

“Please send me the link for tomorrow, María” human-rights based participatory research with people with learning disabilities via Zoom

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Abstract

Background: This paper describes the experience of conducting a co-researched project with people with learning disabilities in Madrid, Spain, during the COVID pandemic and lockdown. I discuss the advantages and limitations of working online and challenges encountered while coordinating and facilitating the research.

Methods: Our research project was on the impact of COVID on the lives of people with learning disabilities, which the eight co-researchers chose. As part of my PhD, I offered my services as researcher to work together with persons with learning disabilities. Eight people took up my offer. We worked together from January 2021 to March 2022 virtually and I recorded this experience. I have written the paper, but as part of my co-researcher agreement, I have shared my reflections and work with my co-researchers, and we have co-written a section to share our findings.

Findings: In this paper, I discuss the advantages and limitations of working online, challenges I encountered while coordinating and facilitating the research and the work together. Remote work enabled the group to work on a biweekly basis and with members from different parts of Madrid. It saved people time and effort getting around town, yet we had to introduce express times and spaces to socialise and create a working relationship that is less natural than during in-person interactions and breaks. During our fieldwork, we found that the pandemic had spurred the access to digital devices and programmes, but people may still be reliant on their environment, carers or supporters to facilitate it. I included a section written with my co-researchers, in which we reflect together on the experience of working online and how we reached out to their peers during our fieldwork. We identified limitations due to our online research methodology such as lack of owning a digital device, the difficulties having access to a private space from which to connect online and the joy of meeting other people to exchange experiences.

Conclusion: Human rights based participatory research can be done online. There are different ways of overcoming barriers to participation. However, there are

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people with no access to the internet or without digital skills that are being excluded and we must ensure that we reach out to them as well.

KEYWORDS

CRPD, learning disabilities, online, pandemic, participatory research, Spain, Zoom

Accessible summary

- I did an online participatory research project with 8 people with learning disabilities from Spain using Zoom. Participatory research means taking part and being involved in the decisions on how the research is done.
- I discuss online way to make decisions, share power and control over the research, have some social connection in the group, and give information.
- I show that people with learning disabilities can work remotely but need more opportunities to learn digital skills. Digital skills are the skills to use technological devices, e.g., a smartphone, a tablet or a computer.
- Digital skills were very important during the pandemic and the lockdown, for example knowing how to find and use information and stay safe online and how to communicate with others over the internet.
- Participatory research projects need to support co-researchers to learn new skills and apply them. The researchers need to be creative to make the online work engaging.

1 | INTRODUCTION

This paper summarises an online participatory research experience with persons with learning disabilities in Madrid, Spain, which took place during the COVID-19 pandemic. It focuses on the research process. In this paper, I discuss how we used digital tools to conduct our research. We learnt how to make the most out of digital programmes at our disposal, our working sessions and to ensure the project was interesting. The paper includes examples of the structure of our sessions, Zoom functions used and our communication and decision process. It presents the findings on digital exclusion from our co-researched project on the impact of COVID-19 on the lives of persons with learning disabilities. This paper can provide some guidance when planning longer online projects with persons with learning disabilities and it calls for more learning opportunities.

2 | BACKGROUND

This paper was written by the academic researcher. The findings and discussion points related to the study on the impact of covid on the lives of persons with learning disabilities are owned by the co-researchers¹ of that project. We put together a research plan,

collected the data, did the analysis and writing online. We discussed different points related to digital inclusion of persons with learning disabilities that transpired during the analysis of their own research findings. The co-researchers agreed to this publication as part of my own research on participatory research methodologies. We published a paper together in Spanish on how we had worked together in an online publication thanks to the Inclusive Research Group at the Universitat de Girona (Palazuelos Velayos et al., 2021). The findings herein presented were discussed with the co-researchers in previous sessions. However, the co-researchers have not been involved in writing this paper due to language barriers and lack of time.

