One Size Does Not Fit All—
Facilitating Participation of People with Intellectual Disability in Design of Digital Technology

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While marginalized groups are increasingly involved in design processes, established methods and techniques require several cognitive and sensory abilities that may not fit when designing with people with intellectual disabilities. Earlier research on design of technology with people with intellectual disabilities has primarily focused on the technological outcomes and less on the techniques and adjustments made by facilitators. In this study, we explore facilitators' experiences of supporting adults and younger adults with intellectual disabilities during participation in digital technology design. The facilitators and users in this study participated in the design of a digital self-reflective career tool and a digital transport support tool. We conducted individual interviews with facilitators who had participated in various design activities and thematically analyzed the data. The findings show that facilitators focus on adapting to individual needs, experience a process of personal development, and learned by doing throughout the design activities. We argue that while the role of facilitating was duty- and task-oriented and challenging, the facilitators also experienced several essential gains. Experienced gains include the development of design-related knowledge, professional development, and a change in attitudes toward people with intellectual disability. This paper provides recommendations for guiding facilitators, considering both structural and individual needs, and offers insight into lessons learned.

Keywords – Codesign, Facilitation, Intellectual Disability, Technology, Action Design Research.

Relevance to Design Practice – The article describes facilitators' experiences of supporting people with intellectual disability during technology design activities. We provide recommendations valuable for design researchers and design practitioners who are interested in designing technology together with marginalized groups.

Introduction

Technology access and use is no longer simply a convenience but a necessity (Wehmeyer et al., 2020). While there has been a rapid transfer of everyday activities to the digital world and digital technology is more embedded in people's lives (Chadwick et al., 2022), the lack of accessible and adapted digital technology can increase digital exclusion (Chadwick et al., 2013). One group of people that is especially at risk of being left behind in the digital transformation of our societies are people with intellectual disabilities who face limited access to digital tools but also inadequate skills (Chadwick et al., 2019), leading to the need for accessible and adapted digital technologies (Chadwick et al., 2013). Intellectual disability is characterized by significant limitations in intellectual functioning and adaptive behavior, including several social and practical skills (Schalock et al., 2021). The diagnostic criteria for intellectual disability include a) significant deficits in intellectual functioning, b) significant deficits in adaptive behavior, and c) that these deficits originate during the developmental period (Rosencrans et al., 2021). The main descriptors include difficulties with memory, managing behavior and emotions, and the development of knowledge and reasoning skills (Carulla et al., 2011). Other aspects that may influence the participation and interaction with others include communication in terms of the production of words, understanding complex grammatical structures and understanding abstract concepts (Sigstad & Garrels, 2018). The estimated prevalence of intellectual disability is estimated to be 1% to 3% of the population (Maulik et al., 2022).

Technology design is the process of designing and developing digital solutions such as software and applications (Safari, 2023). It is well established that user involvement in technology design can contribute to user satisfaction, positive outcomes regarding design aspects, and better quality of the technology (Bano & Zowghi, 2015), and a range of user gains

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(Benton & Johnson, 2015). In addition, there is a consensus that user involvement is particularly important in design with participants whose experiences (life-worlds) are far from the experiences of the designers (Brereton et al., 2015). User involvement (i.e., participatory design, codesign, user-centered design, ethnography, contextual design) is a well-established approach for improving the design of technology (Benton & Johnson, 2015; Kujala, 2003; Robb et al., 2019). In design activities with people with intellectual disability, Participatory Design is the most used approach (Seale et al., 2020). According to Kujala (2003), user involvement is characterized by direct contact with the users during the design process. In recent years, people with intellectual disability have been involved in the design of technological solutions such as web applications (Bayor et al., 2021; Khan et al., 2021), learning tools (Raman & French, 2021), digital e-learning platforms (Nash-Patel et al., 2022), and tangible technologies (Andradi et al., 2021; Bircanin et al., 2021).

Design efforts and research have shown how various methods, practices, and techniques can be used to engage users in technology design processes. This includes, for instance, workshops, prototyping, interviews, role/drama scenarios, and observations (Sanders et al., 2010). While these methods and techniques seek to engage the users, they require several cognitive and sensory abilities that may not be suitable when designing with people with intellectual disabilities (Gibson et al., 2020; Hendriks et al., 2015). For instance, design activities and techniques are often based on verbal and visual expressions, use hands-on techniques, and require cognitive skills such as conceptualization. Moreover, commonly used design techniques are often inaccessible to people with intellectual disabilities due to an overreliance on abstraction skills (Gibson et al., 2020). In order to truly involve people with intellectual disabilities in design activities, it is, therefore, necessary that facilitators adapt existing design techniques and understand the different types of support demands that may occur (Gibson et al., 2020; Raman & French, 2021). Nevertheless, to enable authentic participation and involvement during design activities with people with disabilities, facilitators with a range of backgrounds are usually involved (Benton & Johnson, 2015) and adjustments are often made *in situ* (Hendriks et al., 2015).

In situ facilitation depends on the used design techniques, however, research shows that in situ facilitation such as using concrete examples, rephasing and paraphrasing overly complex speech, and clarification of difficult language or concepts have

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been applied in design activities with people with intellectual disability (Gibson et al., 2020). Other examples include issuing research material in advance (e.g., providing paper prototype features in advance), live capture of key topics during interviews (e.g., placement of sticky notes in sight of participants), and use of caregivers as proxies (e.g., during initial prototype evaluations) (Gibson et al., 2020).

While there is a growing body of research on designing technology with people with intellectual disabilities, the literature has predominantly focused on describing the technology outcomes (i.e., physical artifacts or interfaces) and less on adjustments and techniques during the design of digital technology (Benton & Johnson, 2015; Hendriks et al., 2015). In recent years, as the design of technology with people with intellectual disability has shifted from a designer-centred approach towards a user-centered approach (Safari et al., 2021), researchers have increasingly focused on the user perspective in research as well (see Benton & Johson, 2015; Börjesson et al., 2015; Safari et al., 2021). While the user focus in design with people with intellectual disability is in line with the disability rights movement *Nothing About Us Without Us*, the research exploring the role of the facilitators has been limited, fragmented and largely informal. The role of facilitators has rarely been discussed in detail, making it difficult to learn from earlier efforts and identify how facilitators contribute during digital technology design activities with this population (Hendriks et al., 2015). It is therefore important to build on the insights from design efforts to explore *in situ* facilitation, the adjustments made during technology design activities, and facilitators' experiences.

Aims of Study

This paper studies the experiences of facilitators who participated in an Action Design Research (Sein et al., 2011) project aiming to design two digital technology solutions (see study context). More specifically, we 1) explore facilitators' experiences of supporting adults and younger adults with intellectual disabilities during digital technology design activities and 2) provide recommendations for guiding facilitators. Furthermore, we present insights and knowledge on in situ facilitation and adjustments made by facilitators in digital technology design activities with people with intellectual disability. As the nature of facilitation is rarely the focus of research (Benton & Johnson, 2015; Hendriks et al., 2015), we expand the literature on user involvement in participatory design and codesign by offering insights into facilitators' experiences and providing recommendations to support practice. In exploring the facilitators' experiences and adjustments to codesign practices, techniques, and methods, this research enables researchers and facilitators to learn from earlier design efforts and apply these in their own work with people with intellectual disability.

Background

While user involvement of people with intellectual disabilities is vital for gaining insight into their needs to inform the design, it is both challenging and time-consuming (Safari et al., 2021).

During technology design activities with people with intellectual disability, previous studies have shown that people with intellectual disabilities may experience challenges related to communication (Gibson et al., 2020; Raman & French, 2021), verbal instructions (Gibson et al., 2020) and practical difficulties (i.e., time-restricted access, unsuitable user profiles, increased organizational efforts) (Frauenberger et al., 2011; Raman & French, 2021). These challenges can make it difficult for people with intellectual disabilities to contribute directly with their input and reach *genuine participation* (Benton & Johnson, 2015; Raman & French, 2021). To overcome such barriers to participation, facilitators must modify design techniques and provide individual support based on the skills and abilities of the users (Hendriks et al., 2015; Raman & French, 2021). Elsewhere, previous studies also point to the importance of focusing on the users' abilities rather than disabilities (Hendriks et al., 2015), paying attention to environments and social interactions (Brereton et al., 2015), and ensuring beneficence (Frauenberger et al., 2011)—meaning that the benefits of participation outweigh the demands.

