with participants again to confirm that they understood the project and were still happy to consent to take part. Semi-structured interviews were conducted either individually ( $N = 6$ ) or in focus groups ( $N = 4$ ) using the preferred online platform requested by the participants (Table 1). Data were collected in Summer 2020 (I1, I2, I3, FG1), Summer 2021 (FG2), Winter 2021 (I4, I5, I6, FG3) and Spring 2022 (FG4) to allow longitudinal data throughout the pandemic to be captured. Only three participants were able to be present at more than one interview/focus group (see Table 1). Interviews were conducted with support from the first author via the participants' preferred online platform (Zoom, Facebook, Teams, Skype). Access to online focus groups were facilitated by three coordinators and carers were present to support three of the participants in focus groups. All other participants were independently involved.

During the semi-structured interviews and focus groups, the interviewer was responsive to the direction taken by the interviewees within the topic boundaries. The interview incorporated questions regarding living through the COVID-19 pandemic, changes to society and behaviour and access to support for managing COVID-19 in their daily lives. Where participants mentioned ICT in response to any of these topics these were probed further (Appendix A). Where ICT was not mentioned in responses to discussion about COVID-19 questions about ICT devices and platforms used by participants were asked.

Background and demographic information were collected from participants (Table 1). Participants were debriefed and provided with information about avenues for support relating to COVID-19 and thanked for their participation. They were offered a copy of the study findings in accessible format once the study was complete.

### 3.4 | Data analysis and trustworthiness

Data were auto transcribed using functionality integrated within the videorecording software. Transcriptions were reviewed and corrected for errors during the initial familiarization process. A preliminary framework was developed inductively from initial accounts and deductively using the theoretical lenses noted above. Interview durations ranged between 47 and 91 min (mean = 60.6,  $SD = 17.5$ ) and focus groups lasted between 48 and 89 min (mean = 74.0,  $SD = 17.9$ ). Final transcripts were imported into NVIVO and analysed using thematic framework analysis (Gale et al., 2013). This approach was developed to analyse qualitative data in applied time-limited research (Pope, 2000). Stages include: (i) familiarisation; (ii) constructing an initial thematic framework; (iii) indexing and sorting (applying the framework to the data corpus); (iv) charting (reviewing data extracts and organising them into coherent themes and sub-themes), and finally; (v) mapping and interpreting to find associations and typologies within the dataset and utilising these to address the research questions.

A flexible and pragmatic approach was adopted regarding thematic saturation. Sampling adequacy was judged by the degree to which data sufficiently and meaningfully informed the research questions and the phenomena under study (O'Reilly & Parker, 2013).

Trustworthiness (Nowell et al., 2017) was established via: recording theoretical and reflective thoughts about themes; organised data storage; field note recording post data collection; referential adequacy checking by cross-referencing themes with the raw data; peer and participant debriefing and theme checking; use and charting development of the coding framework; researcher triangulation; theme vetting and consensus checking by team members; and via accounts of analysis and study participants (Table 1) within the paper.

## 4 | FINDINGS

The framework analysis culminated in four themes explicating how ICT had embedded into everyday lives of people with intellectual disabilities (Theme 1), the facilitators and barriers of ICT use (Themes 2 and 3), and the impact on wellbeing (Theme 4) during the COVID-19 pandemic (Figure 1).

### 4.1 | Theme 1. Technology use and daily life

Throughout the pandemic, the introduction of technology in daily life was apparent. As people with intellectual disabilities suffered a loss of 'normal' life, the importance of technology to maintain activities and social connections became one of its fundamental uses. This theme comprised the two sub-themes 'I would be lost without it' and 'maintenance of social and occupational life' (Figure 2).