3 | METHODOLOGY

This research project is a human rights participatory research with persons with learning disabilities in Madrid, Spain. Human rights based participatory research methodology builds on participatory, emancipatory and inclusive research to propose a human rights-based research methodology (Arstein-Kerslake et al., 2020). It uses the United Nations Convention on the Rights of Persons with Disabilities (CRPD, 2007) as a framework to guide the research project and research relationships and the human rights model of disability as enshrined in the CRPD as basis to the research. The use of the CRPD in combination with participatory research methodologies seeks to prevent research from marginalising (Arstein-Kerslake

¹Adela Palazuelos, Adrián Corona, Ángela Sánchez, Gema Alises, Marta Sancho, Paola Cauja, Víctor Sanz.

et al., 2020). The CRPD places a strong emphasis on participation and was the result of a highly participatory drafting process. Following this model, the research process must respect full legal personhood of people with disabilities, including informed consent. The human rights approach highlights the barriers and discrimination people with disabilities face, e.g., limited access to education. In this project, I provided training on doing research and organised meetings with other disabled researchers and inclusive researchers to ensure that my co-researchers met other researchers and heard their perspectives on research.

The CRPD also covers the right to employment, which, when considering potential research projects may translate into hiring disabled researchers or ensuring adequate payment to disabled participants who participate as experiential or professional experts (Arstein-Kerslake et al., 2020). In this case, I included funding to pay my co-researchers for each working session during the 6 months we initially agreed to work together.

Arstein-Kerslake et al. (2020) propose three principles for rights-based disability research: the research must be initiated and led by the disability community, it should respond to a rights concern, and the outputs must directly address this concern and be returned to the community in accessible way. In our project, my co-researchers selected the research topic and all materials were drafted with their participation. The group included experts on validation of easy-to-read texts.

Inclusive research methodologies have opened research for persons with learning disabilities, who were rarely included in participatory research (Mietola et al., 2017). It provides guidance on how to tackle some of the barriers to include people with learning disabilities, e.g., the tension of being academically rigorous and yet producing valuable and accessible research to people with learning disabilities (Walmsley & Johnson, 2003).

Nind and Vinha (2014) highlight the need to establish trusting relationships through informal spaces and the value that connecting with others had for co-researchers. Further, the authors raise the issue of power and privilege held by the academic researcher (such as being paid or getting a PhD) and how to manage these power relationships. They also highlight a need for flexibility and that at the heart of inclusive research is support, negotiation, and interdependence (p. 5).

The pandemic has forced social research to look for remote options, which may be challenging for participants who prefer face-to-face interactions (Hall et al., 2021). Participatory research methodologies rely on establishing trust and nurturing relationships, which can be harder when done remotely (Hall et al., 2021). Other researchers found that it is important to have a creative and sensitive approach, which must be pandemic friendly (Lazarte et al., 2020). Many projects used collaborative working tools (e.g. google slides, padlet) to facilitate the online collaboration (Hall et al., 2021). These authors also found that frequent emails, video calls or mobile messaging promoted engagement and benefitted marginalised participants in maintaining relationships.

Ethics approval was granted by the Scientific Board of the Instituto Superior de Ciências Sociais e Políticas of the University of Lisbon. Plena Inclusión Madrid, an umbrella organisation, held a session with the

researcher to examine the research proposal and appointed a referral person for participants who attended all information sessions and was available throughout the project for all participants.

3.1 | How the project came together

Arstein-Kerslake et al.'s proposal (2020) guided my work. I offered my services as an academic researcher to conduct research together in the field of social policy and law through an inverted job offer,² under which people could hire me to work for them and get paid for our work together. In practice, this meant that a group of people with disabilities would be in control over the work, and could decide what to do themselves, what to delegate and what to do together. I planned information sessions, funds to pay my co-researchers and a potential timeline of six months, which proved to be too short.

In November 2020, I offered my services to people with disabilities in Spain to conduct a small research project and training on research skills. I held two online information sessions and recorded them for further distribution. People could choose to attend the training only, participate in the research project or both. Due to the pandemic, all work was planned to be online. Information sheets were sent as a follow up to the meetings and consent was sought from all participants in written form.