Facilitators from a wide range of backgrounds are usually involved in facilitating technology design activities due to the different additional needs people with intellectual disability may have during the process (Benton & Johnson, 2015). Earlier research has described the involvement of teachers and parents (Nash-Patel et al., 2022), staff and therapists (Bayor et al., 2021), researchers (Andradi et al., 2021; Safari et al., 2022), practitioners and health professionals (Benton & Johnson, 2015). The role and responsibility of facilitators when involving users with intellectual disability in design activities is wide-ranging, as outlined in previous literature (see Benton & Johnson, 2015), including coordination of the design activity, setting the agenda and structure, providing explanations, facilitating consensus, clarifying ideas and opinions, and enabling the design progress (Benton & Johnson, 2015). Thus, the involvement and responsibilities of facilitators can often evolve during the design activities in response to the types of design activities and the needs of the users. For instance, in some cases, the facilitators are predominantly focused on supporting the users' participation, while in other cases, facilitators contribute directly to the design process (Benton & Johnson, 2015). Also, there are examples of facilitators contributing as proxies, on behalf of the users, and as co-designers (Benton & Jonhson, 2015). Elsewhere, facilitators such as parents and caregivers have actively and directly contributed during the design sessions in addition to facilitating (Khan et al., 2021; Neidlinger et al., 2021).

While the role of the facilitator is multifaced and includes a range of associated responsibilities and functions, previous literature has identified that the facilitators are specifically responsible for setting the agenda, motivating and engaging the user, ensuring wellbeing, and creating a supportive environment. Regarding setting the direction/agenda, the facilitators have the responsibility to allow adequate time for tasks, summing up and pointing to the next steps (Fuad-Luke, 2013). This involves guiding the process and sessions towards the goal/aim (Dahl & Sharma, 2022) and ensuring participation in the process and at

what point. As for motivating and engaging the user, facilitators are responsible for encouraging the users to engage themselves in the activities if they wish to (Benton & Johnson, 2015) and getting everyone to voice their opinions (Fuad-Luke, 2013). The facilitators are also responsible for the communication and dissemination of information during the session. Elsewhere, Dahl and Sharma (2022) identified enabler and trust builder as facets of the role. While the facet of enabling concerns helping users voice their ideas, needs, and views, the facilitator as a trust builder motivates active engagement of the user. Facilitators are also responsible for ensuring wellbeing which includes applying appropriate tools for the planned tasks (Fuad-Luke, 2013). Facilitators should strive for creating a positive experience for the users (Benton & Johnson, 2015) and to ensure that the sessions or design activities offer value to the users—meaning their time and efforts yield some type of return (Dahl & Sharma, 2022). Here wellbeing can also be linked to elements such as tone of voice, trust, ethics, and respect. Lastly, facilitators are responsible for creating a supportive environment, meaning providing an environment that fosters mutual learning (Benton & Johnson, 2015). Similar to the facet of the facilitator as an inquirer, facilitators are concerned with developing an understanding of the users and their needs and values (Dahl & Sharma, 2022). Also, the facilitators have an important role in forefronting the users' perspectives and needs and ensuring their voice is heard.

Study Context

This study's research context was an Action Design Research (Sein et al., 2011) project seeking to design digital technology solutions to support the transition from school to work for people with intellectual disabilities (a self-reflective tool and a transport support tool). Action Design Research (ADR) combines action research and design research, which allows researchers to solve practice-inspired problems through the design and development of technology (Sein et al., 2011). ADR consists of four stages: 1) problem formulation; 2) building, intervention, and evaluation; 3) reflection and learning; and 4) formalization of learning (see Sein et al., 2011 for a detailed overview). ADR stresses the need to involve the end-user in the design process to design and develop useful artifacts and services (Sein et al., 2011). The ADR project was seen as a relevant context to explore facilitation during design activities as it involved several people with intellectual disabilities and provided an opportunity to take an in-depth look at the role of facilitators in digital technology design activities. Thus, the rationale for conducting this research in parallel to the ADR project is that one should not artificially create a technology design project for the sole purpose of exploring the effects of such participation (Guha et al., 2010).

The respondents in this study participated as facilitators in the design activities connected to two digital technology solutions. The first solution was a digital *self-reflective career tool*. The goal of the self-reflective tool was to support people with intellectual disability in their transition from school to work by mapping skills, abilities, interests, and goals, as well as creating a CV. The

self-reflective tool consisted of six elements, including 1) login and user details, 2) skill and ability mapping, 3) interest mapping, 4) goal setting, 5) progress evaluation, and 6) generating a CV. The solution was designed iteratively together with seven users with intellectual disabilities who participated in 10 design activities. The design activities focused on codesigning prototypes, design elements, rewards, the use of icons, and ways to map and categorize content and wording. Techniques used in the workshops included usability and accessibility testing (paper prototype and digital prototype on phone, tablet, and computer), card sorting techniques, group discussions, and testing of games (see Figure 1 and Table 1). Moreover, the users participated in the usability testing of the self-reflective tool in a usability lab. The usability testing focused on technical elements and user interface, including factors such as functionality, fault-finding, and graphic design.

Table 1 provides an overview of the activities related to the self-reflective career tool, including number of users (design participants), duration of sessions, focus of design activities and techniques, and involved prototypes.

The second digital technology solution was a digital transport support tool designed with 10 users with intellectual disabilities who participated in three design activities. As transport was identified as a barrier for employment and participation, the aim was to develop a digital transport support tool to support people with intellectual disability in independent travel. The design activities focused on gaining insights into the challenges of independent travel and the design requirements needed to support the user. The techniques used included photovoice, interviews, observations, and user testing in a naturalistic environment. The transport support tool included time visualization, prompts to support way finding, reminders during public transport use (such as putting on the seatbelt), and different modes of communication during unforeseen events. In addition, three users with intellectual disabilities tested a virtual reality transport scenario to evaluate its usefulness.

Table 2 provides an overview of the activities related to the transport support tool, including the number of users, duration of sessions, the focus of design activities and techniques, and involved prototypes presented.

Table 1. Overview of design activities—Self-reflective career tool.

Session (s) Duration	Nr. of users	Focus of design activity - ADR Stage: 2	Techniques and involved prototypes
Session 1 2 hours	3	• Introduction of project • Test of paper prototype and feedback on mapping tools.	Workshop [Individual paper prototype test, interviews, collaborative warm-up]
Session 1B 1.5 hours	4	• Introduction of project • Feedback on design elements, icons, gamification, and motivation in games.	Workshop [Game testing, group discussions, card sorting techniques]
Session 2 1.5 hours	3	Dialogue on the first digital prototype. Insights on visualizing skills, abilities, and interests.	Workshop [Individual digital prototype test, cards sorting and group discussions]
Session 3 1.5 hours	3	Dialogue on icons and wording	Workshop [Digital prototype test, group discussions]
Session 4 1.5 hours	3	Dialogue on design elements, user login, and interest mapping.	Workshop [Individual digital prototype test, group discussions]
Session 5 1.5 hours	3	Dialogue on gamification elements and motivation in games.	Workshop [Testing of games, group discussion]
Session 5B 1.5 hours	4	Dialogue on mapping elements and ways to categorize interests.	Workshop [Individual prototype test, card sorting, group discussion]
Session 6 1.5 hours	3	Dialogue on progress and rewards in games. Insight on login and mapping features.	Workshop [Digital prototype test, group discussion]
Session 7 2 hours	3	Usability test [Test of login, mapping of skills, abilities, interests]	Usability testing workshop [Video recorded] and interviews
Session 7B 1.5 hours	4	Dialogue on progress and rewards in games [Digital session due to Covid-19]	Digital workshop [Group discussions on zoom, collaboration on a digital whiteboard]

Table 2. Overview of design activities—Transport support tool.

