Meeting Participants with Intellectual Disabilities during COVID-19 Pandemic: Challenges and Improvisation

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ABSTRACT

With the COVID-19 pandemic, we all suffered from several restrictions and measures regulating interaction with one another. We had to wear masks, use hand sanitizer, have open-air meetings, feel a combination of excitement and frustration, and eventually depend on online video calls. The combinations of these additional requirements and limitations, while necessary, affected how we could involve users in the different stages of design. It has profoundly hindered our chances of meeting in person with people with temporary or permanent disabilities. In our project, involving people with intellectual disabilities in the museum context, we also had to deal with museums being closed and physical exhibitions being canceled. At the same time, guardians and caregivers often turned to a stricter interpretation of anti-COVID measures to protect people with intellectual disabilities. This paper aims to discuss these challenges and share our lessons about coping with challenging and unpredictable situations by using improvisation.

CCS CONCEPTS

• **Human-centered computing** → *Accessibility theory, concepts and paradigms*; **Accessibility design and evaluation methods**; • **Social and professional topics** → **People with disabilities**.

KEYWORDS

Meeting Participants, Improvisation, COVID-19, People with Intellectual Disabilities

1 INTRODUCTION

When designing interactions with and for people with disabilities, meeting and planning sessions with participants are very important to understand their needs, foster inclusion, creativity, and usability.

The human-centered approach is used to design solutions together with people with disabilities instead of designing for them.

Unfortunately, the COVID-19 pandemic has brought new challenges and added an extra layer of complexity to the organization of sessions for understanding the participants, develop solutions and test them.

We all had to adapt to masks, hand sanitizes, open-air meetings, excitement, frustration, and online video calls. In our project involving people with intellectual disabilities (ID) in the museum context, we also had to deal with museums being closed, physical exhibitions being canceled, and at times, exhibitions being offered in an alternative online version. All of these challenges have an impact on the way we engage and conduct research with people with ID.

Our participants are often part of associations and special schools, having family members, caregivers, or guardians responsible for their safety and well-being. As they can belong to high-risk groups, having direct access to them proves almost impossible, depending on the local level of alert and the corresponding measures taken by their guardians, who were really afraid of the possibility of our participants getting sick and took a very defensive close stand. For dealing with the ever-changing situation, we propose to resort to improvisation. Here, for improvisation, we intend "...a creative act composed without prior thought" [3], and we refer to the work by Lee et al. [5] as an example of improvisation to deal with unexpected circumstances during collaborative design.

This paper will share our experience and what we learned from coping with such a demanding situation by using improvisation.

2 RELATED WORKS

Literature describes methods to deal with improvisation and co-design. Some works have as target groups children, older people, and people with disabilities. Even if the focus is on different groups of people with permanent or temporary disabilities and needs, we report experiences showing how to design in critical situations by taking advantage of improvisation.

Gerber argues that improvisation can build perspectives and experiences that are crucial for designers, such as learning through error, creative collaboration, fostering innovation, supporting spontaneity, and presenting ideas [3]. Conducting synchronous online co-design sessions adds layers of complexity and uncertainty to collaboration [5]. The work published by Lee et al. introduces a model to co-design with youth synchronously and presents improvisation as a method of inquiry for co-design sessions.

Because of the lack of guidelines to support researchers, Ryan et al. [2] propose a procedure to help co-design processes with people with ID. Sitbon and Farhin [9] present what they learned from

a co-design session with adults with intellectual disabilities. The exercise aimed at designing a mobile application to support them using public transports. Additionally, by analyzing video recordings of co-design groups, Chinn and Pelletier [1] explored how the tensions between co-designers and experts' different abilities were manifested.

The Convention on the rights of people with disabilities [8] emphasized the importance of rethinking the concept of accessibility in cultural spaces. Mastrogiuseppe et al. [6] used an inclusive research paradigm to involve people with ID and understand their perceptions and obstacles to knowledge accessibility.

3 RESEARCH DESIGN: DEALING WITH CHALLENGES AND IMPROVISATION

In order to discover how to use technology to make visiting a museum a more accessible, rewarding, and memorable experience, we planned several co-design sessions that unfortunately could not take place due to the COVID-19 second wave restrictions. From previous observations, we noticed that visitors' level of involvement was higher when exposed beforehand to material describing the artworks on display, but that was a demanding process for visitors and their educators. Therefore, we wanted to study how technology could help involving them in the visit. At the same time, we aimed at observing their reaction to the narrative provided by the cultural mediator. A comparison between our initial plans [10] and our results using improvisation can be seen in Table 1 and they will be discussed in this paper.

