

## RESEARCH

# 'I Got To Answer the Way I Wanted To': Intellectual Disabilities and Participation in Technology Design Activities

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User involvement in technology design processes can have positive implications for the designed service, but less is known about how such participation affects people with intellectual disabilities. We explored how 13 individuals with intellectual disabilities experienced participation in the design of a transport support application. The study is based on qualitative interviews, photovoice interviews, participant observations, and Smileyometer ratings. A thematic analysis generated the following themes: a sense of pride and ownership, an experience of socialization, and a sense of empowerment. The findings suggest that participation in design activities is a primarily positive experience that develops the participants' skills. However, experiences such as boredom may occur. The variability within the experiences of the participants show that it is crucial to be aware of individuality, preferences, and personal interests when designing with people with intellectual disabilities.

**Keywords:** Design; Intellectual Disability; Technology; User Involvement; Impact; Participation

## Introduction

Technology design has shifted from a designer-centred approach towards a more user- and human-centred approach. Nowadays, designers are encouraged to involve people from the intended user group in the design process throughout needs identification, design, prototyping, and evaluation. Studies show that user involvement can contribute to positive outcomes on both user satisfaction and design aspects (Bano & Zowghi 2015). This includes the performance and quality of the technology, and empowerment of the participants involved in the design process (Bano & Zowghi 2015). While user involvement has a long tradition and attention is paid to participation in design (Kujala 2003), people with disabilities have previously been overlooked in technology design (Rogers & Marsden 2013).

Given the importance of technology, it is essential to provide people with intellectual disabilities opportunities to contribute in design processes (Benton & Johnson, 2015). User involvement has the potential to democratize the process of design, increase the usability of the service, and empower the participants (Robb et al. 2020). Other positive outcomes include enjoyment, ownership, social skills, and increased confidence (Benton & Johnson 2014). Nevertheless, the majority of previous research on user involvement has focused on children (Benton & Johnson 2015). When outcomes are reported, people with intellectual disabilities are seldom directly consulted, and due to difficulties in examining participation benefits, the research to date has been limited and informal (Benton & Johnson 2015). Frauenberger and colleagues (2015) highlight the need to investigate the direct impact that involvement in design processes can have on participants with intellectual disabilities. In this study, we add to this area of research by focusing on the experiences of people with intellectual disabilities participating in design of new technologies.

To understand how user involvement affects participants, there is a need for researchers to ask the participants directly (Guha, Druin & Fails 2010). Therefore, this study aims to explore how young adults and adults with intellectual disabilities experience participation in technology design activities.

## Background

User involvement has been referred to as participatory design, cooperative design, collective design, and co-design (Bannon & Ehn 2012), all as a means of engaging end-users as active participants in decision-making throughout design processes (Muller 2007). Participatory design can be defined as a collaborative process between designers and end-users that includes mutual learning and both designers and end-users contributing throughout the design process (Sanders & Stappers 2008). Participatory design offers different practices and techniques (Muller 2007), such as design workshops,

photo-elicitation, prototyping, interviews, observations, and role/drama scenarios to engage participants in the design process (Sanders, Brandt & Binder 2010).

### **User involvement of people with intellectual disabilities**

There is general consensus that user involvement is particularly powerful when it includes participants with life worlds far from the experiences of the designers (Brereton et al. 2015). People with intellectual disabilities are an example of such a group. Intellectual disabilities are lifelong conditions characterised by the impairment of cognitive functions, which are associated with limitations in learning, adaptive behaviour, and skills (Carulla et al. 2011). People with intellectual disabilities can have difficulties with verbal comprehension, working memory, processing speed, and social and practical skills (Carulla et al. 2011). Still, traditional user involvement methods and techniques are based on several cognitive and sensory abilities that can pose challenges to people with intellectual disabilities (Hendriks, Slegers & Duysburgh 2015).

