




Digital participation of people with profound and multiple learning disabilities during the Covid-19 pandemic in the UK

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Abstract

Background: During the Covid-19 pandemic, there has been a worldwide increase in the use of digital technology. Many people with learning disabilities have learned new digital skills, taken part in online activities, and kept in touch with family and friends using video calls. However, the experiences of digital participation or nonparticipation for the people with profound and multiple learning disabilities (PMLD) is less understood.

Method: Between December 2020 and August 2021, family carers or paid support workers of adults with PMLD completed an online survey around the experiences of the person they care for during the Covid-19 pandemic, including questions on Internet use. We draw on the findings of this UK-wide study to explore the digital participation of the people with PMLD during the pandemic.

Findings: Around half of the people with PMLD had Internet access at home. Around half of the participants interacted with others on video calls like Facetime or Zoom and most commonly used the Internet for being with family and friends online and streaming TV and films. In the event of another lockdown, 27.5% of the people supporting someone with PMLD said they would like support with technology to make seeing friends and family easier. For some the people, digital participation during the pandemic was not beneficial enough to want to continue when restrictions eased. For others, the new online experiences had the potential to be developed in their postpandemic lives.

Conclusion: Around half of the people surveyed participated in digital activities during Covid-19. Future attention is needed to afford more people opportunities, and respond to access barriers experienced for the people with PMLD and those that support them.

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KEYWORDS

communication, intellectual disability, PMLD (profound and multiple learning disabilities), social interaction

Accessible Summary

- During the Covid-19 pandemic, a lot of people with learning disabilities used the Internet more than they had done before. Before this research, we did not know very much about how people with profound and multiple learning disabilities might be able to use the Internet.
- Family carers or paid support workers of people with profound and multiple learning disabilities filled in an online survey about their experiences during the Covid-19 pandemic. This included how people with profound and multiple learning disabilities used the Internet.
- The researchers found that around half of people with profound and multiple learning disabilities in the study had Internet access at home. People with profound and multiple learning disabilities mostly used the Internet for being with friends and family online and for streaming TV and films. Around half of people with profound and multiple learning disabilities used video calls (like FaceTime or Zoom).
- If there is another pandemic, and people cannot go out, more help with technology is needed so that people with profound and multiple learning disabilities can see their family and friends online. This is very important for people who do not live with family.
- Some people thought digital participation was useful during the pandemic, but they preferred to see people in-person. For others, being online was a new way of being with other people that they wanted to carry on using or make better.

1 | INTRODUCTION

People with learning disabilities are increasingly included in the digital world and smartphone and/or tablet use is becoming more commonplace (Chiner et al., 2017). While concerns about online risk are sometimes expressed by those who support people with learning disabilities (Ramsten et al., 2019), an acknowledgement of positive risk-taking (Wasserman, 2019) and a recognition of the wide-ranging benefits of digital inclusion are increasingly becoming known and accepted (Caton & Landman, 2022).

People with profound and multiple learning disabilities (PMLD) have a profound intellectual disability and a profound motor disability (Nakken & Vlaskamp, 2007) as well as commonly having additional severe communication disabilities, sensory disabilities and often complex health needs (Doukas et al., 2017). Despite what is known about the importance of assistive technology for people with PMLD (Doukas et al., 2017; Goldbart & Caton, 2010; Mansell, 2010), research that has explored possibilities for using the Internet for everyday activities or enjoyment of people with profound and multiple learning disabilities is scarce (Chadwick et al., 2019). This

may be due to assumptions that people with profound and multiple learning disabilities may not benefit from being active participants in the digital world.

The challenging technical requirements of getting online (Lussier-Desrochers et al., 2017) and the accessibility of websites (Shpigelman & Gill, 2014; Williams & Hanson-Baldauf, 2010) are particular barriers for people with complex needs. Additionally, people with profound and multiple learning disabilities often have specific sensory and other challenges that require multisensory approaches to communication. The importance of touch for communication (Elliott-Graves, 2021) can suggest that digital connections may not be ideal for people with profound and multiple learning disabilities. In the early stages of the Covid-19 pandemic, families expressed concerns about these difficulties, for example, the absence of physical means of communication during online interactions (Bradshaw et al., 2020). Despite these multiple barriers, the widespread introduction of touchscreen mainstream devices has changed the accessibility of Internet use for some people with more complex needs (K. S. Kversøy et al., 2020).

1.1 | The Covid-19 pandemic

Social distancing restrictions associated with the worldwide Covid-19 pandemic meant that many families reported substituting in-person visits to their relatives with remote communication (Araten-Bergman & Shpigelman, 2021; McCausland et al., 2021). Online support was available for some people with learning disabilities from friends and family, social care and health care services and organisations such as self-advocacy groups (Chadwick et al., 2022). Some people with learning disabilities took part in online groups (using platforms such as Zoom or MS Teams) as well as psychological therapy (Rawlings et al., 2021), online art therapy groups (Datlen & Pandolfi, 2020; Power et al., 2021) and dance movement psychotherapy (Rothman, 2021). However, online social connections were not straightforward or easily accessible for everyone. It is known that people with learning disabilities often have reduced social networks (Harrison et al., 2021) and during the early stages of the Covid-19 pandemic, social isolation was identified as a worry for people with learning disabilities (Flynn, Caton, et al., 2021).