Session (s) Duration	Nr. of users	Focus of design activity & type of activity – ADR Stage: 2	Techniques and involved prototypes
Session 1 45 min	4	Feedback and dialogue on the digital prototype	User test on a bus [scenario] in a naturalistic setting
Session 2 1.5 hours	3	Feedback on VR and insight in transportation support needs	Workshop [VR testing of scenario, individual and group discussion]
Session 3 1.5 hours	3	Feedback on VR and insight in transportation support needs	VR testing of scenario [VR testing of scenario, individual and group discussion]

Methods

Study Design

A qualitative design was selected as the aim of the study, and the research question lies within a qualitative research paradigm. Qualitative research allows for the exploration of people's experiences and uses a variety of research methods, such as interviews, observation, and visual methods (Hennink et al., 2020). The ability to identify issues and topics from the perspective of the participant is one of the most distinctive characteristics of qualitative research (Hennink et al., 2020).

Respondents and Recruitment

The 11 respondents in this study were all recruited through the Action Design Research project and participated as either facilitators, supporting facilitators, or lead facilitators. *Lead facilitators* were leaders in the Action Design Research project and participated in both planning the design activities and supporting facilitators during the activities (researchers and designers). Lead facilitators had an overview of all design activities as well as the progress of the technology design. *Supporting facilitators* were part of the design team and had the responsibility of helping users and adapting the used methods during the design activities. The supporting facilitators and lead facilitators did not have relations with the users prior to the design activities. *Facilitators* had a prior relationship to the users, working as teachers, employees in social housing or employees in sheltered workshops. Their main responsibility during the design activities was to support and facilitate communication and interactions between the users and the lead and supporting facilitators. The facilitators only participated in the same design sessions as the users they had a relation to prior to the design activities.

During the activities, facilitators, supporting facilitators and lead facilitators worked together as a team in ensuring adequate support. An overview of facilitators, supporting facilitators and lead facilitators, their backgrounds and sessions and experience is provided in Table 3. The facilitators involved in the design projects in this study were not explicitly instructed or restricted to contribute to the designed technology or content in the design activities. The respondents are anonymised for name. It should be noted that the second author participated as a lead facilitator and the first author as an observer in all the digital technology design activities. However, the first and second author are not respondents in the current study.

Table 3. Overview of respondents, background, number of design activities, technology and sessions, design activity experience and earlier experience in disability services.

Name	Background	Nr. of design activities	Technology & sessions	Role	Technology design experience	Experience in cooperation with people with ID
F1	Social educator	2	TST, S: 2 & 3	Facilitator	No	Yes *
F2	Special needs educator	2	TST, S: 2 & 3	Facilitator	No	Yes *
F3	Social educator & Teacher	7	SRT, S: 1,2,3,4,5,6,7	Facilitator	No	Yes *
F4	Social educator & Teacher	3	SRT, S: 1B, 5B, & 7B	Facilitator	No	Yes *
F5	Teacher	2	SRT, S: 1B & 5B	Facilitator	No	Yes *
SF1	Psychologist	3	TSP, S: 1, 2, & 3	Supporting facilitator	No	Yes
SF2	User-experience designer	9	SRT, S: All except S 3	Supporting facilitator	Yes	Yes
SF3	Social educator & Associate professor	3	SRT, S: 1B, 5B, & 7B	Supporting facilitator	Yes	Yes
SF4	Professor in Information Systems	3	SRT, S: 1, 2 TST: S: 1	Supporting facilitator	Yes	No
LF1	Interaction designer & Associate Professor	1	TST, S: 1	Lead facilitator	Yes	Yes
LF2	Service design researcher	1	TSP: S: 1	Lead facilitator	Yes	No

Note:
- *Had a relationship with the users prior to the design activity.
- SRT = Self-reflective tool, TST = Transport support tool, S = Session, F = Facilitator, SF = Supporting facilitator, LF = Lead facilitator
- Technology design experience = Has participated in the design of digital technology (as a facilitator) prior to the design activities,
  Experience in cooperation with people with ID = Has worked in community disability services (as a support worker) prior to the design activities.

Figure 1. Left: Self-reflective tool session 1B, user brainstorming. Centre: Self-reflective tool session 3, users grouping categories. Right: Self-reflective tool session 5B, users suggesting content of categories.

Data Collection

Data was collected through individual qualitative interviews. Semi-structured interviews offer an opportunity to both ask questions that focus on key topics chosen by researchers and the opportunity to follow-up with a series of probing questions (Dalen, 2011). All respondents took part in retrospective individual interviews via zoom (due to Covid-19), which occurred when all the design activities were completed at the end of the project. The interviews were conducted by the first author. The interview guide included questions on the respondents' actions, support choices, difficulties during activities, and the importance of facilitating during design activities. The facilitators were asked the following questions: How did you experience participating in the design activity? Did you learn anything during your participation as a facilitator? How did you facilitate the activities for the users? Elaborate and give examples, which recommendations would you give to facilitators, in a similar role as yourself, supporting people with intellectual disability during technology design activities? In hindsight, if you could do anything differently, what would that be? The interviews lasted between 25 and 45 minutes each. The interviews were audio-recorded and later transcribed by the first author.

Data Analysis

Thematic analysis (Braun & Clarke, 2006, 2013, 2022) was used to analyze the individual interviews. We followed Braun and Clarkes' (2006) six phases of analysis. Firstly, the first author listened repeatedly to the audio recordings and then transcribed them. All authors then read and re-read the transcriptions several times to ensure familiarisation. All three authors then noted down initial thoughts. The data, including interview transcripts and field notes, was then coded with a data-driven approach focusing on the respondents' experiences during the design activities and their recommendations to designers and researchers. Finally, the codes, and then the themes were discussed by all authors to reach a consensus. An example of a thematic analysis is presented in Table 4.

One section of the data concerned recommendations that the respondents shared based on their experiences of facilitating the design activities (see Appendix for an overview of the recommendations). The recommendations were constructed using multiple perspectives, including the facilitators' experiences, suggestions on what they would do differently and the facilitators' recommendations to other future facilitators. Developed through all authors' interpretations and analysis, the recommendations were analyzed with a data-driven inductive approach and then grouped into codes and themes and then categorized as dealing with the individual or the structural levels. As the analysis regarding the recommendations was additional, the developed recommendations were then deductively analyzed with a focus on the main themes as described in the results. Recommendations on the individual level focused on guiding facilitators directly in their practice, while on the structural level, the recommendations focused on supporting leaders and organizers of the design process or the design project. Lastly, the recommendations were mapped to the themes describing the respondents' overall experiences.

Table 4. Example of thematic analysis.

Data Extract	Coded for	Sub-theme	Main theme
"I think projects like this should be rigged differently because we see things take much longer time to develop. For instance, it may well be that the innovation is brilliant, but it may take six months to learn. In that case, you cannot test it in six hours when it takes six months to learn to use it."	Recourse demanding, time-consuming, project planning	Balancing between commitments	Learning by doing

Ethical Considerations

Ethical approval of the study was provided by the Norwegian Centre for Research Data (648227) and the Faculties Ethical Committee at the University. All respondents received and signed an informed consent form. The respondents were informed about anonymity and the opportunity to withdraw from the study at any point without any consequences, even after the interviews were conducted.

Results

The thematic analysis resulted in seven subthemes, grouped into three main themes: adapting to individual needs of people with intellectual disability, Facilitators' process of personal development, and Facilitators' process learning by doing (Table 5). See Appendix for recommendations.

Adapting to Individual Needs of People with Intellectual Disability

The first theme focused on the respondents' experience and efforts to adapt to individual needs. In their efforts to enable a positive experience and to ensure the involvement and engagement of users, three interconnected subthemes were identified: Identifying facilitation needs, adapting individual support, and building relationships.

Identifying Facilitation Needs

The respondents described the need to understand and identify the support needs of the users throughout the design activities. However, the process of identifying support needs was challenging as some of the users were not always able or did not wish to communicate their needs. Therefore, the respondents experienced difficulties in identifying clues of when the users needed support.

> For instance, F2, who participated as a facilitator with a prior relationship to the users (teacher), stated:

> Identifying if someone needs help was one of the challenges we had. Some of the users were easy to read. You can see it in their face. They become very quiet. […] You have to listen to the tone of their voice, facial expression, laughter, and so on. You just have to be observant.

