Intellectual disability and participation in digital technology design activities:

A catalyst for social inclusion

Mugula Chris Safari

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Mugula Chris Safari,
Grimstad 2023

Summary

Social inclusion is a central goal in welfare policies and an essential determinant of people's health and well-being. This doctoral thesis aims to investigate how participation in the design of digital technology can contribute to the social inclusion of young adults with intellectual disability. This dissertation explores 1) How do young adults and adults with intellectual disability experience participation in the design of digital technology? and 2) How can young adults and adults with intellectual disability be supported to enable participation in the design of digital technology?

Four independent studies were conducted in total. Paper I reports on how 13 young adults with intellectual disabilities experienced participating in the design of a transport support application. A thematic analysis based on data collected through qualitative interviews, photovoice interviews, participant observations, and Smileyometer ratings showed that the participants experienced a sense of pride and ownership, an experience of socialization, and a sense of empowerment. However, the analysis also showed that negative experiences such as boredom can occur. The differences and variability within the reported experiences suggest that it is important to be aware of individuality, preferences and interests of the participants when designing digital services with young adults with intellectual disability.

Paper II uses Ryan and Deci’s Self-Determination Theory as a theoretical framework to explore what motivates young adults with intellectual disabilities to participate in digital technology design activities. In particular, we investigated how the participants experienced that participation in design activities contributes to the fulfilment of the needs for autonomy, competence, and relatedness. This case study was based on reoccurring interviews and focus group interviews with seven young adults with intellectual disability who participated in the design of a digital self-reflective tool. In addition, reflective notes from the support staff and notes from participant observations were part of the thematic data analysis. The findings in this study showed that participating in digital technology design activities can lead to the fulfilment of the need for autonomy, competence, and relatedness through a sense of enjoyment, influencing the designed technology and the design activity, enhancing skills and knowledge, experiencing a sense of self-efficacy, developing social relationships, and experiencing a sense of meaningfulness. However, the results suggest that the fulfilment of the basic

psychological needs was initiated because the participants participated over a period of time and that participation in a longitudinal manner may be particularly important for people with intellectual disabilities.

The third paper explores facilitators' experiences of supporting adults and young adults with intellectual disabilities during digital technology design activities. In total 11 respondents (facilitators) participated in this study. The data was collected through individual interviews on Zoom (due to the Covid-19 pandemic) and supported by prior collected participant observation notes. Thematic analysis was used to analyse the data material. The findings show that facilitators focused on adapting to individual needs, experienced a process of personal development, and learned by doing throughout the design activities. In addition, this paper provides recommendations, considering both structural and individual needs, that may be applied in both design activities and other co-production contexts with people with intellectual disability.

Lastly, paper IV reports and reflects on the use of photovoice as a method to understand user needs and to empower participants with intellectual disability in digital technology design. More specifically, the paper aims to answer the following research question: how can photovoice empower participants with intellectual disabilities when participating in an innovation process? Nine participants with intellectual disability were interviewed about their experiences of using photovoice during the design process of a digital technology transport support tool. The data was thematically analysed. The findings show that photovoice can contribute to both the sharing of contextual and individual needs and an empowerment process that includes coping, self-determination and ownership. The results suggest that in digital technology design processes with people with intellectual disability, photovoice can reduce some of the challenges with identifying user needs. Moreover, photovoice can strengthen a person's capacity to cope with participating in digital technology design.

In sum, seen through the Simplican's model of social inclusion where social inclusion is characterised by two domains – interpersonal relationships and community participation - findings of this research suggest that participation in digital technology design activities can potentially facilitate the social inclusion of people with intellectual disability. Participation in digital technology design activities can both support interpersonal relationships between young adults and adults with intellectual disability and different stakeholders and promote access to participation in community activities.

Sammendrag

Sosial inkludering er et sentralt mål i velferdspolitikken og en viktig helsefremmende faktor. Hensikten med denne doktorgraden var å få kunnskap om hvordan deltakelse i design av digital teknologi kan bidra til sosial inkludering av unge voksne med utviklingshemming. Denne problemstillingen er undersøkt gjennom to forskningsspørsmål: Hvordan opplever unge voksne og voksne med utviklingshemming å delta i utformingen av digital teknologi? og hvordan kan de støttes for å muliggjøre deltakelse?

Disse forskningsspørsmålene ble undersøkt i fire studier. Studie I baserer seg på hvordan 13 unge voksne med utviklingshemming opplevde å delta i design av en digital applikasjon for transportstøtte. En tematisk analyse basert på data samlet inn gjennom kvalitative intervjuer, photovoice, deltakende observasjoner og en Smileyometer-skala viste at deltakerne opplevde en følelse av stolthet og eierskap, en opplevelse av sosialisering og en opplevelse av myndiggjøring. Analysen viste imidlertid at negative opplevelser som kjedsomhet kan forekomme. Forskjellene og variasjonen i deltakernes erfaringer tyder på at det er viktig å være bevisst på individualitet, preferanser og interessene til deltakerne når man designer digital teknologi med unge voksne med utviklingshemming.