### **Roles, interaction, and the outcomes of user involvement**

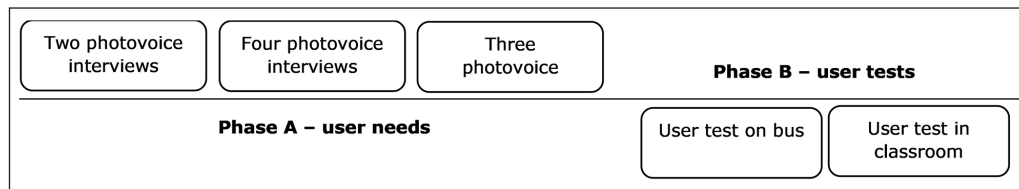
There are a variety of approaches to user involvement, ranging from users having an active role in the design activities to providing information or being observed (Kujala 2003). Several frameworks and models, such as Hart's participation ladder (1992) and Arnstein's ladder of citizen participation (1969), have attempted to define and evaluate participants' contributions. In the field of design, a recognised framework for understanding roles in technology design activities is Druin's framework (2002). Druin (2002) proposed four levels of involvement: *user*, *tester*, *informant*, and *design partner*. As a *user* the participant is observed while using existing technology, as a *tester* the participant tests prototypes, and as an *informant* the participant is involved in several stages of the design process when their input is of value. Lastly, as a *design partner*, the participant is considered an equal partner throughout the entire design process. In addition to the participants' roles in the design process, Druin (2002) defined a continuum of how participants interact with researchers and designers. Interaction can be *indirect* or through *feedback*, *dialogue*, or *elaboration*. *Indirect* input is described as participants communicating what they know by being observed (e.g., while using the technology). *Feedback* can be written or verbal information, such as comments on a prototype. *Dialogue* is when participants engage in discussions about ideas they have. *Elaboration* is elaborating on an idea presented by another design team member or researchers (Druin 2002).

Studies have revealed positive outcomes of participation in technology design (Benton & Johnson 2015). For children with intellectual disabilities, participation can be described on a continuum of being a positive experience (enjoyable experience), initiating positive emotions (empowerment, pride, or confidence), encouraging positive behaviours (responsibility), and developing skills/abilities (teamwork, technical skills). While these outcomes can occur in varying degrees, they are neither distinct nor preferable to one another. Other reported benefits include collaboration skills, content knowledge, and improved problem-solving abilities (McNally et al. 2017). Furthermore, studies on young people with intellectual disabilities have reported learning, ownership, increased creativity, and making friends as impacts of participation in design activities (Raman & French 2021). However, studies have reported adverse outcomes, such as lack of enjoyment (Malinverni et al. 2014), frustration, and boredom (Parsons & Cobb 2014). Therefore, Guha, Druin, and Fails (2010) highlight the importance of examining the impact of participation on participants in technology design activities.

### **Research Context and Design Activities**

The context of this study is an action design research (ADR) project that seeks to design and develop a transport support application for people with intellectual disabilities. ADR allows researchers to solve a practice-inspired problem through the design and development of information technology artifacts (Sein et al. 2011). The ADR method stresses the need to involve the end-user in the design process to design useful services (Sein et al. 2011).

The first phase of the design process (A) aimed to identify user needs regarding transport, and the second phase (B) aimed to test the first prototype (an overview is presented in **Figure 1**). *Phase A* included three research activities, which, in total, consisted of nine photovoice interviews. The participants were asked to take photos of situations they felt were important or difficult on their way to or from work. The following day they were invited to an interview at their workplace. *Phase B* included two research activities that consisted of a user test scenario involving 5 participants on a rented bus and a user test in a drama class with a total of 10 participants, 2 of whom took part in this study. In the design activity on the bus, the participants were given a smartphone with the prototype. The scenarios were structured according to the different themes of the prototype (i.e., identifying the correct bus, time management, managing unforeseen events, and communication). Afterwards, the users were asked to reflect on their experience. Each participant was guided by one researcher and observed by a second researcher who took notes. In the drama class, the prototype was shown on a screen, and the same scenario was discussed as a group. The second author participated as a facilitator and the first author participated as an observer throughout all the design activities.



**Figure 1:** An overview of the research activities in the design project.

## Methods

### Design

Due to the explorative nature of this study, we used a triangulation of methods, which included qualitative interviews, participant observation, photovoice interviews, and a Smileyometer Likert scale. The combination of methods provided an opportunity to gather extensive data and corroborate the participants' experiences of participating in the design process.

A combination of participant observations and short interviews has been recommended for studies with people with intellectual disabilities (Kittelsaa 2014). Participant observations allow the researcher to experience the activity directly and to study verbal and non-verbal communication, behaviour, relationships, and the atmosphere. For instance, some people with intellectual disabilities may use body language to compensate for the lack of fluent verbal language (Kittelsaa 2014). In photovoice, participants take photographs that document different aspects of their lives, supplemented by an interview (Povee, Bishop & Roberts 2014). The combination of visual images and verbal/voice makes photovoice a suitable method for including participants who lack verbal skills or fluency (Jurkowski 2008). The Smileyometer Likert scale is a Visual Analogue Scale that uses pictorial representations to identify feelings or opinions and is an adequate tool for scoring an opinion (*awful, not very good, good, really good, brilliant*) (Read & MacFarlane 2006).