In January 2021, eight adults with learning disabilities from four organisations part of Plena Inclusión Madrid joined the training and research project. We arranged for two online meetings per week, one session for a training module and one session to work on the project. Once the training was finished, we doubled the time to work on the project. We kept this schedule for seven months, and continued meeting once a week after the summer until March 2022. Our data collection started in May 2021 and finished in September 2021. In November, we started working on our report while continuing with our data analysis. The final report was launched on 31 March 2022 over Zoom. One co-researcher dropped out in April 2021. Our initial plan was to work for six months, until June 2021. The payment was issued in August 2021 due to administrative paperwork. All co-researchers were repeatedly offered the possibility of not continuing the work throughout the project. Moreover, the decision to work together for a longer period than initially planned was made during our discussion on our research methodology. My co-researchers preferred continuing on a similar pace and not rushing our work, as well as being able to engage with different data collection methodologies (survey and focus groups). However, they could only be paid for the initially planned six months.

3.2 | Working together

The working sessions were held alternately to the training sessions. There were two subgroups for the training sessions, which included

²I thank Clóna de Bhaillís for this idea.

slides with content and examples, videos and surfing websites from other research projects. I used the Zoom whiteboard to draw schemes, examples or to write out our discussion points. The co-researchers could also use the whiteboard to point to what had not been clear, underline things or draw.

During various sessions, we debated different potential subjects to research, as well as looking at other examples of inclusive research (e.g., from the Irish Inclusive Research Network and from the inclusive research group at the University of Girona) and general research on disability issues or social policy in Spain. The debates were done in breakout sessions and then shared in the common session. We collected eight ideas and then voted anonymously with the Zoom polling tool. After that, we developed a research question, and discussed what exactly we were interested in. The group chose to research the impact of COVID-19 on their lives, out of concern for their peers and friends and because it was a very timely topic. There was a very positive reaction from their peers, who expressed to us that they felt a great need to talk about COVID-19, the lockdown, the pandemic, and the deaths.

We used the polling function on Zoom to spark discussions (the poll asked opinion questions that positioned people and then we debated them), to collect feedback on how we were feeling, to decide on minor issues (dates, times, preferences) or to make final decisions after debating them. The co-researchers enjoyed using the Zoom polling tool and the anonymity it allowed, even if often people disclosed their vote afterwards.

Oral communication was our main form of communicating. I emailed them a small summary or our notes in a PowerPoint presentation after each session. I sent reminders in advance with the link to our Zoom session, which remained the same throughout the project. People received emails but did not respond to them. Responses or questions were usually sent over the phone, SMS or via WhatsApp.

The group agreed to create a WhatsApp group, although initially two group members did not have WhatsApp. One of them joined WhatsApp and the group later. Due to this absence of the whole group being on WhatsApp, we agreed that all communications from the academic researcher would be via email. I also used surveys on various questions, e.g., to get feedback, decide on most convenient dates and preferences.

3.2.1 | The co-researched project

The co-researchers chose to research the impact of COVID-19 on the lives of persons with learning disabilities in Madrid, Spain. The project was supported and disseminated to its members by *Plena Inclusión Madrid*.

The co-researchers conducted a survey, with 118 participants and eight focus group discussions. We adapted the survey on COVID-19 used by the Spanish National Statistics Institute to our context. We developed the focus group guidelines after examining the results of the survey and based on references from the literature,

e.g., a study commissioned by *Plena Inclusión* (Navas et al., 2020). We tested our research tools (survey and focus group guidelines) with people with learning disabilities from another Spanish region (Galicia) over Zoom and edited them accordingly.

Recruitment of participants was done through *Plena Inclusión Madrid's* institutional channels of self-advocates and the co-researchers' peer network. Information sheets, an information video and consent forms were sent in advance and collected via email prior the meetings. Some co-researchers held information sessions at their organisations. At the beginning of each meeting with participants, we reminded them participation was voluntary and the possibility of not answering some or any of the questions. We set up a shared email account with protonmail as server for safety issues and to enable collective control over the email account, rather than having a single person receive all emails. We accessed the email account jointly during our working sessions, which made it easier to set appointments for the survey or focus group.