Studie II bruker Ryan og Deci's selvbestemmelsesteori som teoretisk rammeverk for å utforske hva som motiverer unge voksne med utviklingshemming til å delta i designaktiviteter av digital teknologi. Spesielt undersøkte vi hvordan deltakerne opplevde at deltakelse i designaktiviteter bidrar til å oppfylle behovene for autonomi, kompetanse og tilhørighet. Denne casestudien var basert på individuelle intervjuer og fokusgruppeintervjuer med syv unge voksne med utviklingshemming som deltok i utformingen av et digitalt refleksjonsverktøy. I tillegg ble refleksjonsnotater fra tilretteleggerne og notater fra deltakende observasjoner analysert. Funnene i denne studien viste at deltakelse i design av digital teknologi kan bidra til oppfyllelse av behovene for autonomi, kompetanse og tilhørighet. Resultatene tyder imidlertid på at deltakelse over tid var essensielt i designaktiviteter med personer med utviklingshemming.

Studie III utforsker tilretteleggeres erfaringer med å støtte voksne og unge voksne med utviklingshemming i deltagelse i design av digital teknologi. I tillegg gir studien anbefalinger og veiledning til tilretteleggere, med fokus på både

strukturelle og individuelle behov. Totalt deltok 11 informanter (tilretteleggere) i denne studien. Dataene ble samlet inn gjennom individuelle intervjuer via Zoom (på grunn av Covid-19-pandemien). Videre ble tidligere innsamlede notater fra deltakende observasjon inkludert i datamaterialet. Tematisk analyse ble brukt for å analysere datamaterialet. Funnene viser at tilretteleggerne fokuserer på de individuelle behovene deltakerne har, opplever en prosess med personlig utvikling, og lærer-ved-å-gjøre gjennom designaktivitetene.

Til slutt rapporterer og reflekterer studie IV over bruken av photovoice som en metode for å forstå brukerbehov og for å myndiggjøre personer med utviklingshemming i design av digital teknologi. Mer spesifikt tar artikkelen sikte på å svare på forskningsspørsmålet: Hvordan kan photovoice myndiggjøre deltakere med utviklingshemming når de deltar i en innovasjonsprosess? Ni personer med utviklingshemming brukte photovoice for å identifisere brukerbehov i utformingen av en applikasjon for transportstøtte. Deltakerne ble intervjuet om deres erfaringer med bruk av photovoice. Dataene ble analysert ved hjelp av tematisk analyse og funnene viser at photovoice kan bidra til både deling av kontekstuelle og individuelle behov og til en myndiggjøringsprosess som inkluderer mestring, selvbestemmelse og eierskap. Resultatene tyder på at photovoice reduserer noen av utfordringene med å identifisere brukerbehov og kan styrke en personenens kapasitet til å håndtere utfordringene med å delta i design av digital teknologi.

I sum, sett gjennom Simplicans modell for sosial inkludering der sosial inkludering består av to domener – mellommenneskelige relasjoner og samfunnsdeltakelse – viser funnene i denne doktorgradsavhandlingen at deltakelse i design av digital teknologi kan potensielt bidra til å fremme sosial inkludering av mennesker med utviklingshemming. Deltakelse i design av digital teknologi kan både støtte mellommenneskelige relasjoner mellom unge voksne og voksne med utviklingshemming og ulike deltakere og tilretteleggere og fremme deltakelse i samfunnsaktiviteter.

Accessible summary

- The social inclusion of people with intellectual disability is important. We all have a right to participate in society.

- People with intellectual disability often feel left out of society.

- We know that digital technologies can help people with intellectual disability feel included.

- We know that people with intellectual disability can be included in the design of digital technology.

- Being included in design activities can help make people with intellectual disability feel included.

- We do not know enough about how taking parting in designing digital technology affects people with intellectual disability. Therefore, we asked them and the people supporting them.

- Young adults and adults with intellectual disability and people supporting them told us about how they feel when taking part in design activities.

- The people we talked to said that they had positive and fun experiences, developed new skills, and were motivated. This was because they were together with other people, made choices, learned new things, and participated over time.

- The people supporting people with intellectual disability need help when planning and being part of the activities. This is because they need time and resources to support participants in a good way.

- We found that young adults and adults with intellectual disability can feel like they are a part of society when they take part in such activities.

- Future research should focus on how to best support people with intellectual disability in design activities with other people, and how similar activities can help them be more socially included.

List of papers

I. Safari, Mugula Chris., Sofie, Wass., & Elin Thygesen. (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. DOI: https://doi.org/10.16993/sjdr.798.

II. Safari, Mugula Chris., Wass, Sofie., & Thygesen, Elin. (2022). Motivation of people with intellectual disabilities in technology design activities: The role of autonomy, competence, and relatedness. *Behaviour and Information Technology*, 42(1), 89-107- DOI: https://doi.org/10.1080/0144929X.2021.2015442.

III. Safari, Mugula Chris., Wass, Sofie., & Thygesen, Elin. Facilitation in technology design activities with people with intellectual disabilities. *International Journal of Design*, Submitted 28.02.2023. Status: Under review.

IV. Wass, Sofie & Safari, Mugula Chris (2020). "Photovoice—Towards engaging and empowering people with intellectual disabilities in innovation" *Life 10*(11), 272. DOI: https://doi.org/10.3390/life10110272.

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Figures and tables

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Abbreviations

AAIDD	American Association on Intellectual and Developmental Disabilities.
HCI	Human-Computer Interaction.
UCD	User Centred Design.
ICT	Information Communication Technology.
WHO	World health organisation.
EU	European Union.
NOU	Norwegian Official Report.
TA	Thematic Analysis.
CRPD	The United Nations Convention on the Rights of Persons with Disabilities.