### Data collection and participants

All participants who took part in the design and testing activities were also invited to participate in this study. To ensure informed consent, the participants were informed about the aim of the study and that they could opt-out whenever they wished. In total, 13 participants took part. The data material was anonymised with regard to name, gender, workplace, and school. In addition, we used Sigstad and Garrels' (2018) recommendations, such as repeating, rephrasing questions, silence and encouraging prompts, and summarising responses to facilitate and improve the quality of the interviews.

The participants were 18–40 years old, 3 female and 10 males. All were able to express themselves verbally. Three participants from Phase A (Helge, Stine, and Tobias) also took part in Phase B. An overview of the participants is as follows:

- Anna, female, Phase A.
- Erlend, male, Phase A.
- Morten, male, Phase A.
- Kim, male, Phase A.
- Arne, male, Phase A.
- Ahmed, male, Phase A.
  
- Helge, male, user test on bus, Phase A and Phase B.
- Stine, female, user test on bus, Phase A and Phase B.
- Tobias, male, user test on bus, Phase A and Phase B.
  
- Anniken, female, user test on bus, Phase B.
- Victor, male, user test on bus, Phase B.
  
- Fredrik, male, user test in a classroom, participants' teacher was present in the design activities, Phase B.
- Markus, male, user test in a classroom, participants' teacher was present in the design activities, participant's parent was present during the interview, Phase B.

### Phase A – User needs

In Phase A of the design project, the participants contributed to the design process by taking photos when they travelled to and/or from work. These were used in a follow-up interview by the design researchers to identify user needs connected to transport support services.

To gain insight into the experiences of participating, the first and second authors conducted individual interviews with the participants shortly after the design activity. These interviews took place where the design activities occurred.

All participants had the opportunity to have a proxy present during the interviews, although none did so. During the interview, we asked questions regarding their experiences of participating in the technology design process. The questions were open-ended to facilitate in-depth exploration. For instance, participants were asked if any tasks were challenging, what was important to them during participation, and if the design activity could be improved in any way. The interviews, which lasted for approximately 20 minutes each, were recorded and transcribed. The participants were also asked to complete a Smileyometer to grade their general opinion of participating.

#### Phase B – User tests

In Phase B of the design project, the participants took part in a user test where they tested a prototype of the transport support application. The first group tested the application in a realistic setting (a rented bus), while the second group tested the application during a drama class.

To gain insight into the experience of participating, we collected data through a combination of participant observations, photovoice interviews, and a Smileyometer. The participant observation focused on descriptions of the context, participants' behaviour, nonverbal communication, and the relationships between the facilitators and participants. A field note template was created to record notes during and shortly after the observations. The participants were asked to take photographs related to their experience of participating in the design process. During the design activity, there were three breaks for three to five minutes, which the participants could use to take photographs. The participants were provided with a mobile phone, and as a reminder each participant was given a paper card with the following instructions: Take a photograph of: something important when participating; something that makes you happy during participation; and something that describes the activity you have participated in.

At the end of the design activity the participants were interviewed using the same set of questions as Phase A. All participants had the opportunity to have a proxy present during the interviews; however, only Markus chose to do so. Using the photos taken during the photovoice as visual supports, the participants were asked to describe their photos, why they took them, and what they represented. As in Phase A, questions regarding their experiences of participating in the technology design process were asked. The interviews lasted for approximately 20 minutes and were recorded and transcribed. The participants were once again asked to complete a Smileyometer to grade their general opinion of participating.

#### Data analysis

Thematic analysis was used to analyse the notes from the participant observations, the photovoice interviews, and the individual interviews. Thematic analysis is flexible and contributes to identifying, analysing, and reporting patterns in the collected data (Braun & Clarke 2006). The six phases of thematic analysis recommended by Braun and Clarke (2006) were used as guidance. An inductive approach was chosen, focusing on the informants' descriptions, as this study was designed to explore the participants' experience. We also wished to provide a detailed thematic description of the dataset, which is particularly useful when investigating an under-researched area (Braun & Clarke 2006).

The first author transcribed the interviews. The interviews were then read and reread to ensure familiarisation with the data and initial ideas were noted. Initial codes were generated, collating relevant data to each code. The data was coded with an inductive data-driven approach in regard to the participants' experiences. The codes were then gathered in potential themes and quotes of interest were linked to these themes. The coding was conducted by the first author and themes were reviewed and discussed by all the authors, generating a thematic map of the analysis. The different levels of themes were reached through discussions between all three authors in relation to the significance of individual themes. An extract from the thematic analysis is presented in **Table 1**.