A particular challenge described by the respondents was related to identifying if the support needs were due to the lack of motivation or the lack of skills when the users struggled to accomplish or execute tasks. For instance, when card-sorting during session 5B (self-reflection tool), some of the participants stopped during the categorization of interests. SF3, a social educator participating as a supporting facilitator, stated:

> One of the challenges in supporting people with intellectual disability with tasks that are a little bit abstract is that it is easy to mix the lack of motivation and skills. You have to pay attention to both and give support to overcome both. [...] In both cases, you have to give appropriate support, preferably before the user gives up.

Furthermore, identifying support needs throughout the activities was also described as demanding. They noted that having the role of a facilitator required focus and mental preparation throughout the whole process. As explained by SF1, a psychologist participating as a supporting facilitator:

> To support the user in a good way, you have to be mentally prepared and alert throughout the whole activity, from beginning to the end, or else you miss a lot of important information and observations of when they need support.

Providing Individual Support

The respondents described the need to adapt tasks and support to each user. Providing individual support necessitated the use of a range of different techniques intended to help the users during the design activities. The respondents described techniques such as modeling and different prompting techniques. SF3, a social educator participating a supporting facilitator, explained:

> When it comes to motivating the users during the tasks and when solving them, the support is concrete and lies in small details like a smile, a nod, or just small affirmative sounds. You spread these small prompts out and use them every time you identify or think that the user needs support or encouragement. How much and how you use these techniques depends on the person and the situation. The small encouragement is an important part of the role (as a facilitator). And it helps to make sure that the activity does not stop because pondering on a task for a long time and not getting it done leads to the person giving up.

Table 5. Main themes and subthemes: Facilitators' experiences of supporting people with intellectual disabilities in design activities.

Main themes	Subthemes
Adapting to individual needs of people with intellectual disability	(1) Identifying facilitation needs (2) Providing individual support (3) Building relationships
Facilitators' process of personal development	(1) Professional development (2) Design-related skills development
Facilitators' process of learning by doing	(1) Managing uncertainty (2) Balancing between commitments

It was also observed that the respondents used modeling techniques such as doing the same task correctly while the user observed and prompting techniques such as verbal support which included explaining, pointing at the correct spot, affirmative sounds, and nodding.

The respondents were not only focused on adapting tasks and support, but they were also concerned with doing so correctly and ethically. For example, the respondents wanted to help without attracting attention to the person in need of support or exaggerating their actions when helping the users. For instance, SF3 illustrated:

> While it can feel like a relief to get support, it can also be seen as a failure by the person. So, it is important to *know the craft* and appropriately help the person. And it's about such simple things as how much movement you use in the help, and that you do not exaggerate it. [...] there is a big difference between pointing with a stable and firm pointing finger that makes a sound when hitting the table versus when you just hint with your finger against the right area. [...] you must give support accordingly.

The respondents also talked about practical issues, for example, helping in setting up the technology and dealing with changes or transitions during the design activities. It was for instance observed that the respondents continually checked if the transport support tool worked correctly continuously throughout the user test. They felt responsible for ensuring the users understood and could handle the tasks.

Building Relationships

The respondents described the design activities as a social experience. They experienced that building a relationship with the users was important in fostering trust and safety during the design process. Moreover, they enjoyed social contact with the users. The relationship between the respondents and the users was also described as important in adapting and identifying the support needs. F1, a social educator who participated as a facilitator stated:

> It's important to know the users well. Sometimes, when you get to know the person well, you can *read* the person. Even if they don't say much, you understand what they mean and need straight away. I believe you understand more if you know the person well.

However, the relationship between the respondents and the users differed. While some of the respondents had a relationship with some users before the design activities, others got to know each other during the design activities (see Table 1). For instance, F3, a social educatory and teacher participating a facilitator, illustrated how she could contribute to facilitating because of having a prior relationship with the participants:

> I think my role was to reassure the users and to help them express their opinions, views, and thoughts about the different tasks they were given. My knowledge and relationship with the users before the design activities helped me in supporting and adapting the activities. [...] So, I was both able to support the users as well as help the design team in adapting the design activities.

Nevertheless, the respondents emphasized that it was important to build or have a relationship and social contact with the users. The length of the project, as well as the one-on-one nature of the design activities, allowed the development of connections and relationships. It was also observed that the respondents continued to have conversations with the users about topics other than the design activities during breaks. Topics included leisure activities and preferences regarding digital games. Another factor that seems to have contributed to relationship building was the respondents' mindset. They were enthusiastic about designing with people with intellectual disabilities and described their participation as meaningful, important, and impactful.

Facilitators' Process of Personal Development

The second theme focuses on how the respondents experienced that their participation in the design activities impacted themselves. They described their participation as a process of personal development in which two interconnected subthemes were identified: professional development and the development of design-related skills.

Professional Development

The respondents described the opportunity to take part in the design activities as a process that enhanced their development in their field of work. Here, professional development was closely linked to knowledge and experiences of cooperating with people with intellectual disability in their individual work fields. For instance, while facilitators gained more knowledge on design methods and design activities with people with intellectual disability, researchers without prior experience in cooperating with people with intellectual disability gained more knowledge on communication with people with intellectual disability.

While several of the respondents had earlier experience in supporting people with intellectual disabilities, they did not have experience in supporting and facilitating in a design context. Therefore, for most of the respondents, the facilitation provided an opportunity to build on their existing skills and experiences of working with people with intellectual disability. For instance, the respondents described having a different approach than they usually have. The user-experience designer in the project had prior experience collaborating with people with disability, but not in a similar context. He, SF2, a user-experience designer participating as a supporting facilitator, described:

> When doing user tests, I usually have a different approach. I'm more neutral because I simply don't want to influence the user. [...] But during this project, I had to be more open and adapt myself more. And it made me realise that it is all about making the users feel safe. And that they don't feel like they are failing.

In addition, the respondents described being better prepared to work with people with intellectual disabilities and the disability field in general after participating. They also described discovering similarities and differences between design activities

with people with intellectual disabilities and those without an intellectual disability. For instance, LF1, an interaction designer participating as a lead facilitator, stated:

> …another reflection which I think is interesting, is that all the challenges [we had in designing with people with an intellectual disability] of course applies to all innovation processes. It's just that with this user group everything is pushed to the extremes. So, there are a lot of enriching lessons. It is not that it's especially difficult, or challenging and time-consuming to work on co-creating and involving people with intellectual disabilities because really, it's symptomatic for all innovation processes that wish to innovate useful things. … these things that we have learned here are not just important when involving people with intellectual disabilities, but for all innovation processes.

The experience of facilitating also contributed to curiosity and motivation in designing and cooperating with people with intellectual disability. The respondents described that they experienced a correction of assumptions related to facilitation, people with intellectual disability, and the design process. Overall, it was a positive and enjoyable experience for the respondents. As summarized by SF2, a user-experience designer participating as a supporting facilitator:

> It was a nice time because, first of all, the users and the other project members were all very positive about what we were doing. …I enjoyed that they appreciated being involved, being listened to, and being taken seriously.

Developing Design-Related Skills

While some of the respondents found it difficult to properly understand the design process at first, they soon acquired the necessary knowledge during the activities. Here, developing design-related skills is related to acquired knowledge about design approaches, design activities and technology. For instance, F3, a special needs educator participating as a facilitator, stated:

> In the beginning, we [facilitators and users] did not get a hold of the aims and what the result would be. But as we progressed, we got more knowledge and understanding of the methods used and what the result would be. It was insightful in terms of how people in the project work and which methods they use.

Facilitation in design activities allowed the respondents to gain knowledge about a range of current design techniques and tools and develop concrete skills on how to facilitate people with intellectual disability. Participation in such a context provided the respondents with input into a new *field* in which most of them did not have much knowledge. F5, a teacher participating as a facilitator, described learning new skills and techniques which he intended to use in his daily practice after the project. He stated:

> It's a privilege to be a part of such projects. Participating was not just a plus for the project but for us as well (facilitators). We get to know the users better, but we also get a lot of input on new ways to facilitate and involve them in their daily lives as well. It is basically a win-win.