A Note on language

As the approach to disability has developed in recent years, the labels used have also changed (Shakespeare, 2018) and as did our emotional and intellectual response to certain words and terminology. The language and terminology of yesterday is sometimes shocking to the ears of today (Jarrett, 2022). Some words are now widely regarded as having negative associations, which makes them inappropriate to use in society and, consequently, this thesis. There are ongoing complex debates around language, especially related to language and terminology used to address marginalised populations. Reflecting on language and terminology Svanelöv (2021, p. 19) states: "*Talking about intellectual disability inevitably implies co-constructing categorisation and labelling. However, not talking about intellectual disability, its meaning and importance is to neglect and dismiss its continued construction; it comes down to how, when, and why language is used".* While there is no universal consensus as to what words or terminology is offensive or disabling, this dissertation aims at demonstrating both personal and cultural sensitivity. Therefore, in this thesis offensive or disabling language will not be published knowingly.

Shakespeare (2018) writes that a good principle related to terminology is to call people by the names they themselves prefer. Therefore, people first language was used and acronyms when applied to people is avoided (for example "People with ID"). People first language emphasises the person and their humanity by recognizing the individual first and the disability after (for instance, saying people with intellectual disabilities). To make this thesis accessible and inclusive to all readers, overly technical terminology was avoided. Moreover, an accessible summary of the thesis was included to ensure that the thesis is accessible to as many as possible.

Definitions

Technology – Within the scope of this thesis, the definition of technology is in line with the definition of welfare technology. Welfare technology is defined as "*technological assistance that contributes to increased security, social participation, mobility, and physical and cultural activity, and strengthens the individual's ability to manage himself in everyday life despite illness and social, psychological, or physical impairment. Welfare technology can also serve as support for next-of-kin and otherwise help improve accessibility, resource utilization and quality of service*" (NOU 2016 p. 110 & NOU 2011, p 99).

Design – Design means 'to invent and bring into being'. Thus, design deals with creating a new artefact that does not exist. If the knowledge required for creating such an artefact already exists then the design is routine; otherwise, it is innovative (Vaishnavi et al., 2004).

Designers - Participants who are professionally 'responsible for the information technology design project' (Simonsen & Robertson 2012)

Users - Participants who will interact with the information technologies being designed (Simonsen & Robertson 2012)

1 Introduction

Social inclusion, which refers to the extent that people are able to fully participate in society, is a central goal in welfare policies and legislation (United Nations, 2006; Grung et al., 2022). The UN Convention on the Rights of People with Disabilities (CRPD) emphasises full and effective participation and inclusion in society for all people with disabilities (United Nations, 2006). While social inclusion is a human right (Bertelli et al., 2022) and an essential determinant of people's health and well-being, its antipode social exclusion, characterized by the inability of people to fully participate in society, is one of the driving forces of health inequalities (van Bergen et al., 2019). The concept of 'social inclusion' is variously used in international social policy and academia to highlight the importance of engagement and participation as a means of improving quality of life for marginalised groups (Cordier et al., 2017). People with disabilities, particularly people with intellectual disability, are an example of such marginalised populations.

The social inclusion of people with intellectual disability is not only beneficiary for the person but for members of society as a whole. As stated by Simplican et al. (2015, p. 22): *"[...] social inclusion is for all of us: an individual with an intellectual or developmental disability; for people with intellectual and developmental disabilities as a group; for members of society who will benefit from their inclusion; and for nation states who can benefit from the participation of people with all levels of abilities".* Social inclusion of people with intellectual disability has several benefits and can contribute to happiness, self-esteem, confidence, decision-making capacity (Forrester-Jones et al., 2006), and fulfilling the CRPD proclaiming people's fundamental right to participate and being included (United Nations, 2006). Furthermore, social inclusion can also lead to a decrease in negative attitudes and stigma against people with intellectual disabilities (Simplican, Leader, Kosciulek, & Leahy, 2015). However, without planned efforts, social inclusion is at risk of merely being an ideology (Cobigo et al., 2012) and we will achieve no more than the presence of people with intellectual disability in our communities (Bigby & Wiesel, 2019).

Efforts have been made to increase the social inclusion of people with disabilities through initiatives such as the de-institutionalisation in the late 1960s and 1970s followed by policies and reforms in the 1980s and 1990s, which aimed at engaging and involving people with intellectual disability in society (Bigby &

Wiesel, 2019). While these efforts are in line with The United Nations’ CRPD, people with intellectual disability are still marginalised in different life domains such as employment, education (Garrels et al., 2022; Wendelborg et al., 2022) and community participation (Bredewold & van der Weele, 2022; McCarron et al., 2019). People with intellectual disabilities remain excluded across several social contexts including having fewer meaningful relationships and experiencing loneliness (Overmars-Marx et al., 2014), fewer friendships (Merrells, Buchanan, & Waters, 2019) and fewer intimate relationships (White & Forrester-Jones, 2020) and still live lives constrained within “*distinct social spaces*” (Bigby & Wiesel, 2019). Despite efforts from scholars, policymakers and activists, the social inclusion of people with intellectual disability remains a challenge (Cobigo, Ouellette-Kuntz, Lysaght, & Martin, 2012; Grung et al., 2022; Simplican et al., 2015), and studies internationally continue to identify limited community participation for this population (Bredewold, 2021; Merrells et al., 2019). Scholars have noted that the unsatisfactory outcomes regarding the social inclusion of people with intellectual disability demand action (Grung et al., 2022; Verdonschot et al., 2009).