#### 4.1.1 | 'I would be lost without it'

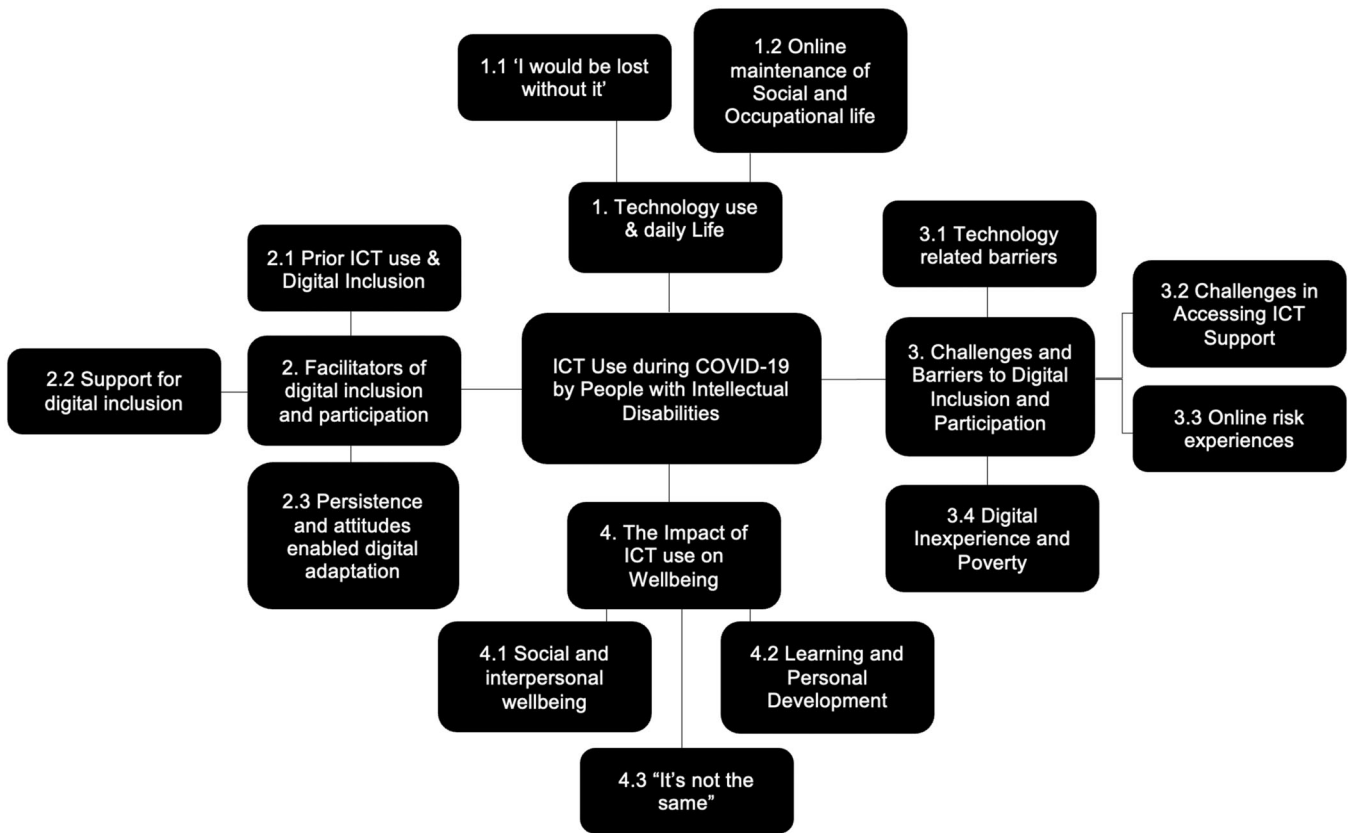
A common reason given by participants for the rapid transfer to online interaction was that they would have been lost without it. Participants indicated that they would have had fewer activities to engage in day-to-day which were meaningful to them during the pandemic.

*"I'd be lost without it. It would feel like losing a limb. If that makes sense."* [I5, Yin]

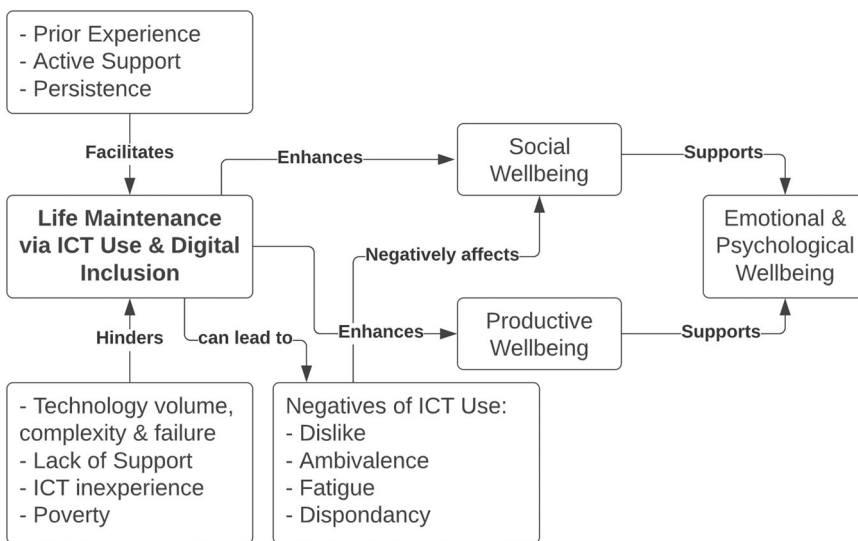
This sub-theme highlighted how getting online rapidly during COVID-19 was important to participants. In the main, this related to the need to use ICT, and in particular video-conferencing software, to maintain different aspects of life, at the beginning, and during the pandemic, whilst maintaining social distancing requirements to prevent the spread of COVID-19. Participants often spoke about newly using ICT and reflecting back on the pandemic how ICT had come into its own during COVID-19.