The current study draws on both quantitative and qualitative data collected as part of a larger study exploring the experiences of people with learning disabilities in the UK during the Covid-19 pandemic. The wider study had a broad focus including exploring areas of people's lives such as Covid-19 infections and vaccinations, health, mental health and wellbeing, social care services, employment and bereavement. The study involved two cohorts of participants. Cohort one was adults with mild to moderate intellectual disabilities who were interviewed by a researcher. Cohort two was family carers or paid support staff of adults with severe or profound intellectual disabilities who were not able to take part in an interview themselves. For this second group, family carers or paid support staff participated through an online survey. The data here is only from Cohort two participants who responded 'yes' to the question 'does the term "profound and multiple learning disabilities" apply to your family member/the person you support?'. In the current study, we focus on specific parts of the wider study to explore ways that Internet use featured in the lives of people with profound and multiple learning disabilities during the pandemic. The data concerning digital participation was limited, but with scarce published research in the area of digital participation for people with profound and multiple learning disabilities this research provides an insight into a little researched area.

2 | METHOD

2.1 | Procedure

The selection and wording of questions for the survey were finalised through extensive consultation with groups of people with learning disabilities, family carers and paid support staff of people with learning disabilities across the four UK countries, including organisations specifically concerning people with

profound and multiple learning disabilities, to maximise relevance and accessibility. Following initial consultation on the selection of questions, the wording of draft questions was further discussed with members of the study's collaborating organisations to ensure accessibility, and adjustments were made where necessary. Recruitment of people into the study was facilitated through multiple methods, including through collaborating organisations in each UK country, social media and wider networks of learning disability and family organisations across England, Northern Ireland, Scotland and Wales. Potential participants were directed to the online survey via telephone, e-mail, social media or via the research project website.

Data were collected at three timepoints: December 2020 to February 2021; April to May 2021; and July to August 2021. Responses were entered directly into the Qualtrics™ online survey by respondents.

2.2 | Participants

Ninety-one family members or paid support workers of people with profound and multiple learning disabilities completed an online survey at all three timepoints. In this study, rather than being a clinical diagnosis, the term profound and multiple learning disabilities is descriptive; one of the survey questions asked respondents if the term 'profound and multiple learning disabilities' applies to the person they care for. In considering findings, family members and paid support workers are acknowledged as the experts in their response to this question.

Most of the people with profound and multiple learning disabilities that respondents cared for were aged 16–34 years (68.5%) with the remainder older and just under half were women (49.4%). Just over a third were living with their family (38.5%) and almost two-thirds were in another living situation (61.5%), largely some form of supported housing/residential care with other people with learning disabilities. Participants (people with profound and multiple learning disabilities) lived in Scotland (51.6%) England (28.6%), Northern Ireland (12.1%) and Wales (7.7%), and 91.2% of participants identified as white (Welsh, English, Scottish, Northern Irish, British, Irish, Gypsy or Irish Traveller).

Although 91 family members or paid support workers of people with profound and multiple learning disabilities completed an online survey at all three timepoints, a total of 163 family members or paid support workers who supported or cared for someone with profound and multiple learning disabilities responded to open-ended questions in the survey on at least one occasion (not all respondents completed the survey at all three time points). Of those 163 family members or paid support workers, 27 (17%) responded to six questions with comments about the digital participation of the person they care for/support. Although the number of participants is relatively small, open-ended questions capture participants' responses where they were free to choose to write about any aspects of the lives of the person they support. For those 27 people, the impact of digital

participation for the person they support was the most important issue they wanted to state in response to the question.

2.3 | Measures

Table 1 shows the set of Internet usage questions used for the quantitative analyses in this paper, including how they were coded for the purposes of analysis. Responses reported by small numbers of respondents were collapsed into broader categories or excluded from the specific analyses involving the relevant variable, but these participants were included in all other analyses (e.g., people identifying as a gender other than male or female were excluded from analyses concerning gender differences, but were included in all other analyses). Where response options were collapsed into a smaller number of categories for analysis, this was done on the basis of creating meaningful categories for analysis with sufficient numbers in each category. For the analyses included here questions included demographic factors and Internet usage (Internet access; whether people interact with others on video calls; internet activities and support participants would want in the event of another lockdown).

The survey contained broad open-ended questions, which included questions that some participants chose to respond to by highlighting an aspect of digital participation:

- 'What has life been like for the person you care for/support during the pandemic?' (asked in December 2020 to February 2021);

- What would make your life as a family carer or support worker better right now? (asked in December 2020 to February 2021);
- Has anything good happened in the life of the person you support/care for because of the coronavirus situation? (asked in December 2020 to February 2021);
- What would make the life of the person you support/care better right now? (asked in December 2020 to February 2021);
- What has life been like for the person you care for/support during the pandemic? (asked in April to May 2021);
- Do you want their life to go back to how it was before coronavirus, or would you like some things to be different to how they were before coronavirus? (asked in April to May 2021).

We report on analyses of responses to these questions and anonymised quotes are used to illustrate themes.

2.4 | Analysis

For quantitative analyses, the data set was analysed using SPSS 27. All variables analysed were binary, and potential associations involving Internet usage versus demographic factors were analysed using Fisher's exact test. The statistical significance level was set at $p < 0.01$ to make some allowance for multiple comparisons; $p < 0.05$ findings are reported as trends. To assist in interpretations of effect size, relative risk (RR) calculations were also conducted (Altman, 1991).

TABLE 1 Internet usage

Surveys with family carers or support workers of adults with PMLD (n = 91) Internet usage	Wave 1	Wave 2	Wave 3
Internet access at home	n = 51 (56.0%)	n = 50 (54.9%)	n = 58 (63.7%)
The person interacts with others on video calls, like FaceTime or Zoom—the person does this now	n = 53 (58.2%)	n = 50 (54.9%)	n = 40 (44.0%)
What does the person use the Internet for at the moment			
Being with friends/family online	n/c	n = 33 (36.3%)	n = 33 (36.3%)
Social media	n/c	n = 10 (11.0%)	n = 7 (7.7%)
Doing online activities with other people	n/c	n = 26 (28.6%)	n = 22 (24.2%)
Streaming TV and films	n/c	n = 33 (36.3%)	n = 36 (39.6%)
Other activities on their own	n/c	n = 12 (13.2%)	n = 12 (13.2%)
Shopping	n/c	n = 5 (5.5%)	n = 6 (6.6%)
Playing video games with other people online	n/c	n = 1 (1.1%)	n = 3 (3.3%)
For paid or voluntary work	n/c	n = 0 (0.0%)	n = 0 (0.0%)
If another lockdown, would support with tech to see friends and family online make it easier?	n/c	n/c	n = 25 (27.5%)

Abbreviation: n/c, data not collected; PMLD, profound and multiple learning disabilities.