The global aim for greater social inclusion of people with intellectual disability is taking place at a time of rapid digital technological advances. The infusion of digital technology in today’s society points to two opportunities i) designing digital technology that facilitates social inclusion and ii) including people with intellectual disability in the design of digital technology. Previous studies have shown that digital solutions and services are possible facilitators for social inclusion as they can help people with disabilities learn, work, travel, and interact with their communities (Manzoor & Vimarlund, 2018; Wehmeyer et al., 2020). Technology is viewed as one of the most essential factors that can contribute to reducing social gaps and encouraging social inclusion (Manzoor & Vimarlund, 2018). Technology is, therefore, important in enabling people, with and without disabilities, to live autonomously and participate fully in all life domains (Wehmeyer et al., 2020). The design process through which technology is designed also presents an opportunity for the social inclusion of people with intellectual disabilities (Wass, Thygesen & Purao, 2023). Scholars have pointed out that given the importance of technology and its impact on the lives of people with intellectual disability, designers and researchers should involve people with intellectual disability in the design process (Benton & Johnson, 2015; Raman & French, 2021; Robb et al., 2019; Rogers & Marsden, 2013). In addition, an important political and human rights dimension is that people affected by a decision should be given an opportunity to influence it (Robb et al., 2019). User involvement is thus in line with the self-advocacy mantra “Nothing About Us Without Us” (Stack & McDonald, 2015). Earlier research suggests that user involvement in the development of digital solutions can positively impact the designed technology and contribute to positive outcomes regarding both user satisfaction, design aspects, and system performance and quality (Bano & Zowghi, 2015). For people with intellectual disability, user involvement can also lead to positive outcomes such as the development of competence, skills, and abilities (see reviews: Benton & Johnson, 2015; Börjesson, Barendregt, Eriksson, & Torgersson, 2015). Researchers have however highlighted the importance and need of examining the further impact of such participation and how the impact has occurred (Benton & Johnson, 2015; Frauenberger, Good, Fitzpatrick, & Iversen, 2015). This involves exploring and discussing a range of different potential outcomes, beyond simply the technological solution.

Social inclusion for people with intellectual disability is a right and a political goal (Grung et al., 2022). Researchers have suggested that user involvement in technology design can facilitate social inclusion (Brosnan, Parsons, Good, & Yuill, 2016; Parsons & Cobb, 2014). While people with intellectual disabilities are increasingly included and involved in the design and development of technology (Benton & Johnson, 2015), there is still little research on how such participation can influence the social inclusion of this population. When exploring outcomes of technology design activity participation, there is a need for more research in which people with intellectual disabilities are consulted directly as the research has to date been limited and informal (Benton & Johnson, 2015). Thus, the scope of this thesis is participation in digital technology design activities, and how such participation can be a catalyst for social inclusion for people with intellectual disability.

1.2 Aim and Research questions

This research aimed to investigate how participation in the design of digital technology can contribute to the social inclusion of young adults and adults with intellectual disability. The following two research questions address the overall aim of this thesis:

I. How do young adults and adults with intellectual disability experience participation in the design of digital technology?

II. How can young adults and adults with intellectual disability be supported to enable participation in the design of digital technology?

Table 1 provides an overview of the individual papers, the research focuses and purposes, included literature or theory, relation to the research questions and contributions.

Table 1. Overview of the individual papers and research focuses.

	Paper I	Paper II	Paper III	Paper IV
Title	I got to answer the way I wanted to': Intellectual disabilities and participation in technology design activities	Motivation of people with intellectual disabilities in technology design activities: the role of autonomy, competence, and relatedness	Supporting people with intellectual disabilities during co-design of digital technology: Perspectives of facilitators	Photovoice—Towards Engaging and Empowering People with Intellectual Disabilities in Innovation
Research focus	Experiences and outcomes of participation	Motivation in design activities	Facilitation during design activities	Understanding user-involvement techniques
Research purpose	Explores how young adults and adults with intellectual disabilities experience participation in digital technology design activities.	Investigates how participation in design activities contributes to the fulfilment of the needs for autonomy, competence, and relatedness during digital technology design activities.	Explores facilitators' experiences of supporting adults and young adults with intellectual disabilities during digital technology design activities.	Investigates the use of photovoice to understand user needs and to empower participants with intellectual disability in a design process

Theory/Literature	Prior literature on roles, interactions, and outcomes of user involvement of people with intellectual disability.	The self-determination theory (Deci & Ryan, 2000, 2002).	Prior literature on facilitation and adaptation of design activities with people with intellectual disability and the role of facilitators	Photovoice and the concept of empowerment
Relation to RQ in dissertation	Research question 1	Research questions 1 & 2	Research question 2	Research question 1
Status	Published in the Scandinavian Journal of Disability Research, volume 23, issue 1.	Published in Behaviour & Information Technology, volume 43, issue 1.	Submitted to the International journal of design, date 28.02.2023. Under peer review.	Published in Life, Special Issue on Advances in eHealth.
Contribution	Gives insight in into experiences and impact of participation in digital technology design on young adults and adults with intellectual disability.	Extends knowledge on the importance of autonomy, competence, and relatedness as per the self-determination theory, and consequently explores what motivates people with intellectual disability in digital technology design activities.	Gives insight into experiences of *in situ* facilitation of digital technology design activities for people with intellectual disability and provides recommendations to inform the recourses needed for facilitators in future design projects.	Gives insight into facilitating user involvement in design activities through the use of photovoice and further explores experiences of using photovoice in technology digital design activities with people with intellectual disability.