*"First of all, I hadn't even tried Zoom before. Until during lockdown"* [I2, Ursula]

*"I think computers have really come in to their own during COVID."* [FG4, Robert].



**FIGURE 1** Depicting the final themes for the qualitative framework analysis.



**FIGURE 2** A tentative model of digital participation of adults with intellectual disabilities during COVID-19. ICT, information and communication technology.

#### 4.1.2 | Online maintenance of social and occupational life

To alleviate loss, people used technology in various important aspects of daily life. People spoke about online education, social contact, leisure and everyday support.

#### Online education

Technology was used for educational purposes during the pandemic as social distancing restrictions meant that in-person teaching was no longer possible. People reported using technology for their own learning either in college settings, completing online courses, as well as technology that their children were using for online learning.

*"I've been doing other courses because they're, they've been online" [I1, Steve]*

#### Online maintenance of social contact

All participants reported using technology to remain in contact with friends and family throughout the first lockdown and beyond. The type of technology used to maintain social contact varied but most reported using text-based apps (text messaging, Facebook, Messenger, and WhatsApp) and videoconferencing software (Zoom, FaceTime, Skype) to stay in contact.

*"I've used WhatsApp, I've used FaceTime. I tend to find FaceTime has become a popular one... because you can see their faces and that" [FG2, Victor]*

People also reported how technology use was the closest they could get to being with friends and family. Moreover, when reflecting on the lockdowns toward the end of the pandemic, the importance of technology to maintain contact was also reported.

*"I'd have been lost especially in the first lockdown if I hadn't had some method of communication... with my family" [FG4, Robert]*

#### Online maintenance of leisure and occupation

Technology was also used to maintain pre-pandemic life in ways other than remaining in contact with friends and family. The use of technology allowed people to continue to work from home and engage in leisure activities.

*"Yeah, in between I was working at home remotely, I wasn't actually at the office, I was actually at home." [I3, Sally]*

*"Well, I'm doing exercising on Zoom" [I2, Ursula]*

In-house digital entertainment featured widely amongst participants and helped to pass the time and to feel better about being at home. Participants talked about watching a number of television channels, being able to access football matches, playing videogames, online shopping and reading. Some also mentioned surfing the internet and chatting online as ways of keeping entertained at home.

*"Yeah. I've got Disney+ now. I like my films like the Lord of the Rings films and that. I'm watching Star Wars, we're watching Star Wars." [FG2, Jois]*

*"[To keep myself busy] I have been online shopping, reading books, reverted to a hardcore gamer. ... you can go on a server and it's always online, got 24 players on the same server... Kills the boredom." [FG2, Mike]*

#### Everyday living support

Throughout the pandemic, people received day-to-day support from different sources including friends, family, support staff and other health care professionals via technology but not necessarily to help with navigation of the technology itself.

*I: "Do you do the online shopping or does your mum do..."*

*P5: "We do it together" [I5, Yin]*

*"... it [Physiotherapy session] was through WhatsApp, and they contacted me through the video camera" [I1, Steve]*

A wide variety of technology was used by participants, demonstrating considerable integration of ICT to help them maintain almost all aspects of their lives.

## 4.2 | Theme 2. Facilitators of digital inclusion and participation

Theme 2 comprised three sub-themes pertaining to factors which were catalysts or facilitators for digital inclusion during the pandemic: prior use, support and persistence.

### 4.2.1 | Prior ICT use and digital inclusion

Prior experience involving development and learning in relation to ICT were prevalent within discussions of ICT use. Some participants felt that they had not needed to learn new ICT skills to engage with new technologies. It was evident from the accounts that prior experience increased both the likelihood and success of individuals transitioning to online and digital modes of interaction and activity. For example, Timothy highlighted his previous use of various technologies including Whatsapp and Twitter.