For qualitative data, a generic thematic analysis was carried out that was suitable for qualitative elements of survey data (Percy et al., 2015). Initially, all responses from family carers or paid support workers to the selected open-ended questions across the different time points were downloaded into an Excel file. In total 163 participants responded to at least one of these questions at least one time point. All 163 participant responses to the selected open-ended questions were initially read individually by the first and second authors to extract answers relating to digital participation. Following this initial reading, 36 responses (from 27 participants) were found to have been about the digital participation of the person they care for/support (responses ranged from one to 14 sentences for each response). Those responses were then coded using an inductive, semantic approach by the first author by assigning a category name or brief descriptor ('code'), before being organised into thematic clusters as suggested by Patton (2002). Discussion of the thematic clusters then took place between the authors S.C., J.B., A.G. and E.O. to 'collaboratively gain richer or more nuanced insights' (Braun & Clarke, 2022, p. 55). Codes were then reviewed and collapsed into final themes.

Research ethics approval was sought and obtained from the Faculty of Health and Education Research Ethics Committee at Manchester Metropolitan University.

3 | RESULTS

3.1 | Quantitative results

Table 1 presents descriptive data on Internet usage among adults with profound and multiple learning disabilities across the United Kingdom. At all three time points of the study, more than half of people with profound and multiple learning disabilities had Internet access at home (56.0%, 54.9%, 63.7%). At all three time points, around half of the participants interacted with others on video calls like Facetime or Zoom (58.2%, 54.9%, 44.0%). At the second and third time points of the study, people most commonly used the Internet for being with family and friends online (36.3%, 36.3%), and streaming TV and films (36.3%, 39.6%). A minority of people were using the Internet for social media (11%, 7.7%), other activities on their own (13.2%, 13.2%), shopping (5.5%, 6.6%), playing video games with other people online (1.1%, 3.3%) and no respondents reported that the person with profound and multiple learning disabilities that they support used the Internet for paid or voluntary work purposes. In the event of another lockdown, 27.5% said they would like support with technology (tablet, phone or computer) to make seeing family and friends easier.

Table 2 shows potential associations between indicators of Internet usage and the demographic variables of age (in two age bands), gender and living situation. As Table 2 shows, there were no associations between Internet access or online activities with age, gender or living situation. If there was another lockdown, family carers or paid support workers who support people with profound and multiple learning disabilities who were not living with the family were 4.5 times more

likely than those supporting people living with family to want support with technology (tablet, phone or computer) to make seeing friends and family online easier. There were trends ($p < 0.05$) at Wave 2 for people with Internet access at home to be more likely to be younger, to be women and to be living with family and for younger people to be more likely to use the Internet for streaming films and TV.

3.2 | Qualitative results

Responses to the open-ended questions concerning digital participation were mostly referring to positive experiences possibly because those with limited or negative experiences with digital participation would not have chosen to highlight this in an open-ended response. Consequently, the first three themes generated by the thematic analysis highlight the benefits and opportunities around online participation for people with profound and multiple learning disabilities. The four themes identified are (1) 'Activities and Relationships', which illustrates that digital participation has been made possible for people with profound and multiple learning disabilities through participation in activities, and in maintaining relationships; (2) 'Life got better' details the way that the pandemic introduced people to a new way of facilitating communication that people wanted to keep in their postpandemic lives; (3) 'Emerging Opportunities?' considers possibilities for the future and ways that some participants might have benefitted from increased digital participation. (4) The final theme, 'Limitations to Participation' identifies that although digital participation was useful during the pandemic, it had limitations for some people.

3.3 | Activities and relationships

The first theme illustrates how it was specifically taking part in activities and maintaining relationships online meant that digital participation for people with profound and multiple learning disabilities was both possible and a positive experience during the Covid-19 pandemic.

...if we're lucky enough to share a session with one of her friends, they are both delighted to see each other and the joy it brings is incredible.

The use of digital platforms meant that people were able to continue their prelockdown lives to some extent, maintaining established relationships with friends, with community groups and with services that people had previously attended in-person:

She has learned how loved she is by our church community who have kept in touch with cards, parcels, and weekly church Zoom meeting.

Life has been quite good for my daughter who has a learning disability because the Day Centre provided excellent online sessions.