1.3 Thesis outline

This thesis is structured into 10 chapters that address the main aim and research questions. After the introductory chapter, Chapter 2 gives an overview of the conceptualisation of disability and establishes a background of the main target group. Chapter 3 starts off by setting the scene by providing a short historical note on intellectual disability and social inclusion. The chapter is rounded off with an overview of approaches to user involvement in technology design. Chapter 4 offers an overview of previous research and related work on the user involvement of young adults and adults with intellectual disability in technology design. Chapter 5 provides the theoretical framework pertinent to the context and aim of this PhD thesis, including social inclusion, self-determination, and the Basic Psychological Needs Theory. Chapter 6 provides an overview of the research context. Chapter 7 presents the philosophical perspective and the research design and methods used in the four included studies. Chapter 8 presents the results of the four included articles (see papers I-IX in the Appendix) and the overall results. Chapter 9 discusses the results, the methodological considerations and implications for practice and future research. Finally, Chapter 10 presents the conclusions.

2 Conceptualizing disability

This doctoral thesis focuses on young adults and adults with intellectual disability. The understanding of the concept of disability has changed over time, reflected by changing views on health and disability. In the following chapter, the medical, social, and bio-psychosocial models of disability are presented. The chapter closes with a summary of how I perceive disability.

2.1 Models of disability

The medical and social models of disability have been the two most prominent disability models (Oliver, 2009). Emerging during the middle of the eighteenth century, the medical model of disability, also called the deficit model, presented disability as a direct consequence of an impairment. This perception of disability places the problem within the individual where the impairment or disability is viewed as a condition that must be treated or rehabilitated as far as possible (Anderberg, 2005; McKenzie, 2013). Consequently, the medical model of disability makes disability an individual problem rather than a social one (McKenzie, 2013).

In contrast, the social model of disability arose in response to the shortcomings of the medical model of disability. The social model has its roots in social movements in the 1960s and 70s, calling for social and structural change to enable people with disability full participation in society (McKenzie, 2013). Within the social model, a distinction is made between impairment and disability, where impairment is viewed as the deficit of the body or mind, and disability as social oppression and exclusion (Shakespeare, 2018). The core message of the original social model was that societal structures should change to accommodate individuals with disabilities (Anderberg, 2005). The redefinition of disability from the medical model to the social model followed the well-established political path of de-naturalising forms of social oppression (Shakespeare, 2018). The social model of disability had two major impacts on society. First, it led to political initiatives that focused on removing or dismantling barriers to promote inclusion. Second, there was the realisation that society was at fault and not individuals with disabilities. This made the social model important in building a strong political identity within the disability movement (Shakespeare, 2018).

Alternative and newer models of disabilities, which attempt to combine the medical and social models to provide a more balanced view of disability have been proposed (Shakespeare, 2014). Conceptually associated with the social model of disability, the International Classification of Functioning, Disability and Health (ICF) draws on both the medical and social models to develop a bio-psychosocial model of functioning and disability (World Health Organization, 2001). Developed by the WHO, the ICF model (2001) differentiates between impairment and disability and includes six components (see Figure 1).