The survey was done in person by pairs of co-researchers at their day care centres or over Zoom to participants from other organisations. The focus groups discussions were all done over Zoom. Two co-researchers led the focus group and I attended all focus groups to support the two facilitators. The focus groups were divided in three categories: people living at home with their families, people living in small group homes and people living in residential care. These categories were subdivided in two age groups: from 18 to 39, and from 40 onwards. In total, 18 women and 10 men participated. While initially we had planned for people join from their own devices, the focus group participants joined from one computer at their day care centres or residence. The group had planned to enable the chat function, which could not be used, and the audio quality was not so good.

The focus group discussions were professionally transcribed, and I proofread them. Following the group's preference, we watched recordings to do our analysis over a span of two and a half months, and I analysed the remaining three focus groups with the categories and themes developed during the first four focus groups. I presented my analysis of the remaining three focus group interviews together with quotes and snippets of recordings to get my co-researchers' feedback. During all meetings, I took notes of our findings and discussions on PowerPoint slides, which I sent to my co-researchers as a summary of our sessions after our meetings. I used these slides to put together a report draft, which we reviewed together in the project's final months.

We presented the research findings over Zoom, hosted by *Plena Inclusión Madrid*. Attendees included a couple of scholars, some professionals and mostly people with learning disabilities from Madrid and one from Galicia. We split the presentation in eight parts: I presented the first two slides with an explanation of what research is and then the seven co-researchers presented three slides each with the research findings. This was followed by 30 minutes of questions on the experience of doing research and the research findings. One attendee expressed the wish to participate in future participatory research project.

4 | FINDINGS AND DISCUSSION

4.1 | Working online

The pandemic had put a halt to any research or work to be conducted with persons with learning disabilities. Initially, the plan was to start in September 2020, but it was postponed in hope for an early end of the pandemic. Eventually, I realised there would not be a foreseeable end to the pandemic and its measures, so I decided to move the project online. I was aware that many people with learning disabilities do not have access to their own smartphone, tablet or computer, but that many had begun to work remotely with their organisations and to participate in *Plena Inclusión's* Madrid self-advocacy and representation programmes. The lack of access to network and devices is a common theme in participatory research, as well as the lack of digital skills (Hall et al., 2021).

I initially planned to have different in person information sessions at different public locations, and to rent an accessible space for our working sessions, to ensure that the research was done beyond the usual programmes run by service providers.

My first encounter with digital exclusion was the fact that many people with learning disabilities are only reachable through their organisations. That meant that I had to get the message of this project going through *Plena Inclusión Madrid*, who had to reach through the active and connected support workers to reach people with learning disabilities.

There was no registration form to attend the information session, to avoid additional barriers, e.g., filling in a form or not having a personal email account. People attended the information sessions at their day centre, and recordings were available for people to rewatch or watch if they had missed it.

The topic to explain during those meetings was complex: what is research, how will the project work, etc. Keeping people's attention over a shared screen in an office or a gym is generally not easy. Zoom presentations do not allow much body language reading and checking if people remain engaged or if one is explaining things right. In a similar line, Strong et al. (2020) advise continuous "check-in" with participants. Participation is also harder, as people might talk over each other, or questions might be misunderstood due to poor connection or background noise.

One of the limitations was that participants had to be digitally knowledgeable to a certain degree. Participants had to be able to access a computer, tablet or smartphone and connect onto Zoom without support or have support available for this endeavor. In this project, only one person had permanent support from her family to connect to Zoom and to unsilence the microphone. We tried to avoid having to silence her microphone unless she had too much background noise. All participants except one had their own email account. One used her mother's email account. Nearly all of them own a smartphone.

I created a single Zoom session ('a room') for the duration of the entire project. It had the same link, session number and password throughout the project. All co-researchers could access the room

without me (the host) having to accept them. I set this to make sure people could start talking even if I was running late or to have a Zoom link available if they ever decided to meet sometime else without me. My co-researchers had learned how to join Zoom meetings, but not how to create them. Further, regardless of having the same link throughout the project, they requested to receive an email some days before the meeting as a reminder with the link. Whenever I forgot to send it, they reminded me over WhatsApp: "Please send me the link for tomorrow, María".