TABLE 2 Associations between Internet usage and demographic variables

Demographic variables			
	Age (16–34 vs. 35+)	Gender (man vs. woman)	Living situation (living with family vs. other living situations)
	RR (95% CI) Fisher's exact <i>p</i>	RR (95% CI) Fisher's exact <i>p</i>	RR (95% CI) Fisher's exact <i>p</i>
Internet usage			
Internet access at home			
Wave 1	57.4% vs. 50.0% 1.15 (0.75–1.76) <i>p</i> = 0.647	57.8% vs. 56.8% 1.02 (0.71–1.46) <i>p</i> = 1.000	68.6% vs. 48.2% 1.42 (1.00–2.02) <i>p</i> = 0.082
Wave 2	70.5% vs. 46.4% 1.52 (0.99–2.33) <i>p</i> = 0.036	53.3% vs. 77.3% 0.69 (0.50–0.95) <i>p</i> = 0.026	77.1% vs. 55.4% 1.39 (1.04–1.87) <i>p</i> = 0.045
Wave 3	65.6% vs. 57.1% 1.15 (0.79–1.66) <i>p</i> = 0.484	40.5% vs. 54.8% 0.74 (0.47–1.17) <i>p</i> = 0.275	68.6% vs. 60.7% 1.13 (0.83–1.54) <i>p</i> = 0.507
The person interacts with others on video calls, like FaceTime or Zoom			
Wave 1	55.7% vs. 60.7% 0.92 (0.63–1.33) <i>p</i> = 0.818	53.3% vs. 65.9% RR = 0.81 (0.57–1.14) Fisher's <i>p</i> = 0.282	57.1% vs. 58.9% RR = 0.97 (0.68–1.39) Fisher's <i>p</i> = 1.000
Wave 2	61.0% vs. 56.0% 1.09 (0.73–1.63) <i>p</i> = 0.808	52.4% vs. 65.1% 0.80 (0.56–1.16) <i>p</i> = 0.274	50.0% vs. 63.5% 0.79 (0.53–1.17) <i>p</i> = 0.266
Wave 3	48.2% vs. 42.9% 1.13 (0.68–1.87) <i>p</i> = 0.817	55.6% vs. 75.0% 0.74 (0.64–1.01) <i>p</i> = 0.075	41.2% vs. 50.0% 0.82 (0.51–1.34) <i>p</i> = 0.509
What do you use the Internet for at the moment?			
Being with friends/family online			
Wave 2	41.0% vs. 25.0% 1.64 (0.81–3.33) <i>p</i> = 0.162	35.6% vs. 38.6% 0.92 (0.54–1.58) <i>p</i> = 0.828	28.6% vs. 41.1% 0.70 (0.38–1.28) <i>p</i> = 0.267
Wave 3	36.1% vs. 35.7% 1.01 (0.56–1.84) <i>p</i> = 1.000	33.3% vs. 40.9% 0.82 (0.47–1.41) <i>p</i> = 0.520	25.7% vs. 42.9% 0.60 (0.32–1.14) <i>p</i> = 0.120
Doing online activities with others			
Wave 2	34.4% vs. 17.9% 1.93 (0.81–4.59) <i>p</i> = 0.136	24.4% vs. 34.1% 0.72 (0.37–1.38) <i>p</i> = 0.358	25.7% vs. 30.4% 0.85 (0.43–1.69) <i>p</i> = 0.812
Wave 3	26.2% vs. 17.9% 1.47 (0.60–3.61) <i>p</i> = 0.435	17.8% vs. 31.8% 0.56 (0.26–1.20) <i>p</i> = 0.146	22.9% vs. 25.0% 0.91 (0.43–1.95) <i>p</i> = 1.000
For paid or voluntary work			
Wave 2	0.0% vs. 0.0% n/c	0.0% vs. 0.0% n/c	0.0% vs. 0.0% n/c
Wave 3	0.0% vs. 0.0% n/c	0.0% vs. 0.0% n/c	0.0% vs. 0.0% n/c
Streaming TV and films			
Wave 2	45.9% vs. 17.9%	26.7% vs. 47.7%	42.9% vs. 32.1%

TABLE 2 (Continued)

Demographic variables			
	2.57 (1.11–5.95) <i>p</i> = 0.017	0.56 (0.31–0.99) <i>p</i> = 0.050	1.33 (0.78–2.29) <i>p</i> = 0.372
Wave 3	45.9% vs. 28.6% 1.61 (0.84–3.07) <i>p</i> = 0.164	37.8% vs. 43.2% 0.88 (0.53–1.45) <i>p</i> = 0.669	42.9% vs. 37.5% 1.14 (0.69–1.90) <i>p</i> = 0.663
Playing video games with others online			
Wave 2	1.6% vs. 0.0% n/c	2.2% vs. 0.0% n/c	2.9% vs. 0.0% n/c
Wave 3	3.3% vs. 3.6% 0.92 (0.09–9.71) <i>p</i> = 1.000	6.7% vs. 0.0% n/c	5.7% vs. 1.8% 3.20 (0.30–34.00) <i>p</i> = 0.556
Social media			
Wave 2	13.1% vs. 7.1% 1.84 (0.42–8.09) <i>p</i> = 0.495	6.7% vs. 15.9% 0.42 (0.12–1.52) <i>p</i> = 0.197	8.6% vs. 12.5% 0.69 (0.19–2.48) <i>p</i> = 0.735
Wave 3	9.8% vs. 3.6% 2.76 (0.35–21.81) <i>p</i> = 0.426	2.2% vs. 13.6% 0.16 (0.02–1.30) <i>p</i> = 0.058	5.7% vs. 8.9% 0.64 (0.13–3.12) <i>p</i> = 0.703
Shopping			
Wave 2	6.6% vs. 3.6% 1.84 (0.22–15.69) <i>p</i> = 1.000	6.7% vs. 4.5% 0.47 (0.26–8.36) <i>p</i> = 1.000	2.9% vs. 7.1% 0.40 (0.05–3.44) <i>p</i> = 0.645
Wave 3	4.9% vs. 7.1% 0.69 (0.12–3.89) <i>p</i> = 0.648	0.0% vs. 13.6% n/c	5.7% vs. 7.1% 0.80 (0.16–4.14) <i>p</i> = 1.000
Other activities on your own			
Wave 2	13.1% vs. 10.7% 1.22 (0.35–4.27) <i>p</i> = 1.000	11.1% vs. 15.9% 0.70 (0.24–2.04) <i>p</i> = 0.550	20.0% vs. 8.9% 2.24 (0.77–6.51) <i>p</i> = 0.201
Wave 3	13.1% vs. 7.1% 1.84 (0.42–8.09) <i>p</i> = 0.495	6.7% vs. 20.5% 0.33 (0.09–1.13) <i>p</i> = 0.069	14.3% vs. 12.5% 1.14 (0.39–3.32) <i>p</i> = 1.000
If another lockdown, would support with tech to see friends and family online make it easier?			
Wave 3	24.6% vs. 32.1% 0.77 (0.38–1.53) <i>p</i> = 0.454	31.1% vs. 25.0% 1.24 (0.64–2.44) <i>p</i> = 0.638	8.6% vs. 39.3% 0.22 (0.07–0.68) <i>p</i> = 0.001

Abbreviations: CI, confidence interval; n/c, not calculated; RR, relative risk.