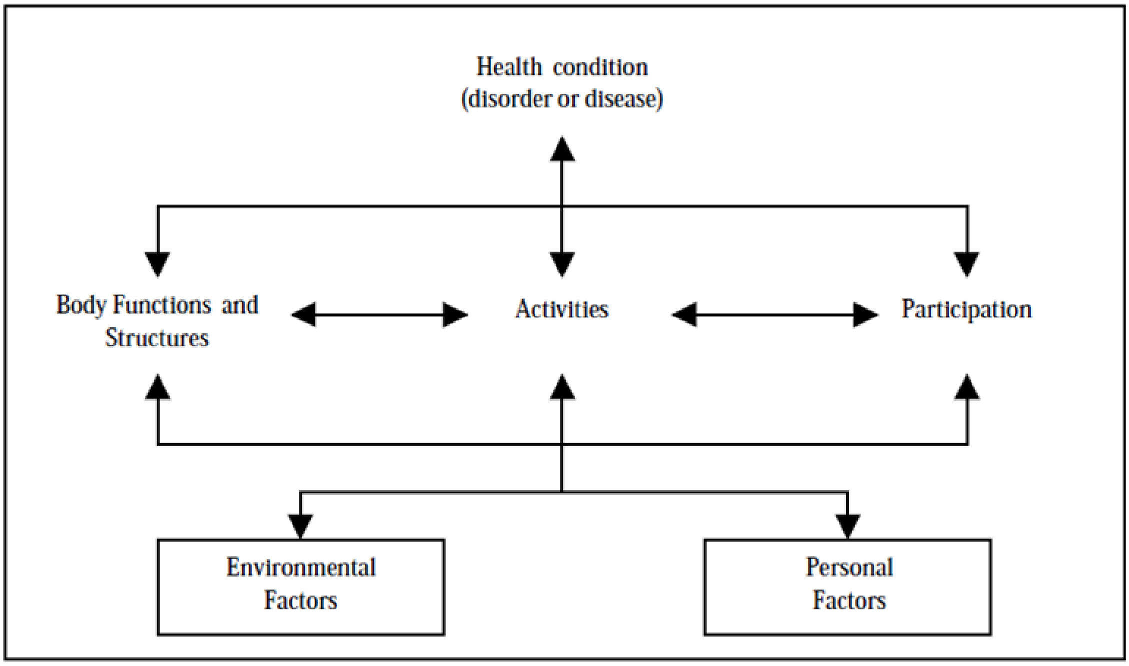

Figure 1. Interactions between the components of ICF (Derived from World Health Organization, 2001 p. 18).

The components in the model are shortly defined as follows: 1) body functions include physiological and psychological functions of the human body; 2) body structures refer to the anatomic parts of the human body; 3) activities include undertaking and executing tasks or actions; 4) participation refers to involvement in life situations; 5) environmental factors are physical, social and attitudinal situations in which the person lives (home, work, transportation, health care, social services, laws, attitudes); and 6) personal factors are the individuals’ background factors that are not part of a health condition (i.e., age, social background, gender). Disability is in this model viewed as a limitation in functioning resulting from any problem in one or more of the three dimensions of human functioning (body functions and structures, activities, participation). The health condition of the individual can indirectly or directly affect the persons functioning in all three dimensions of human functioning. In addition, contextual factors - including environmental and personal factors representing the background of the person's life - can also have an impact on the person's functioning (World Health Organization, 2001).

This model shows that the human experience of functioning and disability should not be viewed as a direct consequence of a disease or health condition or social oppression and exclusion, but as a result of the interaction between a health condition and both environmental and personal influences (Figure 1) (Rauch, Cieza, & Stucki, 2008; Rimmerman, 2013; World Health Organization, 2001). Thus, the ICF emphasises the "fit" between the demands of society or the environment and the individuals' capacities. The ICF's definition of disability is in line with Shakespeare (2018) who points out that disability is multi-dimensional and should be understood as a continuum. Human perfection does not exist and while all humans are in some way limited, most people would not consider themselves as having a disability (Shakespeare, 2018).

In the Nordic context, a similar but simpler model is the Nordic relational model, also referred to as The Gap model or the Scandinavian Model. From this perspective, disability occurs when there is a mismatch between the demands of society and the individual's abilities (NOU 2016). As a result, disabilities can be reduced or removed by changing the environment and/or by strengthening the individual. The introduction of the ICF and the relational model of disability changed how intellectual disability is understood by using person-environment fit models (Wehmeyer & Shogren, 2016). Within both these models, "*disability itself is not a disease or a disorder existing within the person but exists only in the gap between the person's strengths and capabilities and the demands of the environment or context"* (Wehmeyer & Shogren, 2016 p. 564). I put forward a similar view of disability as defined by the ICF model and the Nordic relational model. However, the concept of disability is complex. Therefore, for a more overarching overview and complete discussion of each model, the reader is advised to study and consult the original works.

2.2 Intellectual Disability

Intellectual disability is the most common developmental disorder (Bertelli et al., 2022). The World Health Organization's International Classification of Diseases (ICD-11) defines intellectual disability as "*a group of etiologically diverse* *conditions originating during the developmental period characterised by significantly below average intellectual functioning and adaptive behaviour that are approximately two or more standard deviations below the mean, based on appropriately normed, individually administered standardized tests."* (World Health Organisation, 2018). Elsewhere, by the American Association on Intellectual and Developmental Disabilities (AAIDD), intellectual disability is defined as "*a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates during the developmental period, which is defined operationally as before the individual attains age 22*." (Schalock et al., 2021b, p. 30). While the definitions of intellectual disability have differed, international work has over the last decade resulted in an emerging consensus regarding the diagnosis criteria (Schalock et al., 2021b). The three diagnostic systems including the American Association on Intellectual and Developmental Disabilities (AAIDD), the Diagnostic and Statistical Manual of Mental Disorders (DSM), and the International Statistical Classification of Diseases and Related Health Problems (ICD-11) all agree that intellectual disability is diagnosed when the person's functions meet the following three criteria: *"(a) significant deficits in intellectual functioning, (b) significant deficits in adaptive behavior, consisting of conceptual, social, and practical skills, and (c) these deficits originate during the developmental period"* (Rosencrans et al., 2021, p. 2).

The ICD-11 classifies intellectual disability into four main clinical subcategories; *mild* (approximately 0.1–2.3 percentile), *moderate* (approximately 0.003 – 0.1 percentile), *severe* and *profound* intellectual disability (less than approximately the 0.003 percentile) (Rosencrans et al., 2021). The clinical subcategories are based on the individual's adaptive behaviour and intellectual functioning and are obtained from individually administered standardized tests for each severity level (Rosencrans et al., 2021). Nevertheless, intellectual disability is often characterized as a marked impairment of core cognitive functions necessary for the development of knowledge and reasoning skills (Carulla et al., 2011). Other main descriptors include difficulties with memory and managing behaviour and emotions (Carulla et al., 2011). People with intellectual disability can also experience communicative challenges in terms of the production of words and symbols, understanding complex grammatical structures, and understanding abstract concepts (Finlay & Antaki, 2012; Sigstad

& Garrels, 2018). Other communicative difficulties include understanding turn-taking and processing speed (Corby et al., 2015).