However, the respondents also developed transferable skills in communication, organising activities, technology design, and teamwork. When talking about his participation, SF2, a user-experience designer participating as a supporting facilitator, stated:

> It was a very nice, and very positive experience. It was really good, and I learned an enormous amount. Not just specifically regarding people with intellectual disabilities, but in general. I learned a lot about how to facilitate good experiences in user experience design situations which I believe are universal.

The respondents also described practising skills such as flexibility, patience, and problem-solving.

Facilitators' Process of Learning by Doing

While the design activities were well planned and adapted to the skills of the users beforehand, the respondents described challenges and uncertainty. Moreover, they described adaptations throughout the design activities which were done *in situ* and the process of coping with them. The two interconnected subthemes describe experiences of managing uncertainty and balancing between commitments.

Managing Uncertainty

The respondents described being well-prepared and well-supported both before and during the design activities. Still, most respondents described that it was difficult to be fully prepared for the activities. As observed and described by the respondents some of the planned design activities proved to be challenging for the users even if the tasks were adapted to fit their skill sets. As LF1, an interaction designer participating as a lead facilitator, explained:

> Even if we adapted the questions, double-checked with people who knew them, and talked to interest organizations, it was still difficult and different when we carried out the activities with the person. So, there was a learning-by-doing aspect throughout the project.

However, the respondents noted that it was important not to dwell on the tasks or activities that did not work out as intended. Instead, they adopted a flexible approach as illustrated by LF2, a service design researcher participating as a lead facilitator:

> We tried really hard to adapt the tasks to all the users […] The most important thing for us as designers was not to complete absolutely every planned task. The most important thing was to get the users involved and co-create.

In addition, the respondents also described undertaking a support approach when uncertain situations occurred. An example of such uncertainty was when the users were not able to solve or finish a task. When such cases occurred, the respondents described trying to reassure the users that if something did not work out, they were not at fault. SF2, a user-experience designer participating as a supporting facilitator explained:

> It did happen that there were tasks the users did not understand or solve. But it was important for me to reassure them that if something did not work or if they did not understand, then it always was my fault. Not them.

However, in some situations, the respondents struggled with deciding if omitting the task or adapting the task further was the correct approach. LF2, a service design researcher participating as a lead facilitator, explained:

> We always had a plan which included three activities. And sometimes one of the activities would last longer than expected. In some of the activities, I did not want to stop and transition into a new one as the flow was good. But sometimes, in the back of my head, I also had the desire to try out other stuff as well. But it was not a big deal.

Balancing between Commitments

The respondents talked about challenges with balancing commitments related to the design activities and other tasks. While they felt responsible for adapting the activities and supporting the users, they also had the responsibility of ensuring progress in the technology design and coordinating participation. For instance, there was pressure and stress due to the expectations of developing the technology within the framework of the project. LF2 who was a lead facilitator with an overview of both the design activities and project process stated:

> We wanted to set up co-creation workshops in an exciting way. A way that was fun and exciting for the users. Create an environment in which we could also explore the opportunities that were there. Where we could adapt and change approaches. But in the end, I feel like we, during the whole period, wished we could do more. We wished to stretch ourselves further.

While some of the respondents had enough resources to solely focus on the design activities, others had other commitments simultaneously that they had to balance. F3 who was a facilitator and the users' teacher stated:

> Participating was time-consuming at times. In this project, the users were in school anyway, so it did not affect them that much. But for me participating meant that I just had to do my usual work tasks later in the afternoon (after school). It meant that I lost a working day and had to catch up.

When talking about the pressure to deliver a solution, LF1 explained:

> In such processes, there is a drive towards a solution. That's how these projects are rigged and that's how innovation processes are. You have to go somewhere and achieve something. The insight is not enough in itself; you must use it for something.

Discussion

This study aimed to explore facilitators' experiences of supporting adults and younger adults with intellectual disabilities during technology design activities. The findings show that the experiences and, thereby, also the role of the facilitators are multi-dimensional and formed by a range of different factors such as the project context, design activities, professional experience, the composition of the design team, and the specific needs of the users. Thus, the findings in this study, which are situated in a specific context (see Tables 1 and 2), may not always be relevant for every design project. This is in line with earlier research highlighting the difficulty in pinpointing how specific activities, facilitations, conditions, and roles lead to specific experiences (Safari et al., 2021).

A Duty- and Task-Oriented Approach to Facilitating

The findings indicate that facilitators are duty- and task-oriented when supporting people with intellectual disability in design activities. The facilitators described a focus on adapting the design activities to individual needs by providing explanations and supporting the users in understanding the given tasks. The support provided by the facilitators was similar to graded assistance, which is defined as ensuring that the person gets the right level and the right kind of support (Bircanin et al., 2021). Interestingly, some facilitators went beyond providing help and making user contribution possible (Benton et al., 2012; Benton & Johnson, 2015) to also help interpret the ideas of the users to other design team members who were less familiar with the person. Prior literature suggests that facilitators have two roles when involving people with intellectual disability: 1) support the individual in completing the given tasks, and 2) actively contribute in design (Gibson et al., 2020). In actively contributing, facilitators can either act as proxies or as design partners by, together with the user, elaborating directly upon one another's ideas (Benton & Johnson, 2015). While the literature indicates that a combination of these two strategies is appropriate (Gibson et al., 2020), the findings in this study indicate that the facilitators were solely focused on supporting the users in completing the given tasks. While the set-up and organization of the design project might have led to facilitators solely focusing on supporting the users, the findings also point to the facilitators having to overcome several challenges in facilitating the digital technology design activities for users. Thus, the workload and difficulties faced in facilitating may also contribute to a push towards a fixated focus on supporting the users first.

The facilitators described a focus on providing individual support correctly and ethically by taking a positive, flexible, and active approach to support users in overcoming potential barriers. For instance, facilitators drew upon commonly used communication techniques such as modeling (demonstrating the desired behavior/task) and verbal (pointing) and physical (for instance, stating *continue*) prompting techniques to support, collaborate, and adapt the environment to the users. This is in line with the recommendations (see Appendix, Table 6) suggesting that facilitators should gather knowledge and skills on how to support participants with intellectual disability in such activities. Moreover, in digital design activities with people with intellectual disability, we also recommend engaging a diverse group of facilitators with complementary skills and knowledge, such as learning disability nurses, social educators, special education teachers, practitioners, and specialists (experts in hearing, dyslexia practitioners), psychologists and care professionals. Still, it is important to find a balance as too much support can cause a sense of dependency and reliance which can hinder the autonomy of the users (Rajapakse et al., 2019).

These findings suggest that the facilitators focused on supporting the users and consequently experienced the situational content of the activity to be duty and task-oriented. In line with work or duty-oriented context (Rauthmann, 2015), the facilitators were focused on which, and if, there were tasks that needed to be done. However, by only focusing on supporting the users, there may have been knowledge, input, and suggestions about the design, from the facilitators, that were not discussed or discovered. The knowledge of facilitators, often labeled as *psychological and pedagogical insights*, can be crucial in making the final design decisions before implementation (Ruland et al., 2008). Similar to the users, facilitators bring their own values to the design process (Brereton et al., 2015; Frauenberger et al., 2015). Thus, it would be useful to clearly define the role of the facilitator before the design project. The focus on only supporting the users may, therefore, have been counterproductive as besides supporting the users, a main goal for facilitators is to also provide insights and inform the designed technology. Therefore, finding a balance between offering adequate support and providing psychological and pedagogical insights is important. The multifaced nature of the facilitators is therefore an important factor to consider in future projects. Thus, we recommend that in the future, it may be necessary to establish a consulting group to discuss and provide guidance for facilitators.