3.4 | Life got better

The second theme highlights that for some people with profound and multiple learning disabilities, digital participation was a new positive addition to daily life that was being embraced and sometimes seen as an improvement from prepandemic ways of life.

All of the selected quotes in this theme were in response to the question ‘what has life been like for the person you care for/support during the pandemic?’, where participants chose to highlight the benefits of digital participation:

Some things have improved e.g., more activities, shows, entertainment, group meetings online.

...my son has enjoyed zoom, skype and facetime sessions with different activities that he never had access to before.

Because there were no external community activities, the support team have gone above and beyond to create and source online activities and fun occupations for the tenants which has made the lives of M

and his other tenants more interesting in some ways than before.

For some people with profound and multiple learning disabilities, being able to join activities online alongside a calmer, quieter life that social distancing restrictions created had a positive impact on wellbeing:

It got better! ...I also think we had him in too many activities which overwhelmed him (rushing him to be ready, join in etc) and affected his behaviour. he is sleeping better, funny, more 'cuddles' developed more speech, doing things independently....We are so thrilled. best he has ever been...he has more relaxed time to shower, dress etc.he can use Zoom, presses the 'join meeting' and is using his ipad for facetime with family.

Remote health appointments were reported to make life more accessible, and people wanted it to continue:

We have benefited from remote Drs appointments and meetings via phone/video and hope the option for these will continue to be available going forward to those who prefer it.

3.5 | Emerging opportunities?

The third theme brings together experiences indicating that for some people the Covid-19 pandemic provided the impetus for people to try online participation for the person with PMLD they care for when it had not previously been a consideration, and for others, an awareness of the growth of digital opportunities during the pandemic led to thoughts about emerging opportunity for the future.

Respondents identified that Internet use during the pandemic aided the development of new digital skills:

My daughter has learned to join her support group on zoom!

These new skills aided the experience of new activities, allowing social connections, entertainment and fun. However, like any new skills, participants referred to ways that they and the person with profound and multiple learning disabilities were learning to adapt to the technology, which takes time and practice:

my brother has a dual sensory loss and so his understanding of the world is face to face, close up and personal & he relies on touch from others. His

usual structured week of meaningful activities and connecting with others halted overnight and whilst he is slowly beginning to relate to virtual/online interaction, its nowhere near as meaningful or rewarding for him.

she has got used to seeing people on screens

I think it has been lonely, all day services stopped without any warning... We have had to access online activities in order for my daughter to join in with activities provided by her adult day centre, day activity provider and a music therapist, she is getting used to screens now

The previous theme indicates ways that online connections can be more accessible but here, there is suggestion of ways that opportunities were still emerging. The 'albeit remote' comment below suggests negativity towards online interaction but this quote highlights a possible opportunity because it is unlikely that four sessions a day would happen in-person:

He is unaware of the pandemic. He is generally a happy person and enjoys being around other people, even though he struggles to communicate. He accesses up to 4 zoom sessions per day, so has plenty of social interaction, albeit remote.

To embrace the opportunities online participation might offer, a need for support and encouragement to access online activities was identified where families might have wanted more opportunities to support family members.

... we are always looking for new online activities for him.

If there are online activities being carried out we have not being told about them—despite my sister not being able to verbally communicate, myself or one of our parents would have supported her to take part and be involved....

Access to online groups—despite my sister having a profound physical and learning disability—even a zoom call via the day service (Supported by me, our Mum or dad) with those she used to see at her day service 5 days a week would make her smile.

In response to the question 'What would make your life as a family carer or support worker better right now?', one family member went as far as describing it as 'something easy' that could have been offered but was not:

And something easy, like the day centre actually running some sessions over zoom. There has been no visual connection between the staff and my son, apart from the family taking him for a run in the car to see that the centre is all shut up.

Similarly, the following participant explains that they had been communicating with their son by FaceTime. But despite this being a proven way to communicate, their son was still bored, suggesting a missed opportunity to take part in the online activities that were taking place during the pandemic.

During lockdown from March–July, my son suddenly was cut off from my visits (3–4 times a week) and I couldn't visit at all. We communicated by FaceTime. That was good. He learned that he could communicate onscreen. He kept asking to come home, saying...the name of our village and 'home'—and I kept promising him, 'one day', 'soon', 'it won't be long' trying to keep his hope up. He went along with that, but sometimes he felt really impatient, shouted, broke things, hit out at people... he was FED UP of waiting, FED UP of not going home—he said 'not today, not today' 'not now not now' 'bye bye soon'—HE WANTED THINGS TO CHANGE!...Above all he has been BORED and he has lacked ONGOING LEARNING, CREATIVITY

New ways of support were also highlighted as advantageous when online:

Video call with Speech and language, phone call appointment with photo with gp. He was in the process of applying for his first passport and was able to have his interview done via video call.

Not everyone was able to make use of these emerging possibilities due to not having the technology to make it possible. In response to the question, 'What would make the life of the person you support/care better right now?' this participant needed access to technology:

Her own tablet/device to see and talk to her friends and family and listen/watch music videos.