Different from what we planned, we had only two sessions with our participants. The expectation was to have eight participants, but we had five that, luckily, were available in both sessions. They are all adults, three female and two male, with intellectual disabilities and ages varying from 30 to 61 years old. They all communicate in Italian, live in Lugano - Switzerland, and volunteer to participate in this research. One of the researchers had been working with this group before and established a more open link in terms of communication.

We had access to the participants through an association taking care of people with disabilities and offering them extra activities for their free time, such as "art, chat and coffee" sessions from their culture and education training program. They are keen visitors to art exhibitions and museums in the last few years. Besides, we had also planned to involve a few experts in ID but given restrictions on maximum numbers of participants they could not join us, and so, we missed their valuable insights as well as their help as entertainers during the study.

3.1 Session I: Observing the participants in the museum

The first session (Fig. 1a) happened, after some attempts, in October of 2020 at a local museum called LAC. The whole session took around 2 hours and aimed to understand the user's needs in the museum context. The participants visited a temporary exhibition in a guided tour composed by the participants, cultural mediator, association director, and the authors of this paper. To start, we chose a meeting point in front of the museum. After the five participants arrived, we entered the museum using masks and hand sanitizer. While wearing a mask can be part of the life of some people with disabilities, this is a situation our participants never had to face before, and they had to adapt. The cultural mediator[1] helped visitors to familiarise themselves with the building and with us. She also described what would be their role in the project and the details of their collaboration in the study. She collected their consent as required by our ethics process [7] together with that of their guardians obtained in advance. Once visitors had agreed and were happy to collaborate with us, the cultural mediator guided them to store their belongings in the lockers, and finally, to visit the displayed artworks.

The guided tour took around 40 minutes. We made an ethnography study, collected data from observing the participants' behavior during their visit, recording audio, and taking notes without interfering in their interactions with the cultural mediator and artwork. We tried to be the most discreet we could to make them feel comfortable with their visit.

The cultural mediator engaged in dialogue with the visitors by asking several questions related to the artworks, their personal experiences (a strategy to recall memory and avoid abstraction), and the context where the artworks were inserted. The participants were very different between them and had different reactions and personalities, such as:

- Participation: one female participant was extremely positive and participative. She answered almost all questions or repeated other participants' answers;
- Laughing: one male participant was constantly smiling, laughing, and showing his contentment to be part of the visit;
- Brief answers or no participation: one female participant was very quiet, with no answers or extremely brief ones;
- Getting comfortable: a male participant was quiet during the first half but, after getting comfortable, answered the questions.
- Concentration: one female participant was constantly asking for silence verbally or with the "shhh" sound.

Finally, after the meeting, we also had a coffee, a snack and a chat together. Therefore, we planned to meet one week later as part of our contextual inquiry to discuss how the visit went. Unfortunately, we could not proceed because the cultural mediator was sick. We postponed to the following week, but then we faced the COVID-19 second wave restrictions: avoid closed places and gatherings of more than five people. The safety measures had a massive impact on our plans. Alternative solutions, such as synchronous online meetings, were not possible because of the lack of access to computers and available guidance on how to attend online meetings. After months of unsuccessful attempts, the cultural mediator kindly volunteered to meet the users one at a time, in person and open-air, to help them get connected and proceed with the following research steps. In the week we were going ahead with this solution, Switzerland announced to relax the safety measures and soon it would be possible to meet open-air in a group of up to 10 people, so we proceeded with the in-person plan.

[1]The cultural mediator is part of our research team
[2]Picture by Elia Bianchi

Table 1: Comparison between our plans and final execution of the two Sessions. Main changes appear in italics.