It was important that I sent the link, the room number, and the password, as each one had learned a different way of accessing Zoom. Most of the co-researchers joined the meeting with their name, but some users stated the device (e.g., 'Galaxy 777'). During the first months, I asked them to change it to their own names, but some asked me to do it instead. After those initial months, I stopped asking them to change them.

During our negotiations on how to work together, with what frequency, what happened if somebody missed a meeting, how many meetings could people skip, we also had some housekeeping rules for Zoom. We agreed on including breaks after 45 min, respecting speaking turns and raising hands, silencing our microphones if not talking and not sharing the recordings or discussions beyond the group unless agreed otherwise.

4.2 | The zoom functions

During the development of this project, we learned more about Zoom and its functions. I subscribed to a professional account to have unlimited time sessions. The different functions contributed significantly to our decision-making processes, power sharing and socialising.

4.2.1 | Being a co-host

After a few sessions, I thought of making them co-hosts as a way of sharing the control over the meeting. We tried it out a few times. Some teased others by silencing them. However, we then realised that Zoom users who are co-hosts cannot vote whenever polls are launched. We decided that the poll function was more important than being co-hosts.

4.2.2 | Breakout sessions

I used the breakout session function from the beginning to allow for small group discussions without me and to mix up people from different organisations. During the training sessions, I included short exercises, and opened the breakout sessions for 15 minutes, and sent them a warning when there were 5 minutes left. One participant had major difficulties joining the breakout sessions during most part of the project and relied on family members to assist. Towards the end of the project, it became easier for her and decreased its use. The

breakout sessions were also useful during our quiz sessions. I organised quiz sessions to review the training content or to include some fun content in our working sessions. We split the group in teams and had a short quiz. People had to be silenced to avoid speaking out the response and shared their responses in their breakout session. Afterwards, we compared results and calculated the score. The quiz was particularly popular and helpful to go over doubts and the content explained during the training session and had a relaxing effect on all of us.

4.2.3 | The polling function

I introduced the poll function initially to get feedback at the end of the sessions on whether they were clear and understandable. My co-researchers liked the poll function, so we decided to use it to make final decisions about dates, yes or no decisions and multiple choice decisions. Further, I used it to ask my co-researchers about opinions that would spark our conversation, sometimes to have informal conversations or on research related topics.

The poll function stopped working around November because I had not updated my Zoom application. This was perceived as a major hindrance and led to some frustration, adding up to our general moment of being tired of the project and a feeling that everything was taking too long. It took me a couple of weeks to figure out that I needed to update my Zoom. This incident was an insight into how I learned digital skills.

At the beginning I also used online survey tools to collect feedback on how my co-researchers' experience of the training and project. However, my co-researchers preferred to do all project related activities during our working sessions or having a meeting with me. Some had certain problems with the online surveys (e.g., not pressing the final submit button) but eventually all of them managed to vote. We stopped using online surveys as the Zoom poll function and the small breakout sessions without me worked well to give feedback and make decisions.

4.2.4 | Chat function and opinion buttons

My co-researchers started using the chat function after five months, especially when we were discussing something and somebody wanted to raise their hand, have their idea or opinion noted or somebody joined the meeting later and wanted to greet. We did not use it much but envisioned it as a good tool for the focus group. We thought it was a way of noting your experience or opinion before the conversation's subject changed or one forgot. However, our focus groups ended up being with all participants in front of one single screen, so nobody used the chat function, despite our offer.

We explored the opinion buttons (thumbs up and down, smiley face, heart, go faster, go slower, applause) during our informal conversations but did not use them as part of our decision-making process, nor were they available during our focus groups.

4.2.5 | Screensharing

I employed screensharing to project my slides, share videos or websites. The downside of this was that I could no longer see all co-researchers faces on the screen, which made it harder to 'read the room'. I shared my screen to show the notes I was writing down, which allowed for my co-researchers to correct me or ask me to include certain information. Any online search of information, icons to include into our easy-to-read or other petitions were done over screensharing. This allowed us to elaborate our documents together, to research different illustrators or look at the same information when discussing or deciding certain issues. We had three in person meetings by the end of 2021 and a final one in 2022, all outdoors and to facilitate in-person engagement, not to work.