*I: "But in the past you've used twitter before coronavirus?"*

*P4: "Yeah, yeah yeah, oh God yeah I'm always on twitter." [I4, Timothy]*

Later in the interview he went on to discuss his recent use of new technologies Skype and Facebook messenger which demonstrated the ease with which he had taken these up and could switch between them.

*"If my Skype wasn't working, I could have [video] phoned you that way [via Facebook messenger]." [I4, Timothy]*



Support, as a facilitator of prior use, was also evident in the accounts. In particular, prior use of social media led to easier transitions to extended ICT use during the pandemic. One participant who had not been provided with technology before the pandemic experienced the removal of gatekeeping barriers. The need to maintain everyday life took precedence over previous carer gatekeeping and access restrictions.

*"While COVID was on [I got a new tablet]...My sister got it me."* [FG2, Jois]

#### 4.2.2 | Support for digital inclusion

This was a substantial sub-theme within the data corpus and differs from the everyday support accessed by participants using ICT as a vehicle for that support mentioned in Theme 1. In 2.1, support for online success before the pandemic was identified as an important precursor to successful ICT use during the pandemic. Here, the use of ICT during COVID-19 restrictions highlighted the fundamental need for different forms of positive support for successful digital inclusion.

##### *Sources and types of support*

Family members, support staff, work colleagues, mentors, friends and peers were all mentioned as important sources of support in relation to the uptake and maintenance of ICT use during the pandemic. In addition, support came from people outside of immediate social networks. Sources of support were often reported to be instrumental in: (i) facilitating ICT use, (ii) meeting individual ICT support needs, and (iii) adapting to meet the needs of participants to increase ICT functionality. Types of social support apparent included mentoring, coaching and networking.

[Discussing use of COVID Pass App] *"I went through it with my mum and dad like on the night before ... you need to follow the procedure and do this, do that you know, ... get it off your personal Hotmail, do all that."* [FG3, Sally]

*"I learnt how to do Zoom. ... My sister and [support worker name] [taught me]...Attending them. ...Yeah"* [FG4, Bea]

##### *Support as a facilitator of successful digital inclusion*

Successful ICT use was often contingent on necessary supports being in place. Support was evident in the set up and use of technology to maintain work and employment roles. These successes built confidence and skills and facilitated ongoing and additional digital exploration.

*"Oh yeah, yeah. Our lovely [Facilitator 1] bless her, she created this Facebook page for us. We call it the*

*[Facebook Page Name] page. And basically, I've kinda took over, took over it."* [FG2, Victor]

Peer support from friends to use ICT was also noted to facilitate persistence and tenacity towards successful use and helped overcome confusion participants felt.

*"I have this habit of over saving some of my documents, and I get a bit confused ... I found that a struggle at first so [P5] really helped me with that in computer club.."* [FG4, Amy]

Support staff also helped with access to ICT in relation to reading and other challenges relating to literacy and visual impairments.

*"the support worker that signed the paperwork, she's golden with me.... she does audio for me and reads out what isn't audio. And when it comes to assessment, she reads out the questions ... so I can click, she doesn't tell me the answers."* [I1, Steve]

##### *Interdependence of support*

It is important to note that support did not only occur one way. Examples were given where support had been provided by participants with intellectual disabilities to others.

*"We did two based on technology, we did PowerPoint and we did Excel. I also helped run a computer club every other Wednesday."* [FG4, Colin]

#### 4.2.3 | Persistence and attitudes enabled digital adaptation

Essential to the success of adaptation was persistence and tenacity in engaging with new aspects of ICT.

*"I didn't know how to start it, first of all. I got used to it."* [I2, Ursula]

*"At first, I found it a bit, bit daunting but I'm like, I'm like obsessed with it now. ...."* [FG2, Victor]

Participant accounts demonstrated the trial-and-error learning that took place for many people when engaging with new hardware or software and also the discomfort, uncertainty and struggle that can occur when people learn new digital literacy skills.

*"I think if this COVID situation hadn't have occurred, those skills maybe wouldn't have been developed as fast and pushed people out of their comfort zone...I think you've all done brilliantly."* [FG4, Facilitator]

There was also evidence of the need for flexible thinking and processing information at a more rapid speed than people were previously used to when engaging with aspects of technology.

*"I think it's because of seeing everybody's faces on the screen it's like oh right who's talking to me? Oh, is it [Facilitator 1], is it [Facilitator 2], is it [Participant 3] you know? ... I think it just takes a while for the brain to process what's going on I think because it's a new, a new way of interaction."* [I3, Sally]

Positive attitudes of participants towards the challenge of learning new ICT skills also appeared to be facilitative.