2.2.1 Causes of intellectual disability

The etiological factors of intellectual disabilities are complex and multifaced (Maulik et al., 2022). While a multifactorial understanding of the aetiology has expanded the list of causal factors (types: *biomedical, social, behavioural, educational* and timing: *prenatal, perinatal, and postnatal*), it has historically been divided into two broad types: biological origin and psychosocial disadvantage (Schalock, 2011). The biological factors are further classified into genetic and non-genetic factors. While in most cases the aetiology of intellectual disability is unknown, among the identifiable causes, the leading is genetics. Genetic causes are divided into chromosomal mutations and gene mutations (Maulik et al., 2022). Trisomy 21 (responsible for Down's syndrome) is an example of a chromosomal cause of intellectual disability (Maulik et al., 2022). The causes of intellectual disability can also be classified according to the time of onset, including prenatal, perinatal and postnatal risk factors (Schalock, 2011). However, negative social-environmental conditions, often in the postnatal period, such as inadequate caregivers, low level of stimulation, and social deprivation is also associated with intellectual disability (Maulik et al., 2022).

2.2.2 Prevalence of intellectual disability

The estimated prevalence of intellectual disability ranges significantly and is dependent on the definition used (Rosencrans et al., 2021), but is estimated to 1% to 3 % of the population (Maulik et al., 2022). A meta-analysis of 52 studies estimates that about 1% (10.37/1000) of the world population has an intellectual disability (Maulik et al., 2011). The analysis found that the estimates varied according to the income group of the country of origin and the age group of the study population. For instance, the prevalence was found to be higher in low and middle-income countries, and studies based on children and adolescents also had a higher prevalence of intellectual disability compared to studies on adults (Maulik et al., 2011). Among the subcategories of the severity of intellectual disability, 85% have mild, 10% have moderate, 4% have severe, and 2% have a profound intellectual disability.

In Norway, there have been reports suggesting estimates ranging from 1-3% of the population (NOU 2016). On the other hand, a Norwegian White Paper

(Bufdir, 2013) deemed 1.5% as a reasonable estimate of the prevalence of intellectual disability, giving an estimate of 75.000 people. While there are no reliable estimates of the prevalence of intellectual disability in Norway, approximately 20.000 adults and around 5000 children with intellectual disabilities receive municipal health and care services (Helsedirektoratet, 2022).

2.3 Understanding of intellectual disability in this thesis

In this thesis, intellectual disability is understood as described by the American Association on Intellectual and Developmental Disabilities (AAIDD) as it possesses a relational perspective. Based on a disability perspective, the AAIDD views intellectual disability as culturally and socially conditioned since it is evidenced by a poor 'fit' between the individual and their context. This is particularly clear in the classification of subcategories (mild, moderate, and profound) of intellectual disability as AAIDD proposes that the subcategories should be based on the intensity of support needs (Schalock et al., 2021a, Schalock et al., 2021b). This is a move away from the classification of intellectual disability based on intelligence tests and the belief that low intellectual functioning was the main characteristic of intellectual disability. The multi-dimensional approach to subgroup classification within the AAIDD bases the subgroups on support needs, the extent of adaptive behaviour limitations in conceptual, social, and practical skills, and the extent of limitation in intellectual functioning (Schalock et al., 2021b). This approach is consistent with the ICF and the relational model of disability.

As a consequence of understanding intellectual disability as defined by AAIDD, the participants involved in the included studies were recruited based on their support needs and conceptual, social, and practical skills rather than intelligence levels measured by individually administered standardised tests.

3 Setting the scene

People with intellectual disability have throughout history been stigmatised and mistreated. In the last decades, there has however been a major shift in disability services and a move from segregation towards inclusion. In the following chapter, first, a brief historical note describing the move from segregation towards inclusion in society is given. Thereafter, an overview of user involvement in design is described. Lastly, the chapter is rounded off with approaches to user involvement in technology design.

3.1 Moving from segregation towards social inclusion

The segregation of people is stigmatising and a human rights violation. In 1954, in the case of Brown v. Board of Education of Topeka, 347 U.S. 483, the United States Supreme Court ruled "*that segregation by nature has associations that are not compatible with equality, partly because it implies that those who are segregated are less valued socially*" (Tøssebro, 2015 s.44). In the Nordic disability setting, this ruling was, among others, translated into the argument that sending people with disabilities to institutions and facilities reinforced stigmatisation and deprived them of their human rights (Tøssebro, 2015, 2016).