Responses to the open-ended questions were largely comments on positive aspects of digital participation. However, for a minority of people, online interactions caused distress and were not successful:

Zoom etc has had little effect as he will perk up on hearing our voices but as soon as he realises we are not physically there he withdraws...this has resulted in his general mental health deteriorating and a significant increase in his seizure frequency.

3.6 | Limitations to participation

The final theme illustrates that while participants could identify ways in which online connections had been a way to provide continuity in relationships during lockdown, it was seen as useful during the pandemic but that there are challenges that may be insurmountable for some people with profound and multiple learning disabilities or had significant limitations. In response to the question, 'has anything good happened in the life of the person you support/care for because of the coronavirus situation?' a couple of respondents highlighted both the benefits and the challenges:

Communicating with people online, but as previously stated, needs support to do this and it's very limited.

He's enjoying the benefits of online activities—the external professionals facilitates the session and his familiar staff directly engage him. He sometimes interacts with us (family) online... but the virtual world is still a challenging concept for him.

The following quotes illustrate that being able to connect with other people online brought happiness to some people with profound and multiple learning disabilities, but they still missed seeing people in real life and family members or paid support workers recognised that social distancing meant that in-person contact was not possible:

Pre-pandemic she was a busy sociable woman attending classes 4 days a week. Now she is only accessing the community for local walks or for health appointments. She is accessing online classes but misses her friends and family.

I would prefer to be able to get back to doing my visits to see D and other people with [learning disabilities] and autism, but I know the safest option right now for everyone is to stay at home and communicate over the phone or video chat.

4 | DISCUSSION

At all three timepoints of the study, only around half of the people with profound and multiple learning disabilities had Internet access at home and around half interacted with others on video calls (like FaceTime or Zoom). In contrast, nearly 90% of people with mild or moderate learning disabilities who took part in the wider study (Cohort 1) had access to the Internet at home during the Covid-19 pandemic (Caton et al., 2022). It is, perhaps, unsurprising that fewer people with profound and multiple learning disabilities had Internet access, but this notable difference may illustrate the expectation that people with profound and multiple learning disabilities would not be able to participate in online activities due to the complex nature of

their cognitive, physical and sensory disabilities and lack of knowledge about how to support engagement.

People with profound and multiple learning disabilities were most commonly using the Internet for being with friends and family online and for streaming TV and films. Qualitative analysis of open-ended questions support these findings, suggesting that activities and relationships were the main benefits of online participation. Responses suggested that for some people, digital participation for the person with profound and multiple learning disabilities they support was a new experience during times of social distancing restrictions. For some, this new experience was not beneficial enough to want to continue when restrictions eased but for others, the new online experiences had introduced people to a new way of interacting with others that family members or paid support workers wanted to keep or even further develop in their postpandemic lives.

Internet use has been shown to often be a positive experience for people with learning disabilities, enabling the maintenance of existing social connections (Barlott et al., 2019; Raghavendra et al., 2018; Shpigelman & Gill, 2014). The use of the Internet for connecting with friends and family and streaming TV and video as activities is also in line with research by K. Kversøy et al. (2022). They have referred to 'doing and talking' as a way of remote communication which was an approach developed following experiences of remote communication during the Covid-19 pandemic, whereby the experience of daily video communication with relatives was identified as being most rewarding when it involved one of the communication partners taking part in practical activities while the other watched (e.g., preparing meals, washing—shared activities, playing with toys, art, crafts). In K. Kversøy et al. (2022)'s study, it was the role of remote communication partners that was primarily considered but the quantitative findings from the current study also suggest a core role for communication partners who are physically present with the person with PMLD during digital participation. Small numbers of people with profound and multiple learning disabilities were shown to be taking part in social media, shopping and playing video games with other people online suggesting that respondents possibly used a broad definition of digital participation in their responses to questions about activities the person they support took part in whereby activities such as online shopping were seen as shared experiences (looking at pictures, talking about choices etc).

In the event of another lockdown, 27.5% of people supporting someone with profound and multiple learning disabilities said they would like support with technology to make seeing friends and family easier. People who support people with profound and multiple learning disabilities who were not living with family were 4.5 times more likely than those supporting people living with family to want that support. Previous research has suggested that sometimes staff in residential homes might perceive Internet use as risky (Ramsten et al., 2019), and that expectations of caregivers can be an additional barrier, so suggestions that more support is needed is encouraging.

In the current study, there was a suggested need for more support both in terms of support with technology if there was another lockdown and suggestions from open-ended responses that indicate that some digital opportunities were missed. Alongside the

hints of potential for the benefits of digital participation are suggestions that new ways of communication and new experiences can take time for people with profound and multiple learning disabilities to get used to. However, K. Kversøy et al. (2022) argue that it is just as much the case that it is the communication partners that importantly need to learn new skills and strategies to make real inclusion possible. Previous research has shown that the active participation of people with profound and multiple learning disabilities in any event is dependent on quality of the support provided by both people and the environment (Nakken & Vlaskamp, 2007).