*"So yeah, so Microsoft Teams I find absolutely amazing I love using it. I've learned a few things from being on it, too, for example, learning how to share my screen with someone, to virtual coffee mornings to virtual lunches ... It's been great I use it all the time."* [I5, Yin]

Humour was evident in the interviews and focus groups and appeared to be used to make meetings more enjoyable, and as a coping strategy to deal with the challenges of communicating using ICT.

*"We also seem to have learnt a brand new language in Zoom and that's called broken English."* [Laughter from the group] [FG4, Robert]

### 4.3 | Theme 3. Challenges and barriers to digital inclusion and participation

Participants also discussed challenges they faced in using ICT during COVID-19. Within this theme, the sub-themes of technology, support, risk, inexperience and poverty posed barriers to digital inclusion.

#### 4.3.1 | Technology related barriers

Participants in the focus groups spoke about barriers to using technology. Some of these barriers arose from the complexity of technology, its intrusiveness and the variety of platforms available.

*"the more apps you have the more confusing it gets."* [FG2, Victor]

*"I can't remember half of anyway so. ... you get confused with which username is for what, is for which social app... I struggle sometimes with passwords sometimes I've got that many passwords for that many different things"* [FG3, Victor]

*"and it comes up on my phone ... If I click on if someone who's had it, it comes up ... I turn it off."* [FG4, Mark]

*"It's quite complicated to figure out at the start... they were trying to teach us how to use it on Zoom which was quite complicated when you've got maybe 60 or 70 parents on one Zoom call."* [FG4, Rachel]

In addition, the lack of reliability of some technology (i.e., video-conferencing), was off-putting to some and impeded communication.

*"This has become the normal hasn't it really, talking via screen. It's not always the most reliable way of communication... Zoom has its moments"* [FG4, Victor]

#### 4.3.2 | Challenges in accessing ICT support

Participants demonstrated variable levels of independence in ICT Use. Support was necessary to enable ICT use and this support was not always available, forthcoming or successful. The findings related to ICT support in this sub-theme stand in direct contrast to the support outlined as a facilitator of success in sub-theme 2.2. It also differs from the more readily available face to face support before the pandemic identified in Theme 1.

*"Right, with the Zoom program, I tried to do it myself, but I need the help to work it cause it's a bit too difficult for me to do."* [FG1, Carl]

*"...and I'm like 'I can't do it, you've sent it me through PDF not Word. I can't do it through PDF it's got to be on a Word document'. And I'm sitting here screaming going you've sent it again through PDF what, what are you trying to do, explain? Seriously!"* [I3, Sally]

For some participants, more support was needed to ensure they could access ICT. Some people appeared to feel left behind as aspects of everyday life moved online at a fast pace during the pandemic. Some also needed carer input to identify their ICT support needs. Without proactive support from staff to do this, success in ICT contact and use sometimes failed.

P17: *"But I have tried to twice [get] on it but I just can't do it."*

P8: *"Did you ask [Support Worker Name] to help you?"*

*Support worker: She hasn't but yes now that she mentioned it, I can help you with it."* [FG4, Rose]

### 4.3.3 | Online risk experiences

Participants reported that they had experienced negative online behaviour such as attempted phone scams and grooming during the pandemic. However, no-one reported that this had reduced or stopped their use of technology.

*"I have had somebody who tried to groom me on Facebook they tried to get me to send them naughty photos of myself which obviously I declined."* [FG3,P7,Victor]

### 4.3.4 | Digital inexperience and poverty

Focus group discussions indicated that there was a lack of awareness regarding technology at the start of the pandemic. This knowledge gap appeared to be due to a lack of digital experience.

*I: "Do you know what WhatsApp is?"*

*P10: No."* [FG2, Jois]

*"I want to try and get messenger ... I just can't get to messenger."* [FG4, Rose]

When considering the uses of technology, the issue of the high cost of purchasing devices and software was raised as an access barrier.

*"They've rolled out one of these pens [iPen] that you put over the, you know letters, that could be too expensive for me."* [FG4, Geoff]

## 4.4 | Theme 4. The impact of ICT use on wellbeing

Theme 4 addressed the effects that using ICT had on wellbeing. This super-ordinate theme comprised three sub-themes relating to 'social and interpersonal wellbeing' and 'productive wellbeing'. Activities in support of these aspects of wellbeing subsequently facilitated maintenance of emotional and psychological wellbeing. A third sub-theme acknowledges the ambivalence some felt towards ICT use and negative aspects of technology use during COVID-19.