**Table 1:** Example of a structured thematic analysis.

Data Extract	Coded for	Subtheme	Overarching Theme
'It was important to participate because we need new solutions. Well, at least try to help find new solutions. Maybe it can help others as well. [...] There are many who struggle and may need help (with transport) just like me.'	Experience of meaningfulness/ Meaningful participation	Sense of contribution	Sense of pride and ownership
'I thought it was fun that I could take pictures of whatever I wanted. Because you did not set any limits to what I could take pictures of.'	Sense of control over participation, influence on participation	Experience of autonomy	Sense of empowerment

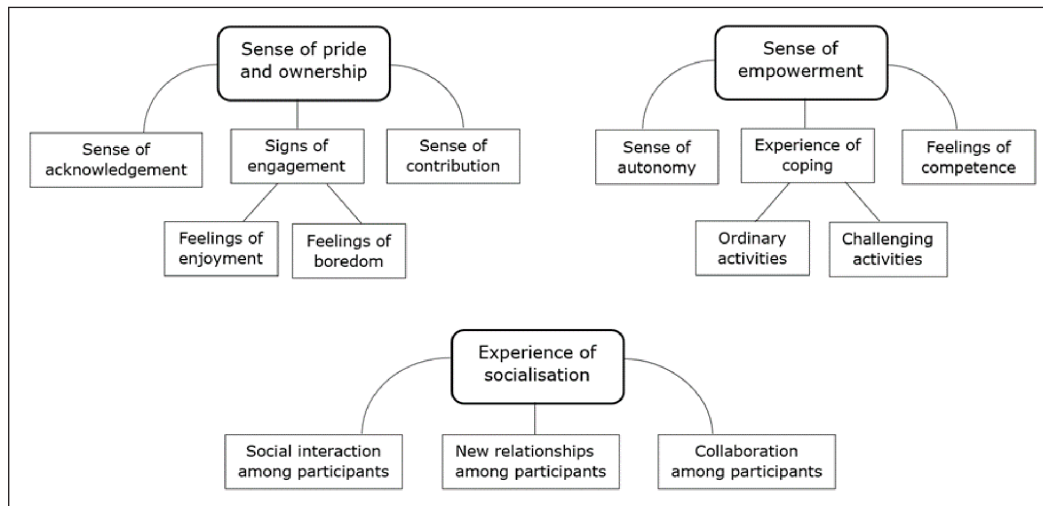
#### Ethical considerations

This study was approved by the Norwegian Centre for Research Data (648227) and the Faculty's Ethical Committee at the University. All participants signed an adapted voluntary informed consent form. Their parents or guardians were informed and asked to observe if there were signs of a wish to withdraw from the study. Due to privacy concerns, during

the photovoice sessions, the participants were instructed to take photos of things and/or themselves but not of other individuals. Any pictures of individuals who had not formally consented to take part in the study were deleted. It was stressed that participation was voluntary and that the participants could withdraw from the research project at any time without any consequences.

## Results

The participants evaluated the experience of taking part in the design activities using a Smileyometer. In Phase A, five of the participants rated their experience as *really good* and three rated it as *brilliant*, while one participant said the activities were *good*. In Phase B, three participants rated their experience as *brilliant*, three as *really good*, and one as *good*. The thematic analysis resulted in three main themes, nine subthemes, and four subcategories (Figure 2). The following main themes were identified: a sense of pride and ownership, experience of socialization, and a sense of empowerment.



**Figure 2:** Thematic map showing the three main themes, nine subthemes, and four subcategories.

### *Sense of pride and ownership*

A sense of pride and ownership was identified in the participants' descriptions of participating in the design activities. The analysis generated three subthemes: signs of engagement, a sense of contribution, and a sense of acknowledgement.

#### Signs of engagement

The participants were engaged and paid attention during the activities and expressed interest in the design activities and the prototype. When presenting the project, several of the participants asked questions about the intended use of the technology. They seemed motivated and interested in how their input could shape the technology and valued the opportunity to be part of something different from their usual activities at work or in school. If the participants did not understand tasks, they asked the researchers to elaborate or explain. When asked about the length of the activity, several of the participants said that they wished that the design activities had lasted longer.