5 | IMPLICATIONS

Although the current research has shown that digital participation may not be ideal for some people with profound and multiple learning disabilities, it has also shown that for some people with profound and multiple learning disabilities, family carers or paid support workers reported clear benefits and that there may be untapped potential in digital participation. People with learning disabilities typically have fewer social contacts (Harrison et al., 2021). Increasing opportunities for expanding social contacts may provide new, previously unconsidered opportunities for social connections and entertainment. The future impact of Covid-19 is unclear; in July to August 2021, 22% of people with profound and multiple learning disabilities were still minimising face-to-face contact to avoid Covid-19 infection ('shielding') (Flynn, Hayden, et al., 2021) meaning that online social connections may continue to provide vital ways of keeping in touch with friends and family members. If skilled communication partners are receptive to the possibilities that digital participation might allow, and if specialist equipment and adapted environments are provided (e.g., bigger screens, darkened rooms, skilled support staff) to support people's cognitive, physical and sensory challenges, the implications of digital participation go beyond social connections and entertainment. If digital participation becomes a day-to-day activity for people with profound and multiple learning disabilities and their communication partners, there is potential for it to be a vehicle to support people with other new experiences (e.g., if going to a new place can be initially experienced online, it could ease any concerns around multiple new experiences of a new place, a new activity, a new journey and meeting new people). It is important that people have access to the technology and that people with profound and multiple learning disabilities are included in future government funded projects that provide technology for people with learning disabilities (Bourlet, 2022). For this potential to be possible, universal design must be truly universal, embracing creative ways to develop the potential of the Internet to be beneficial for people with profound and multiple learning disabilities.

6 | LIMITATIONS

This research was part of a larger study that took place at three timepoints and explored a wide range of experiences of people with intellectual disabilities during the Covid-19 pandemic in the United

Kingdom. The study was responsive to urgent and important issues for people with learning disabilities and the people who support them. As such, there was limited scope to explore some issues relating to Internet use in more depth.

Research that has taken place during the Covid-19 pandemic has suggested that barriers to digital inclusion for people with learning disabilities persist (Chadwick et al., 2022). It is therefore important to note that taking part in the online survey for the current research required the digital participation of family carers or paid support workers. As people able to take part digitally, it is possible that respondents were more likely to embrace digital participation for their family member; most of the responses to the open-ended questions were highlighting positive experiences but as they relate to a relatively small number of people there is a need for conservatism in consideration of the findings.

Finally, although respondents appeared to be referring to active participation by people with profound and multiple learning disabilities, we were unable to ascertain the extent to which the online experiences actively engaged the attention of people with profound and multiple learning disabilities.

7 | CONCLUSION

The purpose of the current study was to explore how people with profound and multiple learning disabilities have taken part in Internet use during the Covid-19 pandemic in the United Kingdom. This study contributes to the growing research in the area of digital inclusion for people with learning disabilities by providing evidence that suggests that digital participation for people with profound and multiple learning disabilities might be more beneficial than previously thought.

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CONFLICT OF INTEREST

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

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

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REFERENCES

- Altman, D. G. (1991). *Practical statistics for medical research*. Chapman & Hall.
- Araten-Bergman, T., & Shpigelman, C. N. (2021). Staying connected during COVID-19: Family engagement with adults with developmental disabilities in supported accommodation. *Research in Developmental Disabilities*, 108, 103812. <https://doi.org/10.1016/j.ridd.2020.103812>
- Barlott, T., Aplin, T., Catchpole, E., Kranz, R., Le Goullon, D., Toivanen, A., & Hutchens, S. (2019). Connectedness and ICT: Opening the door to possibilities for people with intellectual disabilities. *Journal of Intellectual Disabilities*, 24(4), 503–521.
- Bourlet, G. (2022). 'Digital lifeline project is the beginning not the end'. Retrieved April 6, 2022. <https://www.learningdisabilityengland.org.uk/news/latest-news/digital-lifeline-project-is-the-beginning-not-the-end/#more-14550>
- Bradshaw, J., Flynn, S., Hatton, C., & The Coronavirus and People With Learning Disabilities Study Team. (2020). Coronavirus and people with learning disabilities: What are the some of the issues for family carers supporting people with profound and multiple learning disabilities? *PMLD Link*, 32(3), 44–45.
- Braun, V., & Clarke, V. (2022). *Thematic analysis. A practical guide*. Sage.
- Caton, S., Hatton, C., Gillooly, A., Oloidi, E., Clarke, L., Bradshaw, J., Flynn, S., Taggart, L., Mulhall, P., Jahoda, A., Maguire, R., Marriott, A., Todd, S., Abbott, D., Beyer, S., Gore, N., Heslop, P., Scior, K., & Hastings, R. P. (2022). Online social connections and internet use among people with intellectual disabilities in the UK during the Covid-19 pandemic. *New Media and Society*. Advance online publication. <https://doi.org/10.1177/14614448221093762>.
- Caton, S., & Landman, R. (2022). Internet safety, online radicalisation and young people with learning disabilities. *British Journal of Learning Disabilities*, 50(1), 88–97. <https://doi.org/10.1111/bld.12372>
- Chadwick, D., Alfredsson Ågren, K., Caton, S., Chiner, E., Danker, J., Gómez-Puerta, M., Heitplatz, V., Johansson, S., Normand, C., Murphy, E., Plichta, P., Strnadová, I., & Flygare Wallén, E. (2022). Digital inclusion and participation of people with intellectual disabilities during COVID-19: A rapid review and international bricolage. *Journal of Policy and Practice in Intellectual Disabilities*. Advance online publication. <https://doi.org/10.1111/jppi.12410>
- Chadwick, D., Chapman, M., & Caton, S. (2019). Digital inclusion for people with an intellectual disability. In A. Attril-Smith, C. Fullwood, M. Keep, & D. J. Kuss (Eds.), *The oxford handbook of cyberpsychology*. Oxford Handbooks Online. <https://doi.org/10.1093/oxfordhb/9780198812746.013.17>
- Chiner, E., Gómez-Puerta, M., & Cardona-Moltó, M. C. (2017). Internet use, risks and online behaviour: The view of internet users with intellectual disabilities and their caregivers. *British Journal of Learning Disabilities*, 45(3), 190–197.
- Datlen, G. W., & Pandolfi, C. (2020). Developing an online art therapy group for learning disabled young adults using WhatsApp. *International Journal of Art Therapy*, 25(4), 192–201. <https://doi.org/10.1080/17454832.2020.1845758>