### 4.4.1 | Social and interpersonal wellbeing

As people were not able to meet face-to-face during the pandemic, technology became the main way that people maintained contact. This interpersonal contact with friends, family and colleagues combatted loneliness and isolation that people felt due to lack of

face-to-face contact and fostered a sense of connectedness which supported emotional and psychological wellbeing.

*"When my niece was born kind of my sister and her husband were sending pictures of when the baby was born so that was good."* [I4, Timothy]

*"We use them a lot more to kind of like just fill up the gaps where we would normally have met people, it like, I WhatsApp my girlfriend two three times a day."* [FG2, Mike]

People's abilities and opportunities for social inclusion were drastically hampered throughout COVID-19 UK lockdowns. Nonetheless, connections were made with groups and organisations through Zoom, texting on their phones or using WhatsApp.

*"[Online group quiz] entertains you really because ... it takes up the majority of your night like ... so it's something to look forward to really."* [I3, Sally]

*"Since the coronavirus I've been kind of texting different people in the church ... when the lockdown happened every Sunday, I would text the, the priest saying well done, great mass you know. Keep up the good work, giving them encouragement and all and it was kind of my way of keeping in contact."* [I4, Timothy]

Participants spoke about feeling bored and unable to join social activities such as youth club, or to get to work where having live company was important to feeling satisfied and happy. In these instances technology helped people to maintain a sense of social inclusion easing isolation.

*"[It was difficult] not seeing my friends for one... I'm a hugger."* [I2, Ursula]

*"I just feel like, you know, quite bored and like just nothing to do like you know everyday like, just nothing."* [I3, Sally]

*"I found [Zoom] very good. Found it really good. When you get to see people."* [I4, Timothy]

### 4.4.2 | Learning and personal development

Learning and personal development as aspects of productive wellbeing were evident in participants accounts of their ICT use during COVID-19. This included meaningful occupation and developing both new ICT skills and self-determination in ICT use. A sense of empowerment was also evident in discussions of participant ICT achievements when people had successfully broadened their technology skills.

*"I learnt how recently how to reply to people [via email]... I can put like a vlog on something I learnt how to do that." [FG4, Rose]*

One group recounted a programme of learning they had developed to enhance their digital literacy skills, and other skills, during the pandemic. Learning new ICT skills led to increased confidence, self-worth and self-efficacy in relation to technology use.

*"We did [an award for skill development achievement in], passionate about people's rights, understanding others, computer skills, Excel and PowerPoint, working with others, reading, being organised, and self-confidence." [FG4, Rachel]*

*"I love it yeah. I'm on it all the time [tablet device]. Yeah. Playing games on it and that. ... Angry Birds and the colouring, painting by number. ... And Messenger, like a text app, it's like on Zoom, there's one on that. ... Confidence. You use your confidence aren't you." [FG2, Victor]*

*"I am the computer genius." [FG4, Colin]*

Speaking in the later focus groups, highlighting longitudinal change, participants reflected on their own success stories throughout the pandemic:

*"I've learned a lot. I've learnt how to share things via Zoom, I've learnt how to share my screen, how to, I've learnt all sorts. ... I've learnt how to use PowerPoint. We've all, we all did our personal development ... I've learnt quite a lot while using Zoom. I suppose really, we've had no choice really but to learn because this has become the new normal" [FG4, Victor]*

Enhancing skills and confidence in ICT use increased motivation and a sense of ICT self-determination. Evidence of development in autonomy and mastery of ICT skills, accompanied by a sense of relatedness via shared experience, was apparent across the narratives. Support was a fundamental catalyst for development of self-determination in ICT use.

*"I think it's [Using technology during the pandemic] kind of made us, made us be a bit more independent and a bit more self-sufficient, I think." [FG3, Sally]*

#### 4.4.3 | "It's not the same"

Negative aspects or ambivalence towards ICT use during COVID-19 were also acknowledged in focus groups and interviews. Participant accounts highlighted waiting for a time when face-to-face contact

could resume, with a sense of longing for and personal loss of offline contact. Longitudinal changes in ICT use and perceptions during COVID-19 often arose in this sub-theme.

*"I'd rather see them in person but if I can't I think Zoom is the best way" [FG2, Tony]*

*"It's not the same as being there and talking face-to-face even though you're still talking on the screen but it's not the same as interacting with them in the room." [I4, Timothy]*

Others, considering changes during COVID-19, talked about the oddness of interacting online initially and how this had become the 'new normal' but not the new normal they necessarily wished to continue.