*Enjoyment.* Enjoyment was identified as a frequent experience. Throughout the interviews, feelings such as joy, fun, and pleasure were associated with their participation. When asked about participating, Anna's response illustrated that she enjoyed participating and why, '... it was really fun [to participate]. I like to take pictures'. The participants often described their experiences by saying, 'That was fun', 'I liked that', or 'That was a pleasure [to do]'. Feelings of enjoyment were illustrated by the participants' responses to researchers and teachers using humour throughout the design activities. The participants were often observed smiling and laughing. When asked if they would like to participate in design activities again, only one participant said no.

*Boredom.* In contrast to enjoyment, participation contributed to feelings of boredom related to aspects of personal dislikes. It was observed that one of the participants did not want to participate in certain activities during the workshop and some participants showed signs of lack of interest and did not focus. It was observed that on some occasions the participants lacked assistance and had to wait during group activities. When asked about the length of the workshop, Victor noted 'I think it was okay. But we had to wait sometimes, and that was boring'.

#### Sense of contribution

Participation in the activities was described as contributing to something important and meaningful. The participants explained that they had accepted the invitation to participate because the technology being designed could help others with disabilities and they themselves could learn about design activities. Marcus stated that it was important



to participate 'so we can try to find new solutions that can make it easier for myself and others [to travel]'. Stine also mentioned the idea of helping when she was asked about the importance of participating, 'Because I think the app [application] can help in my daily life'.

#### **Sense of acknowledgement**

The participants expressed a sense of acknowledgement through descriptions of being an essential part of the activities. For instance, it was often observed that they were told that they were experts and that no answers were wrong. The sense of acknowledgement related to being an expert was closely connected to a sense of pride. When asked about the activities, Fredrik said, 'We were greeted in a good and worthy manner. You saw the whole of us, not just our faults'. The participants also noted the element of reinforcement from the researchers. Victor explained, 'I was listened to.... He listened to what I was saying, and he paid attention'.

#### **Experience of socialisation**

Participation in the design activities provided a social context that contributed to social interaction, new relationships, and collaboration.

#### **Social interaction among participants**

The participants described social interaction as an experience of participating in the design activities. Participants were observed having conversations with peers, teachers, and researchers. They were comfortable asking questions and talking about things, such as hobbies and leisure activities. However, it was observed that the participants required assistance in certain situations. For example, Victor had difficulty reading and asked the researcher to help explain the instructions, commenting 'I liked the way the tasks were explained'.

It was common for the participants to mention the importance of communication and being listened to. When asked about interacting with the researchers, Erlend explained, 'I think it's nice to talk to someone alone without anyone coming and interrupting me, or the person I am speaking to all the time. Because it is not very easy to talk to someone when that happens'. He verbalised the experience of communicating and expressing himself without interruptions. Moreover, throughout the activities, the participants communicated verbally, via text, and visually through pictures.

#### **New relationships with other participants**

Several participants described new relationships as an essential experience and said that their relationships with the researchers were different from their existing relationships. Helge explained:

**Researcher:** What was your experience of participating?

**Helge:** It was pretty good, pleasant atmosphere.

[...]

**Helge:** The mood was a little different, the communication was a little different, the interactions were a little different and I had good conversations with the researcher.

**Researcher:** Do you think it is different than at work?

**Helge:** Yes, it is completely different. I got to talk about what I had in here (pointing to the heart/chest). I do not do that at work, or I do talk like that at work but not as much. But I do not talk about everything because I concentrate more on the job.

This illustrates the participants' relationship with the researchers and how they differed from the sheltered workshop. When asked to take a picture of something important during the design activities, Stine and Helge asked to take a picture of two of the researchers.

Several participants stated that they liked meeting new people and that the design activities were an opportunity to do so. Helge said, 'I feel good about participating because I enjoy getting into contact with new people and communicating'.

Still, it was vital for some of the students to have their teachers present. When asked about facilitators in the drama workshop, Marcus said, 'I think having our teachers involved was important, they made us feel more comfortable'. This demonstrates the need for some safety and predictability during workshops.

#### **Collaboration among participants**

Several participants frequently mentioned collaboration with their peers and the researchers as an essential part of their experience. While working in small groups, the researchers often provided feedback to the participants and were

interested in their input. For example, when testing the app, a researcher asked Anniken, 'Do you like the colour red [on the stop button], or could it be different?' She responded, 'Maybe red, because it looks like the stop sign on the bus'. The researchers often gave positive feedback, such as, 'I did not even think of that before you pointed it out' and 'Well done'.