All our email correspondence with potential participants or with the organisation that was supporting our dissemination efforts was written together, using the screensharing function. We checked our email inbox together and coordinated appointments during those meetings. At some point, some co-researchers learned how to use screensharing and shared their personal photos during our social rounds. The screensharing function enabled me to share information, to be transparent and it allowed my co-researchers to instruct me or to do searches together. It was very useful and effective.

4.3 | Benefits of working online

Despite the pandemic, we managed to work together on a regular basis and to complete a project within 15 months. My co-researchers had some experience with Zoom (joining bigger meetings, going into breakout sessions) and this project increased their experience using other functions. Our co-research benefited from this previous experience. One co-researcher was also familiar with excel and did most of the data processing from our surveys.

Working remotely allowed us to meet frequently. During the first six months, we met twice per week, and allowed my co-researchers to meet from different locations. One of them moved from living at home to a shared accommodation during our project. Some co-researchers went back to their day care centres and attended working sessions, especially the data collection ones, from there or from home, depending on the scheduled time. It gave us enough flexibility to adapt to all schedules.

Secondly, it reduced travelling costs and times. During the first six months, our meetings were an hour and a half long. From September 2021 to March 2022, we shortened them to 1 hour, to avoid exhaustion. By then, all co-researchers had resumed their attendance to day care centres and other activities, and had busy schedules.

Thirdly, my co-researchers attend different organisations, which is rare unless it is a working group of the umbrella organisation Plena Inclusion Madrid. All co-researchers agreed that they particularly enjoyed meeting and working with new people.

Fourth, working online allowed co-researchers to join from a private space, outside of organisational spaces, which contributed to talk different realities and concerns beyond the day-to-day of their organisations.

However, the final elaboration of the report and analysis were harder to manage. We were feeling tired, re-watching our focus group interviews or reading the transcripts took a long time and our screens were too small to elaborate big pictures or to have different documents open to facilitate the analysis or illustrate connecting themes. It was around this time that we shortened the duration of our meetings and included a 5-minute break. Additionally, it was sometimes difficult to keep the attention and interest in the conversation and leave enough time for reflection.

Finally, working online allowed us to meet other researchers and peers from different regions in Spain. These encounters and meeting new people were very valued by all co-researchers and some of the participants in our fieldwork.

4.4 | Control over the research

Participatory research requires that the research is controlled by people with disabilities. Working online enabled this to a certain degree because the project was put together beyond the control of their organisations. My co-researchers decided the meeting frequency, duration and how to involve their own organisation. For instance, some co-researchers decided to do information sessions and a call to participate within their organisations, while others left it to the dissemination efforts of the umbrella organisation.

Secondly, I had structured my offer to work together so I could hand control over to my co-researchers, but sometimes during delegation of complex or arduous tasks the academic researcher may regain control. In this regard, I found that being able to share my screen and show the documents or decisions I was writing down, and that my co-researchers could comment, criticise, or suggest edits was very helpful to return the control over the research to them. Thirdly, the digital forms of communications allowed for private spaces (within the Zoom breakout sessions, our breaks or if they wished to join the room without me there) or over WhatsApp. All co-researchers had each other's numbers in a natural way and kept in touch.

More symbolic ways of sharing powers failed. For instance, I tried to make them co-host to share the control over the meeting space, but this hindered the polling function from working, so we stopped making people co-host. Further, considering conflicts or misunderstandings, my co-researchers sometimes turned to me to mediate or intervene. I actively tried to refrain from assuming that role but rather asked the people involved to find time to discuss what had happened, have a working session to talk about social rules or whenever we felt somebody had been hurt, at least one co-researcher would join me to talk to the offender and work around it.