*"It's very strange you know, online but it's very different than meeting in person, like it's all very well seeing a top half and seeing your lovely face on screen, you know. But it's not the same as in being in physical contact or in the same proximity of each other, if you know what I mean." [I5, Yin]*

Some participants indicated their dislike of everything being online leading to loss of existing activities and contact with people.

*"I don't go to the Church anymore, where I used to twice a week for a cuppa and a chat. I don't know how to contact 'em now. ... I don't go to the [name of local football team] ... not been to [name of pub] after COVID ... [name of cat] and [name of second cat] keep me company" [I6, Sameer]*

Considering longitudinal change during COVID-19, as the duration of the pandemic extended over the 2 years later accounts sometimes revealed fatigue, digital overload, and despondency in relation to the ongoing restrictions and necessity for ICT use.

*"Well, I've taken myself out from a couple of groups 'cause they're very annoying when you get a couple of hundred messages per hour." [FG2, Mike]*

## 5 | DISCUSSION

### 5.1 | Maintenance of daily life

By facilitating maintenance of daily life, use of technology allowed some sense of equilibrium and homeostasis to be maintained (Dodge et al., 2012) and a semblance of normality for people with intellectual disabilities when there was ongoing uncertainty during the pandemic. This is not to say no disruptions occurred, but digital solutions

ameliorated the potential negative impact on people's lives of the pandemic. Findings regarding ICT use and its facilitators, barriers and impacts mirror those found previously (Chadwick et al., 2022) but provided more detail about the nuances of embedding ICT use in people's lives. A tentative model of digital participation during COVID-19 is presented in Figure 1.

## 5.2 | Facilitators

Successful digital participation and digital resilience appeared contingent on active support for ICT use, positive attitudes towards ICT, enhanced digital confidence, pre-existing and developing digital skills and persistence in the face of challenges in ICT use. Narratives of successfully beginning to access and use new ICT and overcoming challenges surrounding adoption of technology during the pandemic were evident in many of the accounts.

Reasons for the need to rapidly transfer from face-to-face to online day-to-day activities were not often explicitly mentioned by participants, in a sense being tacitly embedded in their lives. Nonetheless, they included maintaining contact with family and friends, engaging in social and leisure time with them online, a key benefit also reported in other studies (Caton et al., 2022; Lake et al., 2021; McCausland et al., in Early View; Navas et al., 2021; Rothman, 2021; Scheffers et al., 2021). Few participants mentioned making new friends via ICT during the pandemic in this study. Structural and bridging social capital were evident in the use of ICT to maintain work life, engage in educational pursuits and maintain advocacy work and networks during the pandemic.

## 5.3 | Barriers

Barriers related to technology volume, complexity and failure and also to inexperience and poverty (Caton et al., 2022). Critically, absence of and inadequate support to engage with ICT and understand their own ICT support needs impeded participants' digital participation. Counter-intuitively, risks were seldom mentioned as a barriers by participants in this study, contrary to findings by Caton et al. (2022). This may be due to people feeling competent to manage risks and/or as result of only including participants in this study who had used ICT. Individual impairments were not discussed in detail in many of the focus groups or interviews. However, dyslexia, visual impairments, literacy and processing challenges were all mentioned and served as barriers to using ICT without adequate support (Chadwick et al., 2019).

## 5.4 | ICT use over time during COVID

Mirroring prior findings, third sector organisations working with self-advocates in this study appeared quick to see the value of using digital technology to enable the occupation to continue (Chadwick

et al., 2022). They worked in person-centred ways with people with intellectual disabilities focussing on tackling barriers to digital exclusion by building on existing strengths, implementing peer and coaching support and positively reinforcing skill development through achievement acknowledgement, celebration and use of awards. Future work could evaluate the utility of digital micro-credentials for people with intellectual disabilities as incentives and acknowledgement of personalised learning and achievement when digital skills are gained.

Narratives for those who have been using technology for a prolonged period of time before COVID-19 demonstrated the bleeding together and overlaps that exist between digitally mediated and non-digitally mediated interaction, activities and support (Lieberman & Schroeder, 2020). For example, participant 1 fluidly moved between discussing health related support online from care staff who helped him search the internet for health information to offline from his mum who supported to pick up his medication from the chemist. This online aspect to life needs acknowledgement and consideration in future research if the effects of this change on interaction of people with intellectual disabilities are to be fully represented and understood.