The Social Side of Facilitating

Prior studies show that facilitators may find it difficult to identify and carry out adjustments of design methods and techniques as their own experiences differ from those of the users (Hendriks et al., 2015). In the current study, the facilitators described relationship building as a strategy to better understand and support the users. This finding aligns with earlier studies pointing to the importance of trusted relationships when designing with marginalized groups (Hendriks et al., 2018; Rajapakse et al., 2019; Safari et al., 2022) and how open and honest communication can enable better individual support (Topping et al., 2022). People with intellectual disability can have complex communication challenges which can make it challenging to express needs and desires as well as their communicational features can also be difficult to notice (Bircanin et al., 2021). However, caregivers with knowledge of the individual's traits can be able to recognise when inappropriate strategies are being implemented, and subsequently provide alternative approaches (Gibson et al., 2020). Furthermore, as response bias can be prominent, a relation and knowledge about the user can be useful in recognizing and pinpointing response biases. This is echoed by the findings in the current study as facilitators described knowledge about the user and a relationship prior to the design activities as an important factor in providing appropriate support. Also, our study suggests that the length of the project and the one-on-one nature of the interactions led to the development of connections and relations between facilitators (with and without a prior relationship) and the users. Previous research suggests that design activities with people with intellectual disability ranging from one activity to activities over extended periods that can last up to years (Benton & Johnson, 2015). Our findings suggest that

participation over time may be favorable in developing relations during the design activities. A possible explanation is that relations take time to form and develop and that repeated social contact, as described in this study, supported the development of relations between users and facilitators. In turn, the formed relations may lead to more appropriate support strategies due to increased knowledge on the needs of the user.

The experiences described by the facilitators point to the importance of social elements in design activities. Most noticeably, the facilitators highlighted the importance of informal conversations about leisure activities and gaming preferences during activities and breaks in the development of interpersonal relationships. The social side of participation can thus facilitate the development of interpersonal relationships between facilitators and users. From Simplican et al.'s (2015) research, we know that facilitators who had a prior relationship with the participants, the design activities lead to the bonding of relationships, meaning developing relations between people who share a common bond. This may, in turn, offer opportunities to develop trust and confidence. For facilitators without prior knowledge of the users, design activities can foster the bridging of relationships meaning putting diverse people in contact. The bridging of relationships during design activities may, therefore, support the expansion of the facilitator's and users' social networks. As people with intellectual disability often have small social networks consisting of mostly peers with intellectual disability, participation in design activities with diverse facilitators may be a context that can facilitate the development of new social relations. Thus, we recommend ensuring continuity in facilitators, design sessions over time, and building a relationship with the users.

The Gains of Facilitating

Design activities with users with intellectual disability present challenges but also opportunities and positive outcomes (Benton & Johnson, 2015; Frauenberger et al., 2011). Previous research has identified outcomes such as empowerment (Robb et al., 2019), enjoyment (Benton & Johnson, 2014), enhanced technology knowledge, and self-determination and ownership (Safari et al., 2021) for people with intellectual disability. Our study adds to this by showing that facilitators can also experience gains from participating in design activities with users with intellectual disability. The facilitators explained a process of personal development, which included professional development and the development of design-related skills. This development may be crucial as the experience of working with people with intellectual disability is one of the most effective ways to prepare support workers to provide quality support and can contribute to developing empathy and communication skills (Topping et al., 2022).

Moreover, our study suggests that facilitators experienced a correction of assumptions when designing with people with intellectual disability. This finding may relate more to the facilitators without prior relations to the users with intellectual disability. The correction of assumptions is an important finding as prior literature has suggested that negative attitudes towards people with intellectual disability are linked to having low

expectations related to their skills and abilities (Mumbardó-Adam et al., 2020). The social elements and the development of a facilitator-user relationship may, therefore, be important factors to consider when identifying why facilitating design activities may have been a positive experience for the facilitators. The facilitator-user relationship can lead to understanding, acceptance, and compassion. Further, the facilitators described the development of design-related knowledge. As some facilitators had no experience in participating in technology design activities, participating provided an opportunity to gain knowledge on design techniques, technology, and teamwork. While the facilitators pointed out that the adaptations require a targeted and individual approach, they gained experience in collaborating with people with intellectual disability can be transferrable to other contexts, situations, and workplaces. Primary elements such as engagement, mutual learning, and reciprocity (Brereton et al., 2014) are all examples of gains that are transferable to other similar contexts.

Limitations of the Study

Whilst there is a growing amount of research on design activities with people with intellectual disability, there is still little research on the role of the facilitators. This study is one of few in-depth explorations of the experience of facilitators in this context. Nevertheless, the findings of the current study should be interpreted in light of some limitations. Both people with intellectual disabilities and facilitators are a heterogeneous group; the design project itself was tailored for users and facilitators with certain abilities, interests, and skills. Therefore, the findings in this study may have been impacted by the methods and strategies used in the design project as well as the skills, abilities, and needs of facilitators and users. With this in mind, it is likely that the facilitators' experiences may differ according to the structure of the design project and the user involvement approach used. Another possible limitation of this study is that we present an individual reflective perspective of the facilitators, they did not reflect on or discuss each other's experiences. In addition, another limitation is that we did not collect the experiences and feedback of the users on the facilitation they received during the digital technology design process. While the roles of the researchers provided information that would otherwise be inaccessible, it may also have an impact on the findings of this study. Despite these limitations, the current study provides valuable insights into the experiences and needs of facilitators participating in design activities with people with intellectual disability.

Implications for Practice and Future Work

Findings from the current study raise a question about how design activities with people with intellectual disability should be organized. As mentioned, while the facilitators described positive experiences with participating, they shared concerns regarding balancing commitments and managing uncertainty. These challenges are attributed to the structure of the project and

the unpredictable support needs of the users. Possible stressors include limited resources to engage the facilitators combined with the user's reliance on the facilitators to support them throughout the design activities. These stressors may influence and have a negative impact on the facilitators' experience and motivation. However, they also illustrate the facilitators' awareness of the demands placed on their roles and tasks throughout design activities. Interestingly, while on one hand, facilitating people with intellectual disability was a positive task, it was also a challenge to cope with and master the responsibility of ensuring support and beneficence. Here the respondents described identifying needs and communication of needs as a particular challenge. Communication is, however, a common challenge in designing with people with intellectual disability, as the sharing of a common language between the different stakeholders is often a perceived challenge (Sitbon, 2018).

Overall, this study shows the complexity of the experiences of facilitators in design activities with people with intellectual disability. The findings and recommendations in this study can prepare researchers and design practitioners before taking on the role of a facilitator. Moreover, this study can support project managers in recruiting a competent set of facilitators that meet the support needs of the users. Whilst the recommendations presented in this study may not be exhaustive (see Appendix, Tables 6, 7, and 8), they can be of benefit to design activities involving users with diverse needs, not just people with intellectual disabilities.

The current study explored the collective experiences of facilitators with a range of different backgrounds. This research can be extended by focusing on how the experiences of facilitators with different backgrounds may vary and why. Such research may provide valuable knowledge on how to ensure a positive experience for users and how to best support facilitators from different backgrounds. Secondly, there is a need to explore the different power structures between facilitators and users with intellectual disability. This may be particularly important if the design activities are over a period of time as power structures and relations may change over time. In addition, in line with the *Nothing About Us, Without Us* movement, there is a need for more research on the involvement of people with intellectual disability in design teams as facilitators. Such research can support increased inclusion and diversity in design teams and provide knowledge on the empowerment of people with intellectual disability.

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References

1. Andradi, M., Bircanin, F., Sitbon, L., & Brereton, M. (2021). Expanding designing for one to invite others through reverse inclusion. In *Proceedings of the 23rd international conference on computers and accessibility* (Article No. 64). ACM. https://doi.org/10.1145/3441852.3476517

2. Bano, M., & Zowghi, D. (2015). A systematic review on the relationship between user involvement and system success. *Information and Software Technology, 58*, 148–169. https://doi.org/10.1016/j.infsof.2014.06.011

3. Bayor, A. A., Brereton, M., Sitbon, L., Ploderer, B., Bircanin, F., Favre, B., & Koplick, S. (2021). Towards a competency-based approach to codesigning technologies with people with intellectual disability. *ACM Transactions on Accessible Computing*, *14*(2), Article No. 6. https://doi.org/10.1145/3450355

4. Benton, L., & Johnson, H. (2014). Structured approaches to participatory design for children: Can targeting the needs of children with autism provide benefits for a broader child population? *Instructional Science, 42*(1), 47-65. https://doi.org/10.1007/s11251-013-9297-y

5. Benton, L., & Johnson, H. (2015). Widening participation in technology design: A review of the involvement of children with special educational needs and disabilities. *International Journal of Child-Computer Interaction, 3-4*, 23-40. https://doi.org/10.1016/j.ijcci.2015.07.001

6. Benton, L., Johnson, H., Ashwin, E., Brosnan, M., & Grawemeyer, B. (2012). Developing IDEAS: Supporting children with autism within a participatory design team. In *Proceedings of the conference on human factors in computing systems* (pp. 2599-2608). ACM. https://doi.org/10.1145/2207676.2208650

7. Bircanin, F., Brereton, M., Sitbon, L., Ploderer, B., Azaabanye Bayor, A., & Koplick, S. (2021). Including adults with severe intellectual disabilities in codesign through active support. In *Proceedings of the conference on human factors in computing systems* (Article No. 486). ACM. https://doi.org/10.1145/3411764.3445057

8. Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101. https://doi.org/10.1191/1478088706qp063oa

9. Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. SAGE.