In terms of collaboration, Marcus said, 'It was good with group work because it is always okay to get opinions from everyone else so you can use them to come up with your ideas'. Furthermore, the participants elaborated on others' ideas. For example, when asked about stopping to get off the bus, one participant said, 'The bus stops and starts to drive off quickly'; another participant agreed, elaborating, 'And often you get even less time to get off because of people in the way'.

### **Sense of empowerment**

Active involvement in the design activities contributed to the participants' sense of empowerment. The context provided a sense of autonomy, an experience of coping, and feelings of competence.

#### **Sense of Autonomy**

Participation in the design activities was characterised as open and with few limits. The ability to influence the participation and the technology was an essential element. The participants felt free to say what they wanted and to take part in the activities of most interest. As Helge stated, 'I got to answer her the way I wanted to'. When talking about the photovoice activities, Martin stated, 'Well, I got to talk about the pictures I liked and the pictures I did not like. When I took pictures I did not like, I could delete them quickly'. One of the participants could leave the workshop to take breaks. Marcus explained, 'If I feel tired or something like that, I am allowed to go out of the room, then come back a few seconds later. Just so I can breathe'. The participants were also encouraged to give ideas: the researchers often asked the participants 'What are your thoughts on this?' or 'Should anything be different?' These opportunities to express themselves provided the participants with autonomy throughout the design activities.

#### **Experience of coping**

The participants enjoyed the opportunity to demonstrate their skills and to cope with the tasks in the design activities. Although we were not always able to observe when the participants mastered different tasks, they verbalised feelings of coping and mastery. For Anniken, participating was a challenge. When she managed to participate without the need to be distracted by music, she expressed a sense of mastery and coping:

**Researcher:** What was the best thing about participating?

**Anniken:** That I managed to participate without having to listen to music. It is because I am used to listening to music when I take the bus.

Several of the participants explained that participating itself was coping with something new. Stine elaborated: '...to show that I can do it. It is important to show that I can [participate]'. Other participants articulated that they mastered new tasks throughout the design workshops. Speaking about coping, Stine noted, 'I was very quick to find out what I had to do [on the phone]'. She elaborated by saying that it was fun to manage the task. While several of the participants described coping as an important experience, some described the activities as challenging or familiar.

*Challenging activities.* Some participants mentioned that activities were difficult to complete and found communication challenging. Tobias said, 'Sometimes I find it hard to explain things' and elaborated:

**Researcher:** Did you say what you wanted throughout the workshop?

**Tobias:** Yes, I did. But it is not always easy...I think it is hard...it is difficult to ask.

**Researcher:** You think it is difficult to ask questions? [...] Why?

**Tobias:** Because I have a..., what should I say...I have a syndrome; I do not always manage to speak. I have an intellectual disability.

Several of the participants mentioned problem-solving as a challenge. For instance, when asked about the activity, Anna stated, 'I think it was difficult'. She then elaborated, 'I did not know what to do or how to take the pictures'.

*Familiar activities.* Many of the participants were familiar with activities, such as reading, writing, brainstorming, and taking pictures. Kim noted, 'Well, it was great (to take pictures). Because I often take pictures anyway. It was completely natural to me'. When talking about the pictures, several of the participants also showed pictures they had taken in other settings before the workshops. Observational notes confirmed that the participants were comfortable with many of the activities.

### **Feelings of competence**

The participants described feelings of competence and said that they had learned more about technology and design activities. When asked if he had learned anything, Helge said, 'Yes, I learned about how the app works', elaborating, 'I have learned a bit, but I am not sure I will use the app the same way [the researcher] does'. The combination of performing tasks they had already mastered and learning new skills and knowledge fostered a feeling of competence. The participants demonstrated competence in different ways: when testing the app, it was observed that several read and understood the instructions themselves and many were confident in using technology.

### **Discussion**

Prior studies have highlighted the importance of examining the impact of participation in technology design activities (Guha, Druin & Fails 2010). However, few studies have presented the experiences of people with intellectual disabilities. The findings revealed that the participants had mostly positive experiences, including a sense of pride and ownership, experiences of socialisation, and a sense of empowerment.

#### ***Roles and interaction during participation***

The participants were involved in two phases of the design process: user needs identification and prototype testing. Relating to previous research on different levels of involvement and roles (Druin 2002), the participants were involved as informants and testers. As informants, they informed the design process, and as testers they gave feedback on and were observed while using the prototype (Druin 2002). Our findings suggest that the participants experienced themselves to be an essential part of the design process, describing a sense of pride, contribution, and acknowledgement.