The co-researchers established housekeeping rules for Zoom and WhatsApp. These included not using WhatsApp for research unrelated topics and not sending chain messages. They also established the hours during which messages could be sent. These rules were respected, and the group has functioned very well. I left it to each co-researcher to contact or reply to me in their preferred mode of communication: I sent emails with information or questions,

and four people replied over WhatsApp, a private message or in our group, one over SMS and two over phone calls. This was in line with the findings reported by Hall et al. (2021).

4.5 | Equal exposure

I had not considered the importance of the background of our meetings. When explaining the working methodology, I recommended joining the training and working session from a quiet and private space to be able to talk freely and not have background noise. However, I did not foresee the effect of being able to see into people's bedrooms or homes. Research with persons with disabilities has often been criticised because of the position, control, and power the academic researcher holds. Research with persons with learning disabilities has said to be confusing for persons with learning disabilities, who may interpret the relationship as friendship. In general, people with learning disabilities' lives may be more exposed to researchers, due to intrusive research or to the need to explicit support needs, the researcher visiting private homes or day care centres. In this case, the online research exposed our private homes equally. I did not use background filters (this Zoom option appeared later during our project), although we played with them and learned how to use them. My co-researchers were aware of what was visible, we spoke about it during one of our preparatory meetings for our data collection. My co-researchers saw parts of my personal home and other places I connected from, my dogs, my partner, occasionally family members. Due to the pandemic, they found out about my own family's health, and difficult periods of time. Our work continued throughout complicated times for all and it became a respite from other lockdown/pandemic realities. We knew what was going on in each other's lives, without getting too involved. I soon realised that we needed some informal space at the beginning and end of meetings to get to know each other and work as a group, so we decided to start with social rounds. This consisted of going around the room and talking about how one had been, something remarkable from their past days or something one was looking forward to. After one had finished, one chose the next person to speak. In combination with the visibility of our personal spaces, it meant that our privacy was equally exposed. I did not talk to my co-researchers' support workers or family except to assist with administrative paperwork for the university to pay them. My co-researchers had control over what they wished to share from their personal lives, and I was open about mine whenever they asked, without ever feeling that it was too intrusive either way. The need for these informal spaces has also been identified by Nind and Vinha (2014).

4.6 | Friendly yet professional

The clarity on the nature of the relationship with the research is a frequently raised concern when discussing participatory research with persons with learning disabilities. Some might misinterpret it as friendship or as a promise for something in the future (Walmsley & Johnson, 2003). In this project, we signed a working agreement at the

beginning of the project, and I provided clear information to manage future expectations. I explained early on and throughout the project that I had no further funding and could not guarantee new projects. I also made sure they met other researchers, including an inclusive research group from the University of Girona, to enhance potential collaborations and to learn how other people work.

Throughout the project, my co-researchers expressed satisfaction with the work and a desire to engage in new projects. We managed to share personal things during our social rounds and during our in-person meeting, without becoming too engaged or losing sight of our professional framework.

4.7 | Learning new digital skills

I included a training course on research skills to make sure that my co-researchers or people who were interested in doing only the training course had an opportunity to learn more about research, why and how it is done. I included sufficient time to try different methods out, e.g., filling in surveys, exploring results from other surveys, or looking at qualitative research projects. However, I realised that I had not included enough time to acquire new skills on secondary issues, e.g., searching on the internet, or trying out how to do a PowerPoint presentation. In my experience, people with learning disabilities are often required to do a formal course before letting them try out their skills or use their knowledge. In this project, I realised afterwards that I had never considered asking them to prepare the slides or whether they even have Microsoft Office on their devices. Secondly, many of the digital skills we learn is because we explore apps, programmes and tools. I am not sure whether people with learning disabilities are given the same opportunity and time to do so. In our project, we did play around with Zoom at certain times, e.g., when all of them were co-hosts and they silenced each, or using emojis, but never beyond Zoom. In my own learning process, exploring and trying to figure out how things are done has been key. I shared some of these exploratory learning processes with my co-researchers when working with Excel and Canva. They saw how I typed what I was looking for in google and watched the explanatory tutorial with me. It is nevertheless not the same as doing it oneself.

4.8 | Shared findings during our co-researched project

This section is a translation of the findings related to digital inclusion we discussed during our project. This debate was sparked because we asked participants during the focus group interviews whether they had learned how to use new technology and what they used it for. I have translated the findings from Spanish into English, maintaining the bullet point format.