10. Braun, V., & Clarke, V. (2022). *Thematic analysis: A practical guide*. SAGE.

11. Brereton, M., Roe, P., Schroeter, R., & Lee Hong, A. (2014). Beyond ethnography: Engagement and reciprocity as foundations for design research out here. In *Proceedings of the conference on human factors in computing systems* (pp. 1183-1186). ACM. https://doi.org/10.1145/2556288.2557374

12. Brereton, M., Sitbon, L., Abdullah, M. H. L., Vanderberg, M., & Koplick, S. (2015). Design after design to bridge between people living with cognitive or sensory impairments, their friends and proxies. *CoDesign, 11*(1), 4-20. https://doi.org/10.1080/15710882.2015.1009471

13. Börjesson, P., Barendregt, W., Eriksson, E., & Torgersson, O. (2015). Designing technology for and with developmentally diverse children: A systematic literature review In *Proceedings of the 14th international conference on interaction design and children* (pp. 79-88). ACM. https://doi.org/10.1145/2771839.2771848

14. Carulla, L. S., Reed, M. G., Vaez-Azizi, M. L., Cooper, S., Leal, M. R., Bertelli, M., Adnams, C., Cooray, S., Deb, S., & Dirani, A. L. (2011). Intellectual developmental disorders: Towards a new name, definition and framework for 'mental retardation/intellectual disability' in ICD-11. *World Psychiatry 10*(3), 175–80. https://doi.org/10.1002/j.2051-5545.2011.tb00045.x

15. Chadwick, D., Wesson, C., & Fullwood, C. (2013). Internet access by people with intellectual disabilities: Inequalities and opportunities. *Future Internet, 5*(3), 376-397. https://doi.org/10.3390/fi5030376

16. Chadwick, D. D., Chapman, M., & Caton, S. (2019). Digital inclusion for people with an intellectual disability. In I. A. Attrill, C. Fullwood, M. Keep, & D. Kuss (Eds.), *Oxford handbook of cyberpsychology* (pp. 261-284). Oxford University Press.

17. Chadwick, D., Alfredsson Ågren, K., Caton, S., Chiner, E., Danker, J., Gómez-Ouerta, M., Heitplatz, V., Johansson, S., Normand, C. L., Murphy, E., Plichta, P., Strnadová, I., & Wallén, E. F. (2022). Digital inclusion and participation of people with intellectual disabilities during COVID-19: A rapid review and international bricolage. *Journal of Policy and Practice in Intellectual Disabilities*, *19*(3), 242-256. https://doi.org/10.1111/jppi.12410

18. Dalen, M. (2011). *Intervju som forskningsmetode* [Interview as a research method]. Universitetsforlaget.

19. Dahl, Y., & Sharma, K. (2022). Six facets of facilitation: Participatory design facilitators' perspectives on their role and its realization. In *Proceedings of the conference on human factors in computing systems* (Article No. 484). ACM. https://doi.org/10.1145/3491102.3502013

20. Dieringer, S. T., Zoder-Martell, K., Porretta, D. L., Bricker, A., & Kabazie, J. (2017). Increasing physical activity in children with autism through music, prompting, and modeling. *Psychology in the Schools, 54*(4), 421-432. https://doi.org/10.1002/pits.22003

21. Frauenberger, C., Good, J., Fitzpatrick, G., & Iversen, O. S. (2015). In pursuit of rigour and accountability in participatory design. *International Journal of Human-Computer Studies, 74*, 93-106. https://doi.org/10.1016/j.ijhcs.2014.09.004

22. Frauenberger, C., Good, J., & Keay-Bright, W. (2011). Designing technology for children with special needs: Bridging perspectives through participatory design. *CoDesign, 7*(1), 1-28. https://doi.org/10.1080/15710882.2011.587013

23. Fuad-Luke, A. (2013). Activist frameworks and tools: Nodes, networks and technology. In A. Fuad-Luke (Ed.), *Design activism: Beautiful strangeness for a sustainable world* (pp. 191-210). Routledge.

24. Gibson, R. C., Dunlop, M. D., & Bouamrane, M.-M. (2020). Lessons from expert focus groups on how to better support adults with mild intellectual disabilities to engage in codesign. In *Proceedings of the 22nd international conference on computers and accessibility* (Article No. 48). ACM. https://doi.org/10.1145/3373625.3417008

25. Guha, M. L., Druin, A. & Fails, J. A. (2010). Investigating the impact of design processes on children. In *Proceedings of the 9th international conference on interaction design and children* (pp 198-201). ACM. https://doi.org/10.1145/1810543.1810570

26. Hendriks, N., Huybrechts, L., Slegers, K., & Wilkinson, A. (2018). Valuing implicit decision-making in participatory design: A relational approach in design with people with dementia. *Design Studies, 59*, 58-76. https://doi.org/10.1016/j.destud.2018.06.001

27. Hendriks, N., Slegers, K., & Duysburgh, P. (2015). Codesign with people living with cognitive or sensory impairments: A case for method stories and uniqueness. *CoDesign, 11*(1), 70-82. https://doi.org/10.1080/15710882.2015.1020316

28. Hennink, M., Hutter, I., & Bailey, A. (2020). *Qualitative research methods*. Sage.

29. Khan, A. M., Dunlop, D. M. D., Lennon, D. M., & Dubiel, D. M. (2021).Towards designing mobile apps for independent travel: Exploring current barriers and opportunities for supporting young adults with Down's syndrome. *ACM Transactions on Accessible Computing, 14*(3), Article No. 13. https://doi.org/10.1145/3460943

30. Kujala, S. (2003). User involvement: A review of the benefits and challenges. *Behavior & Information Technology, 22*(1), 1-16. https://doi.org/10.1080/01449290301782

31. Maulik, P. K., Lakhan, R., Kishore, M. T., Sahu, A., Bertelli, M. O., & Sagar, R. (2022). Prevalence and aetiopathogenesis of intellectual developmental disorders. In M. O. Bertelli, S. Deb, K. Munir, A. Hassiotis, & L. Salvador-Carrula (Eds.), *Textbook of psychiatry for intellectual disability and autism spectrum disorder* (pp. 51-70). Springer.

32. Mumbardó-Adam, C., Vicente Sánchez, E., Simó-Pinatella, D., & Coma Roselló, T. (2020). Understanding practitioners' needs in supporting self-determination in people with intellectual disability. *Professional Psychology: Research and Practice, 51*(4), 341-351. https://psycnet.apa.org/doi/10.1037/pro0000292

33. Nash-Patel, T., Morrow, E., Paliokosta, P., Dundas, J., O'Donoghue, B., & Anderson, E. (2022). Codesign and delivery of a relational learning programme for nursing students and young people with severe and complex learning disabilities. *Nurse Education Today*, *119*, Article No. 105548. https://doi.org/10.1016/j.nedt.2022.105548

34. Neidlinger, K., Koenderink, S., & Truong, K. P. (2021). Give the body a voice: Codesign with profound intellectual and multiple disabilities to create multisensory wearables. In *Proceedings of the conference on human factors in computing systems* (Article No. 375). ACM. https://doi.org/10.1145/3411763.3451797

35. Rajapakse, R., Brereton, M., & Sitbon, L. (2019). A respectful design approach to facilitate codesign with people with cognitive or sensory impairments and makers. *CoDesign*, *17*(2), 159-187. https://doi.org/10.1080/15710882.2019.1612442

36. Raman, S., & French, T. (2021). Enabling genuine participation in codesign with young people with learning disabilities. *CoDesign*, *18*(4), 431-447. https://doi.org/10.1080/15710882.2021.1877728

37. Rauthmann, J. F. (2015). Structuring situational information: A road map of the multiple pathways to different situational taxonomies. *European Psychologist, 20*(3), 176-189. https://doi.org/10.1027/1016-9040/a000225

38. Robb, N., Boyle, B., Politis, Y., Newbutt, N., Kuo, H.-J., & Sung, C. (2019). Participatory technology design for autism and cognitive disabilities: A narrative overview of issues and techniques. In A, Brooks, S. Braham, B. Kapralos, A. Nakajima, J. Tyerman, & L. C. Jain (Eds.), *Recent advances in technologies for inclusive wellbeing: Virtual patients, gamification and simulation*. (pp. 469-485). Springer.