- Doukas, T., Fergusson, A., Fullerton, M., & Grace, J. (2017). *Supporting people with profound and multiple learning disabilities. Core and essential service standards* (report). PMLD Link. Retrieved April 3, 2022. [Standards-PMLD-h-web.pdf](https://pmldlink.org.uk/Standards-PMLD-h-web.pdf) (pmldlink.org.uk)
- Elliott-Graves, L. (2021). Healing touch: Using the arts to increase health touch between people with PMLD and their carers. *Journal of Applied Arts & Health*, 12(2), 73–85.
- Flynn, S., Caton, S., Gillooly, A., Bradshaw, J., Hastings, R. P., Hatton, C., Jahoda, A., Mulhall, P., Todd, S., Beyer, S., & Taggart, L. (2021). The experiences of adults with learning disabilities in the UK during the COVID-19 pandemic: Qualitative results from Wave 1 of the Coronavirus and people with learning disabilities study. *Tizard Learning Disability Review*, 26(4), 224–229.
- Flynn, S., Hayden, N., Clarke, L., Caton, S., Hatton, C., Hastings, R. P., Abbott, D., Beyer, S., Bradshaw, J., Gillooly, A., Gore, N., Heslop, P., Jahoda, A., Maguire, R., Marriott, A., Oloidi, E., Paris, A., Mulhall, P., Scior, K., & Todd, S. (2021). *Coronavirus and people with learning disabilities study Wave 3 results: September 2021 (full report)*. University of Warwick.
- Goldbart, J., & Caton, S. (2010). *Communication and People with the Most Complex Needs: What works and why this is essential*. Mencap.
- Harrison, R. A., Bradshaw, J., Forrester-Jones, R., McCarthy, M., & Smith, S. (2021). Social networks and people with intellectual disabilities: A systematic reviews. *Journal of Applied Research in Intellectual Disabilities*, 34(4), 973–992.
- Kversøy, K., Alhassan, A., Kellems, R., Kversøy, S., & Cusworth, Z. (2022). Doing and talking: People with intellectual disabilities' handling of challenges of remote communication. *International Journal of Disability, Development and Education*, 69(1), 319–330. <https://doi.org/10.1080/1034912X.2021.1958200>
- Kversøy, K. S., Kellems, R. O., Alhassan, A. R. K., Bussey, H. C., & Kversøy, S. D. (2020). The emerging promise of touchscreen devices for individuals with intellectual disabilities. *Multimodal Technologies and Interaction*, 4(4), 70.
- Lussier-Desrochers, D., Normand, C. L., Romero-Torres, A., Lachapelle, Y., Godin-Tremblay, V., Dupont, M. É., Roux, J., Pépin-Beauchesne, L., & Bilodeau, P. (2017). Bridging the digital divide for people with intellectual disability. *Cyberpsychology*, 11, 53–72.
- Mansell, J. (2010). *Raising our sights: Services for adults with profound intellectual and multiple disabilities*. Department of Health.
- McCausland, D., Luus, R., McCallion, P., Murphy, E., & McCarron, M. (2021). The impact of COVID-19 on the social inclusion of older adults with an intellectual disability during the first wave of the pandemic in Ireland. *Journal of Intellectual Disability Research*, 65(10), 879–889. <https://doi.org/10.1111/jir.12862>
- Nakken, H., & Vlaskamp, C. (2007). A need for a taxonomy for profound intellectual and multiple disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 4(2), 83–87.
- Patton, M. (2002). *Qualitative research & evaluation methods* (3rd ed.). Sage.
- Percy, W. H., Kostere, K., & Kostere, S. (2015). Generic qualitative research in psychology. *The Qualitative Report*, 20(2), 76–85. <https://doi.org/10.46743/2160-3715/2015.2097>
- Power, N., Dolby, R., & Thorne, D. (2021). 'Reflecting or frozen?' The impact of Covid-19 on art therapists working with people with a learning disability. *International Journal of Art Therapy*, 26(3), 84–95. <https://doi.org/10.1080/17454832.2020.1871388>
- Raghavendra, P., Hutchinson, C., Grace, E., Wood, D., & Newman, L. (2018). "I like talking to people on the computer": Outcomes of a home-based intervention to develop social media skills in youth with disabilities living in rural communities. *Research in Developmental Disabilities*, 76, 110–123.
- Ramsten, C., Martin, L., Dag, M., & Marmstal Hammar, L. (2019). A balance of social inclusion and risks: Staff perceptions of information and communication technology in the daily life of young adults with mild to moderate intellectual disability in a social care context. *Journal of Policy and Practice in Intellectual Disabilities*, 16(3), 171–179.
- Rawlings, G. H., Gaskell, C., Rolling, K., & Beail, N. (2021). Exploring how to deliver videoconference-mediated psychological therapy to adults with an intellectual disability during the coronavirus pandemic. *Advances in Mental Health and Intellectual Disabilities*, 15(1), 20–32. <https://doi.org/10.1108/AMHID-06-2020-0014>
- Rothman, K. (2021). Expanding: A case study exploring online work and relationship in one-to-one sessions in an adult learning disability service. *Body, Movement and Dance in Psychotherapy*, 16(1), 47–55. <https://doi.org/10.1080/17432979.2021.1880968>
- Shpigelman, C. N., & Gill, C. J. (2014). How adults with intellectual disabilities use Facebook? *Disability & Society*, 29(10), 1601–1616.
- Wasserman, D. (2019). A case for greater risk tolerance in Internet use by adults with intellectual disabilities: A comment on Chalhouni et al. *Ethics and Behavior*, 29(3), 223–226.
- Williams, P., & Hanson-Baldauf, D. (2010). Testing a Web information portal for people with learning disabilities. *Journal of Research in Special Educational Needs*, 10(1), 42–51.

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