The level of involvement can be defined by interactions between participants and researchers (Benton & Johnson 2015; Druin 2002). Collaboration with the researchers and peers was a frequently reported and observed experience. The participants described dialogues with researchers and elaboration of other participants' ideas as an essential part of collaborating. Interaction by elaborating is linked to the role of being a design partner during design activities (Benton & Johnson 2015), signalling that the participants experienced a balanced power relationship during some of the activities. In design activities, researchers' ability to share power is crucial to achieving involvement (Benton & Johnson 2014). Nevertheless, the participants also reported that it was essential that people they already knew, such as their teachers, were present during the activities, which suggests that including trusted proxies is important.

#### ***Positive outcomes of participation***

The participants frequently described participation as a positive experience. This finding supports earlier studies involving children (Benton & Johnson 2015) and young people (Raman & French 2021), suggesting that participation in design activities can foster feelings of enjoyment. In our study, some enjoyed drawing and writing, others mentioned interaction with technology. While the role of people with disabilities in design activities is often limited to few sessions (Benton & Johnson 2015), this finding emphasises the importance of mapping individual preferences and abilities over time to ensure enjoyment. While aspects of fun tend to be overlooked, prior studies have noted its importance (Brereton et al. 2015).

In line with Benton and Johnson (2014), the participants experienced pride, ownership, and empowerment. In participatory design, users are considered to be experts. Therefore, design activities provide opportunities to influence and generate ideas for people with intellectual disabilities, a population that has few opportunities and experiences where they can contribute in general (Arvidsson, Granlund & Thyberg 2008). The participants showed interest in how their input could shape solutions and showed it was important to participate as the technology could help both themselves and others. Our study shows that design activities fostered feelings of acknowledgement because researchers listened and valued their contributions.

Our results indicate that social interaction can be encouraged by participation in design activities. This is in line with earlier studies reporting that design activities can encourage positive social experiences in young people with intellectual disabilities (Raman & French 2021), responsibility in children with disabilities (Benton & Johnson 2015), and engagement (Sitbon & Farhin 2017). Our study supports that communication during design activities with people with intellectual disabilities is vital to obtain productive outcomes (Sitbon & Farhin 2017). On the other hand, participants with intellectual disabilities can have problems with communicating and expressing their contributions (Benton & Johnson 2015). A possible explanation for the positive experience of social interaction in our study may be connected to the amount of facilitation. This assumption is supported by the participants' description of assistance with interaction and communication as essential. Interaction and communication during the workshops also led to new relationships between the participants and the researchers. For people with intellectual disabilities being one of the most socially excluded groups (Xu et al. 2014), participation in design activities may provide an opportunity to meet new people outside their usual networks.

It was prominent for the participants to be able to cope with the tasks given and to demonstrate their skills during the activities. Benton and Johnson (2015) suggested that developing skills and abilities can be an outcome of participation in design activities. On the other hand, Berget and MacFarlane (2019) argued that it would be unethical to place participants in situations where they might fail. The participants and the researchers



collaborated closely to ensure that adequate assistance was provided whenever the participants needed it. Moreover, several participants expressed a sense of mastery, coping, and competence. The participants reported that they had gained knowledge about technology and design activities. These findings are in line with Druin (2002), who found that design activities can build academic confidence in children. Our study suggests that design activities with young adults and adults with intellectual disabilities may be an opportunity to learn and increase competence.

Interestingly, some participants were familiar with some of the design activities, such as taking pictures. Today, people with disabilities have access to and experiences with technology (Xu et al. 2014). Therefore, activities like photovoice may be a suitable design activity. This finding emphasises the importance of not underestimating people with intellectual disabilities and their knowledge and skills. In fact, Author and Author (2020) [left out for review] support this and state that photovoice can contribute to the inclusion of people with disabilities in design activities and the assessment of user needs.

### ***Challenges and adverse experiences***

In contrast to the positive impacts described, some participants experienced feelings of boredom and showed signs of non-engagement and low levels of focus. These findings support earlier research suggesting that design activities can also foster adverse experiences (Benton & Johnson 2015). The minimum positive impact of participation is that participation is a positive and enjoyable experience (Benton & Johnson 2015); we therefore view boredom as an adverse experience rather than a positive experience in design activities with people with intellectual disabilities. However, in this study, feelings of enjoyment outweighed feelings of boredom.