In our co-researched project, we found that:

- To reach out to people with learning disabilities, despite many of them having phones and access to internet, we went through the organisational channels and professionals.

- However, we did receive four emails from individuals with learning disabilities with interest in participating in our study.
- Most people had learned how to use videocalls, WhatsApp and Zoom or similar programmes but only as attendees.
- Participants used their digital skills to keep in touch with family and friends and for entertainment (music, games and tv or films).
- There is now, post lockdown, more training on digital skills available.
- People who lived or relied on the support of older family members who were not familiarised with technology have less chances to access tablets, computers or smartphones or internet connections.
- People in residential care are more dependent on the institution to set up calls and had less access to digital devices of their own.
- Participants considered digital skills important to keep or find jobs in the future.
- The locations where people joined were not always private.
- During the lockdown, the common prohibition at some day care centres or residences of using one's phone during working hours was lifted.
- People with learning disabilities' access to the internet or phone is often subject to control.

During our literature review, we found a study from Spain that reported that students with disabilities had been left behind due to lack of digital skills (Bonilla-del-Río & Sánchez Calero, 2022). This gap can increase the education gap between people with disabilities and the rest of the population. We also identified that we had only been able to reach those participants who had access to a device, or who had been informed by their organisations of our call for participants.

We also debated the lack of privacy of the space where the participants were versus their desire to participate, and which to prioritise. Most times, participants agreed to having support workers present or were sat in a common room with other workers or peers passing through. This also affected the audio quality.

5 | CONCLUSION

Our experience doing human rights based participatory research together shows that it is possible to conduct participatory research projects online, taking into consideration the need for informal and check-in spaces (Strong et al., 2020) and to allow for sufficient time for reflection and to connect the personal experience with the findings (Nind & Vinha, 2014). People with learning disabilities learned many new digital skills during the pandemic and this has enabled new possibilities to connect with academia and other projects. There are many possibilities within new technologies to be explored that can increase opportunities to participate in research.

As our co-researched project on the impact of COVID-19 shows, these digital skills were key to ensure participation and social connection. Our findings show that people highlighted the possibility to talk and the online connection as very important to stay informed and to be in touch with their friends and family.

Learning new digital skills was only available to them if they already owned or could afford a device, and if they had access to support. In certain instances, people who live with family who also struggle with digital skills, the acquisition of these skills is harder. This experience has proven again that people with learning disabilities are not given opportunities to benefit from new technologies or to learn digital skills. Our co-research findings also show that participants felt that digital skills were important for employment and social connection.

Online connection has worked when the circumstances required it, but I am unsure whether this will go beyond the pandemic. One of my co-researchers expressed a desire to work from home a couple of days per week, but the administrative regulation of her day care centre does not allow hybrid attendance. Staying home or not attending due to other unrelated projects means risking losing one's spot at the organisation.

Despite having some digital skills, there are other barriers to fully access the opportunities the internet and the digital world present. For instance, not having a personal email account will make it difficult for someone to register, download or subscribe to blogs or newsletters of their interest.

Zoom provided great tools for a collaborative project but is more tiring and creativity is required to make the most out of the available options and make the work engaging, rather than simply presenting and talking.

Finally, our co-research project included spaces to acquire and try new skills, yet not sufficient to practice and deepen the learning process. Both in the outset of my proposal and in the development of our co-researched project, we did not reach to people without digital skills or internet access (e.g., people with higher support needs, organisations who decided not to engage in this type of activities or people with no support at home to use new technologies). The CRPD advocates for participation and digital inclusion for all people and highlights the need for new technologies and the internet to become accessible to all. It affects the right to participation and information, and ultimately, the right to freedom of expression. However, this project shows that we are still leaving people behind and that there is much to do to ensure that all can learn, formally and informally, and enjoy digital inclusion and benefit from research.

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CONFLICTS OF INTEREST

The author declare no conflicts of interest.

DATA AVAILABILITY STATEMENT

Research data are not shared.

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