It was challenging for some participants to reflect back to earlier in the pandemic and how things had changed. It was, however, evident from some accounts that participants had reflected on their technology use before COVID-19, and during COVID-19. Throughout the pandemic, there was a shift in how these people viewed technology. They found it hard at the start, however over time there was a change in how technology was perceived and increasing confidence, as reported by Rothman (2021). These changes over course of the COVID-19 pandemic revealed the developmental nature of ICT engagement and that learning for people with intellectual disabilities, as for others, can be a difficult process and may position people in a state of constructive discomfort or disequilibrium until they begin to master digital literacy skills. This is akin to Vygotsky's 'zone of proximal development' (Vygotsky, 1978); a place just beyond a learner's current skill and knowledge base in relation to ICT use, but where learning remains within the learner's reach.

## 5.5 | Impacts

Use of ICT during COVID-19 resulted in positive impacts on social, productive and emotional wellbeing. Despite this people missed their offline lives and although a reasonable substitute, it was not the same for people as non-digitally mediated interaction and activity.

## 6 | LIMITATIONS

This study included people who were able to participate in interviews and focus groups and many self-advocates who lived independently or with their families. As a result, some issues including fear of online

risk and presence of digital access gatekeeping did not arise as much as might be expected in people's accounts. Hence, further work is needed to look at digital inclusion in those greater risk of digital exclusion. Recent research has identified people who are older, live in housing supported by paid staff, with higher support needs as those at higher exclusion risk (Anrijs et al., 2022). In addition, it has been noted previously (Chadwick et al., 2019), that people with profound intellectual and multiple disabilities are more likely to be overlooked in relation to digital inclusion than those who do not have such severe disabilities. The impacts of the move to online service provision on this group and others with higher support needs needs further consideration.

## 7 | ADDITIONAL OBSERVATIONS AND FUTURE DIRECTIONS

Subtle support for digital inclusion which involved support to set up of ICT and guidance during its use were evident in some accounts. This led to people feeling independent and successful in their use of new ICTs. This is evidence of good quality ICT support facilitating people to recognise their strengths in learning and using new ICT. Due to this subtlety, it was often difficult to discern the nature of support from the accounts of the participants or types of support people required. Therefore, although it remains crucial to gather the experiences of people with intellectual disabilities to enhance ICT support and access, it is important that future research also uses more direct observational methods and reflections from those providing support. This will enhance understanding of the processes of successful direct support and guidance and how unobtrusive, empowering ICT support and hands on coaching is enacted. Findings from other marginalised groups may also provide useful insights here.

Notable by its absence was the notion of digital inclusion as a human right. This was not explicitly present in the participant accounts; hence this did not appear to be a lens that participants with intellectual disabilities employed when thinking about and discussing their use of technology. Nonetheless, the sense of being a full participating citizen appeared contingent upon the maintenance of their lives, facilitated in many instances, during the pandemic by ICT use, and in particular videoconferencing. The belief in the human right to live in the community, be employed, have opportunities for family and social life and development and education implicitly underpinned participant assertions of the need to utilise ICT during the pandemic. As participants reported, they would have been "lost" without it.

### CONFLICTS OF INTEREST STATEMENT

The authors declare no conflicts of interest.

### DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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## APPENDIX A: TOPIC GUIDE FOR INTERVIEWS AND FOCUS GROUPS

- (1) What has living through the Coronavirus pandemic been like for you?
  - Probes: How have you been keeping busy? What has been different?
- (2) How have you stayed in touch with people during Corona Virus?
  - Have you used the internet keep in touch with people?
- (3) What was it like using (name of ICT)? (Follow up question about any ICT use mentioned in response to questions 1– 3)
- (4) What technologies have you used? (Asked if not ICT mentioned in previous questions otherwise probes follow mentioning of any ICT use)
  - Probes/Prompts: Websites (Like Google, Facebook), Online videos/TV (Like Netflix, Prime, Disney), Video-chats (like Skype, Zoom, Teams). Mobile phone apps (Like WhatsApps (Asked if not forthcoming from other questions). Probe: What do you use to use/get on (Name of online activity)?
  - Hardware probes/prompts: Do you/Who has a Tablet, Phone, Computer/laptop, Smart TV, Gaming console (PS4/5, Xbox, Nintendo Switch, Steam).
  - Activity Probes/Prompts: Keeping in touch, advocacy work, finding out about COVID-19, shopping, accessing support
  - What do you like/dislike about (Name of online activity/ICT mentioned)?
  - Has anyone helped you use (Name of online activity/ICT use mentioned)?
- (5) Is there anything else you want to tell me about using technology during COVID-19?
- (6) How have things changed for you since the beginning of COVID? (Asked during 2021 and 2022 data collection).