Still, designers, researchers, and facilitators have the responsibility to accommodate participants who, for instance, can only focus for a short period of time or have difficulties with communicating. Earlier studies have emphasised the importance of adjusting design activities and methods when involving people with disabilities (Hendriks, Slegers & Duisburgh 2015). The challenges some participants with intellectual disabilities may have should not be seen as a barrier for participation but rather a starting point for facilitation. This is supported by the Nordic relational model of disabilities that views a disability as a mismatch between the demands from a context and the individual's ability (Norwegian White Paper 17 2016). With this view, a disability can be reduced or removed by either changing the environment or by strengthening the person or both. Earlier research has reported a range of different design approaches, methods, and techniques used to mitigate some of the challenges in design activities with people with disabilities (Benton & Johnson 2015). However, these strategies do not fit all. Therefore, we suggest involving the person in tailoring the design activities to ensure positive outcomes. While it may require a longitudinal approach, building a relationship with the participants can provide in-depth knowledge that can be used to tailor the activities.

The participants in this study justified their participation because the solution may be of help in their lives. This finding is in line with earlier studies (Benton & Johnson 2015) and suggests that participants may have expectations of the solution being developed beyond the prototype stage and that it could positively impact their lives. However, the expectations of a finished solution may negatively impact the experience of participation if not met. Therefore, managing expectations in design activities is important. Providing an overview of potential benefits, and the importance of their involvement, without overcommitting is therefore essential to avoid disappointment. Moreover, if possible, the designers and researchers should collaborate with the participants' proxies or other stakeholders to ensure that the expectations of the design process are realistic. Also, while it is expected that some ideas are excluded from the final solution, the designers and researchers should not solely focus on the design of the solution but rather the design process as a whole. Thus, encouraging the participants on every occasion providing support and care throughout the design activities may help create and secure positive experiences even if the participants' ideas are not directly included in the solution.

### ***Implications and future research***

This study shows that when researchers and designers are aware of the individual needs and preferences of the participants they can create design activities that enable participants to contribute with insights and, at the same time, gain positive experiences and emotions and support development of skills and abilities. It seems essential to establish a relationship with the participants to motivate them during the design activities. In addition, there should be a focus on individual needs and preferences rather than impairments or diagnosis. Furthermore, researchers and designers should evaluate design activities together with the participants throughout the design process in order to adjust the activities to contribute to a positive experience. This could include breaks, support by proxies, and bridging communication difficulties.

While our study indicates that the design process was carried out *with* people with intellectual disabilities there is a need for more research on how design processes can be conducted *by* people with intellectual disabilities. We suggest that future design activities should allow participants to independently switch between roles rather than being given a particular role. Thus, more research is needed on structures, frameworks, and accessible design activities that can increase the agency of people with intellectual disabilities.

### Limitations

While this study has taken a rigorous approach to explore the experiences of people with intellectual disabilities in design activities, there are potential limitations. Although the number of interviews and participants is deemed sufficient for a small project (Braun & Clarke 2013), this study had a limited number of participants. While the double roles of the researchers as both facilitators and observers might have impacted the results of this study, it did also provide information about the participants that would otherwise have been inaccessible. Moreover, people with intellectual disabilities are not a homogenous group, and this study was tailored for participants with certain abilities. With this in mind, it is likely that participants in this study were more capable of using technology. We explored the experiences of participating in design activities; a possible limitation is that we did not compare these motivational aspects to other settings. While the instructions aimed to facilitate participation during photovoice, they may also have impacted the pictures taken. However, the current study provides useful information by presenting first-hand experiences of people with intellectual disabilities.

### Conclusions

This study contributes with findings on experiences of people with intellectual disabilities who participated in technology design activities. Moreover, we contribute with new insights on user involvement where people with intellectual disabilities are asked about their experiences. The results show that young adults and adults with intellectual disabilities can have different roles and that their participation in design activities can initiate positive emotions, encourage positive behaviours, and foster the development of new skills. However, adverse experiences may occur. The experiences of participating in design activities are dynamic and individual throughout the same design activity. While some participants find certain activities to be difficult or challenging, others find them enjoyable or familiar. Therefore, it is difficult to pinpoint how specific activities, facilitations, necessary conditions, or roles lead to specific experiences. The variability within the experiences of the participants, and the display of the different experiences, show that it is crucial to be aware of individuality, personal preferences, and interests and to constantly allow the participants to evaluate and influence the activities. We argue for the importance of individual strength-based approaches and facilitation in design activities to ensure a positive impact for people with intellectual disabilities.

### Additional File

The additional file for this article can be found as follows:

- **Appendix.** Participants' contribution to design. DOI: <https://doi.org/10.16993/sjdr.798.s1>

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### Competing Interests

The authors have no competing interests to declare.

### Author Contributions

All authors have made substantial contributions to the conceptualization, methodology, formal analysis, and writing of the paper.

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