Topic	What we planned	What we had
People	Cultural mediator, researchers, *experts*, and *eight* participants	Cultural mediator, researchers, and *five* participants
Time	Meeting *one week* after the first meeting	Meeting *five months* after the first meeting
Place	Museum and *lab*	Museum and *open-air*
Accessibility	Online and physically accessible exhibitions	*Restrictions to physical exhibitions*
Restrictions	Freedom to meet in closed spaces	COVID-19 restrictions: private *gatherings of five people* from two households
Activities	*Contextual inquiry* (Field observations and Interviews), *Co-design hands-on activities, Individual use of technology*	Field observations, Interviews, *Researcher demonstrating the available tools*
Ratio	*Five to eight* participants	*Three to five* participants

(a) Session I
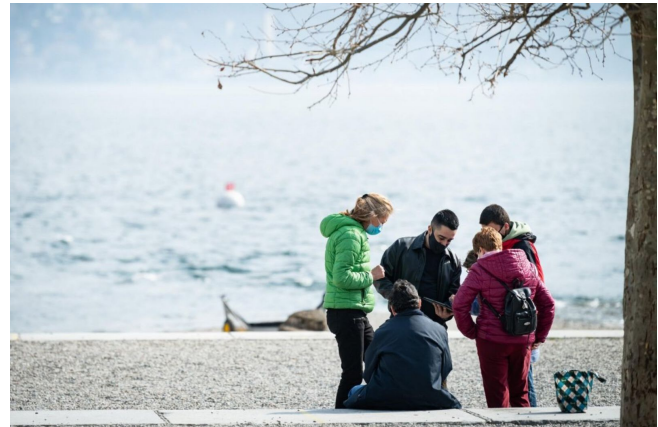
(b) Session II - Part I [2]

Figure 1: Pictures from the different Sessions that happened during COVID-19 pandemic.

3.2 Session II - Part I: Remembering the visit collectively in open-air

After few cancellations due to participants being unwell, we finally managed to meet our co-designers with the relaxation of restrictive measures in place locally in March 2021. As required, we met them in a park, wearing masks, with plenty of quiet corners to sit and chat. We scheduled the meeting on a Saturday to allow our co-designers not to miss a working day. The cultural mediator joined us too. We had asked permission to record our conversations and divided the meeting into two parts. In the first part, a collective one, as in Fig. 1b, we encouraged our participants to recall what they had seen in the museum in their previous visit. To help them remember, given that a few months had passed since then, we showed them the exhibition through an iPad. We presented the museum's official virtual tour (3D navigation) and redid the path they visited in Session I. The works were described by the same cultural mediator, with highlights to the most memorable ones. Everybody liked to visit the virtual exhibition and to choose where to navigate and what to see. This first activity was intended to get us back into the mood to discuss how to make the experience of visiting a museum more rewarding and engaging.

3.3 Session II - Part II: Individual interactions

After a break for a snack and a chat, we moved on to the second part of the meeting. We approached each of our co-designers individually, keeping the required distance and using hand sanitizer and masks. We asked few questions about their attitude, preferences, likes, and dislikes when visiting museum exhibitions. Each session took about 10 minutes. We started by showing the static website of the exhibition, with pictures of the artworks. We followed literature and advice from experts to make sure to ask questions in a way that was conducive to further elaboration and not just a yes or no answer. Then, we asked if they preferred the static website or the 3D navigation and if they would like to read on the iPad or paper. We also asked how they usually access information and if they use mobile phones. Next, we showed a prototype, called AIMuseum [4], an accessible augmented reality app to interact with virtual artworks via QR code, with text-to-speech information. The content was related to the visited exhibition. Even accounting for the novelty effect, we were delighted with their unanimous, spontaneous, and positive reaction and the expectation it created in our participants. Lastly, we showed a multimedia app with text-to-speech content about museums and asked them if they preferred read-aloud techniques or to read alone. We used improvisation to keep participants engaged and avoid distraction by choosing when

and how to run individual and group activities. Still, because of the restrictions, we could not run the originally planned co-design session. Nonetheless, we achieved a good understanding of our users and are ready for the next ideation stage.

4 CONCLUSION AND FUTURE WORKS

By engaging our participants in a series of activities, some carefully planned, and some more improvised, we managed to understand their needs better. As future online meetings have been discarded, we need improvisation and flexibility to take advantage of the rare occasions when it is possible to meet in person, bringing at times more successful results than trying to achieve consistency and accuracy at all costs. A possible solution would be to involve other stakeholders and apply multimodal qualitative research, where researchers collect data using more than one method, prompting participants in different ways and then generating multiple forms of the same data. We should be ready to quickly adapt our research plans:

- find the right time and space to share the screen with the participants;
- keep them engaged and avoiding distractions;
- change the order of individual and group activities

We will keep using improvisation and proceed with in-person co-design sessions to explore different types of interactions with artworks: from text-to-speech to tangible artworks miniatures to produce multisensory experiences.

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