39. Rosencrans, M., Tassé, M. J., Kim, M., Krahn, G. L., Bonardi, A., Rabidoux, P., Bourne, M. L., & Havercamp, S. M. (2021). Invisible populations: Who is missing from research in intellectual disability? *Research in Developmental Disabilities*, *119,* Article No. 104117. https://doi.org/10.1016/j.ridd.2021.104117

40. Ruland, C. M., Starren, J., & Vatne, T. M. (2008). Participatory design with children in the development of a support system for patient-centered care in pediatric oncology. *Journal of Biomedical Informatics, 41*(4), 624-635. https://doi.org/10.1016/j.jbi.2007.10.004

41. Sanders, E. B.-N., Brandt, E., & Binder, T. (2010). A framework for organizing the tools and techniques of participatory design. In *Proceedings of the 11th biennial participatory design conference* (pp.195-198). ACM. https://doi.org/10.1145/1900441.1900476

42. Safari, M. C., Wass, S., & Thygesen, E. (2021). 'I got to answer the way I wanted to': Intellectual disabilities and participation in technology design activities. *Scandinavian Journal of Disability Research, 23*(1), 192-203. https://doi.org/10.16993/sjdr.798

43. Safari, M. C., Wass, S., & Thygesen, E. (2022). Motivation of people with intellectual disabilities in technology design activities: The role of autonomy, competence, and relatedness, *Behavior & Information Technology*, *42* (1), 89-107. https://doi.org/10.1080/0144929X.2021.2015442

44. Safari, M. C. (2023). *Intellectual disability and participation in digital technology design activities: A catalyst for social inclusion* (Doctoral dissertation). University of Agder, Kristiansand, Norway.

45. Schalock, R. L., Luckasson, R., & Tassé, M. J. (2021). *Intellectual disability: Definition, diagnosis, classification, and systems of supports, 12th ed*. American Association on Intellectual and Developmental Disabilities.

46. Seale, J., Carrizosa, H. G., Rix, J., Sheehy, K., & Hayhoe, S. (2020). In search of a decision-making framework for involving users who have learning disabilities or sensory impairments in the process of designing future technologies. In *Proceedings of the future technologies conference* (pp. 844-861). Springer. https://doi.org/10.1007/978-3-030-32520-6_61

47. Sein, M., Henfridsson, O., Purao, S., Rossi, M., & Lindgren, R. (2011). Action design research. *MIS Quarterly, 35*(1), 35-56. https://doi.org/10.2307/23043488

48. Sitbon, L. (2018). Engaging IT students in codesign with people with intellectual disability. In *Proceedings of the conference on human factors in computing systems* (Article No. LBW538). ACM. https://doi.org/10.1145/3170427.3188620

49. Simplican, S. C., Leader, G., Kosciulek, J., & Leahy, M. (2015). Defining social inclusion of people with intellectual and developmental disabilities: An ecological model of social networks and community participation. *Research in Developmental Disabilities, 38*, 18-29. https://doi.org/10.1016/j.ridd.2014.10.008

50. Sigstad, H. M. H., & Garrels, V. (2018). Facilitating qualitative research interviews for respondents with intellectual disability. *European Journal of Special Needs Education, 33*(5), 692-706. https://doi.org/10.1080/08856257.2017.1413802

51. Topping, M., Douglas, J., & Winkler, D. (2022). "Let the people you're supporting be how you learn": A grounded theory study on quality support from the perspective of disability support workers. *Disability and Rehabilitation, 45* (25), 4259-4271. https://doi.org/10.1080/09638288.2022.2148300

52. Wehmeyer, M. L., Davies, D. K., Stock, S. E., & Tanis, S. (2020). Applied cognitive technologies to support the autonomy of people with intellectual and developmental disabilities. *Advances in Neurodevelopmental Disorders, 4*, 389-399. https://doi.org/10.1007/s41252-020-00179-2

Appendix

Recommendations for Guiding Facilitators

The following recommendations were developed to guide and support facilitators in design activities with people with intellectual disability. While these recommendations are not exhaustive, they offer an insight into lessons learned and may be applied in both design activities and different co-production contexts with people with intellectual disability.

To support facilitators in adapting to the individual needs of the users, we suggest that facilitators should be provided with a facilitator-supportive environment during the design activities. The facilitators described a need for a supportive culture which is rooted in perceived and received support. Thus, creating a culture in which facilitators feel welcomed, respected, appreciated, and valued as members of the design team may lead to facilitators feeling better equipped to support the users. This is particularly important for the facilitators with a prior relation to the users. Moreover, on an individual level, facilitators are recommended to build relations with users to enable individualized facilitation. Examples of actions to enable these recommendations are shown in Table 6.

Table 6. Recommendations to support adapting to individual needs.

	Level	Recommendation	Examples of action
Adapting to individual needs	Structural level	Establish a facilitator-supportive environment	• Provide a consulting group to provide guidance for facilitators • Involve facilitators in design activities over time (not one-off activities) • Include support workers with prior knowledge of the users in the design activities
	Individual level	Build relations with users to enable individualized facilitation during design sessions	• Gather knowledge and skills on how to support the target population/individual • Build a relationship with the users prior to the design activities • Plan flexible design activities and tasks that enable facilitators to customise tasks and differentiate the degree of difficulty

The results show that personal development was a positive outcome for the facilitators. To ensure and support the facilitators' process of personal development, the involvement of the facilitators should be conducted strategically. Furthermore, on an individual level, facilitators are recommended to stay open to learning as the design sessions unfold. An overview and examples of actions are presented in Table 7.

Table 7. Recommendations to support the process of personal development.

	Level	Recommendation	Examples of action
Process of personal development	Structural level	Conduct strategic recruitment of facilitators	• Engage a diverse group of facilitators with complementary skills and knowledge • Conduct training sessions to prepare facilitators for participation prior to design activities • Carry out reflective evaluations with facilitators throughout the design process (not only at the end)
	Individual level	Stay open to learning as the design sessions unfold	• Engage in knowledge, skills and experience sharing with other facilitators and support workers • Document and reflect on experiences throughout the design activity process

The respondents described unexpected challenges and uncertainty which led to an experience of learning by doing throughout the design process. To guide facilitators through the process of learning by doing, we recommend leaders and organizers of technology design projects to value and use input and feedback from facilitators to adapt the design sessions. Meanwhile, on an individual level, we recommend facilitators to adapt to emergent challenges and difficulties as uncertain challenges can occur even if the design activities are well planned. In Table 8, possible examples of action are presented.

Table 8. Recommendations to support learning by doing.

	Level	Recommendation	Examples of action
Learning by doing	Structural level	Value and use input and feedback from facilitators to adapt the design sessions	• Apply a flexible design process framework and approach • Acquire resources and time to handle unexpected events • Minimise the facilitators' additional demands and tasks outside of the design project
	Individual level	Adapt to emergent challenges and difficulties	• Seek guidance/supervision from a consulting group (see structural recommendation Table 6) • Request and use both internal and external resources to help cope with unexpected and challenging events (refining, adapting, and monitoring sessions) • Ensure continuity in facilitators and predictability