For people with disabilities, the foundation for a shift towards a "non-institutional" society was first laid in the 1960s. Critical voices pointed to similarities between the segregation of people with disabilities and apartheid policies in both the United States and South Africa (Tøssebro, 2016). Questions were raised as to whether institutions provided people with disabilities with environments that facilitated personal development. Subsequently, living conditions for people with disabilities in institutions conflicted with prevailing values such as citizenship and community participation. While institutions came to be seen as barriers to social justice, equality and participation, the deinstitutionalisation process was first triggered by scandals in institutions in the 1970s and 1980s where conditions were described as "humanly, culturally and socially unacceptable" (Tøssebro, 2016, p. 113). Special boarding schools were confronted with a lack of qualified staff, abuse, horrendous living conditions and deprivation of human rights (Tøssebro, 2015). Regardless that Norway has been one of the forerunners in the deinstitutionalisation of people with intellectual disabilities, central institutions were first closed only in 1991 and closures lasted up to 1995 (Mansell, 2006; NOU 2016).

As a criticism of long-stay residential institutions, the concept of normalisation evolved and spread internationally (Tøssebro, 2016) to guide community inclusion for people with intellectual disabilities (Wehmeyer & Shogren, 2016). The Normalisation Principle, which had Scandinavian roots, provided guidance for developing services which support people with intellectual disabilities to “obtain an existence as close to the normal as possible” (Nirje, 1969 p. 363). Nirje (1969) identified eight facets and implications of the Normalisation Principles. The eight facets, of normalisation implied 1) a normal rhythm of day, 2) a normal routine of life, 3) experiencing the normal rhythm of the year, 4) an opportunity to undergo normal developmental experiences of the life cycle, 5) choices, wishes, and desires have to be taken into consideration and respected, 6) living in a bisexual world (meaning both female and male staff members), 7) normal economic standards, 8) standards of facilities should be the same as for ordinary citizens. The deinstitutionalisation process and reforms that followed led to a process of replacing institutions with community care. This process resulted in improved housing and living arrangements for people with disabilities. However, several other aspects such as employment, social networks and social integration never came true (Tøssebro, 2016).

The Principle of Normalisation later received criticism as questions were raised about whether equality is achieved by living up to the standard of mainstream society (Culham & Nind, 2003). Echoed by self-advocacy movements in the late 1990s with the mantra Nothing About Us Without Us, people with intellectual disabilities demand control, empowerment, and full inclusion in all aspects of community life and a say in matters that affect them (Stack & McDonald, 2014). Shifting from normalisation, nowadays the concept of social inclusion is preferred as it implies that it is the responsibility of the ‘mainstream’ rather than of those with intellectual disability to achieve and create a more inclusive society (Culham & Nind, 2003). Today, the CRPD, which is the world's most ratified human rights treaty, states that all people with disabilities have the right to enjoy all human rights and freedoms (United Nations, 2006). In Article 19, the convention emphasises the right to appropriate support in ensuring inclusion and community living (United Nations, 2006).

While people with intellectual disabilities have become more visible in the social landscape in cities and communities, they are still not fully socially integrated into society (Grung et al., 2022; Tøssebro, 2015) and their community participation is limited (Bredewold & van der Weele, 2022). Thus, a necessary step towards the inclusion of people with disabilities is to recognise that the segregation of people with disabilities is on par with other forms of oppression (e.g., gender, race and sexuality) (Thomas, 2004). Regardless of deinstitutionalisation, reforms and the Normalisation Principle, people with intellectual disabilities are still often treated unequally, separated from their communities, and they tend to experience several forms of exclusion (Bertelli et al., 2022; NOU 2016). A systematic review of literature suggests that people with intellectual disability are less engaged in community participation, less likely to be employed, and have limited interpersonal relationships (Verdonschot et al., 2009). Nevertheless, only a limited body of strategies to improve social inclusion has been identified in literature (McCausland, Murphy, McCarron, & McCallion, 2022). Strategies such as person-centred planning (McCausland et al., 2022), leisure activities (Siperstein, Glick, & Parker, 2009), employment (Amado, Stancliffe, McCarron, & McCallion, 2013) and sports (McConkey, Dowling, Hassan, & Menke, 2013) have shown good potential in increasing social inclusion of people with intellectual disability. An overriding factor in increasing social inclusion is regular contact in integrated environments (Amado et al., 2013). Individual factors such as improving social skills, enhancing social support, increasing opportunities for social contact have also been identified as important factors in improving social inclusion for people with intellectual disability (Alexandra, Angela, & Ali, 2018). Given the importance of social inclusion, there is a need for more research on possible strategies to improve and promote the social inclusion of people with intellectual disability. One possible strategy is participation in various activities, including digital technology design activities.

3.2 Increasing user involvement in technology design

In today’s society, digital technology can be an important factor in improving, promoting and facilitating the social inclusion of people with intellectual disability. Digital technology can allow for real-time support that enables people with intellectual disability to learn, work, travel, socialise, and interact with the community (Lancioni, 2020; Manzoor & Vimarlund, 2018; Wehmeyer et al., 2020). Similar to the shift from segregation to inclusion in society, involving users in the development of technology has become a widely accepted principle (Kujala, 2003). While the tendency has been to develop technology based on designers’ understanding of what people with intellectual disability need, today designers are encouraged to involve people from the intended user group in the design of technology. The user involvement of people with disabilities in technology design is in line with the self-advocacy movement and the cry of “Nothing About Us, Without Us” (Koontz, Duvall, Johnson, Reissman, & Smith, 2022; Rogers & Marsden, 2013). The core idea is that the future user of technology should have an opportunity to influence the design (Robb et al., 2019).

User involvement in design has its roots in several fields including human-computer interaction, design science, service design, education, as well as social movements. Regardless of its interdisciplinarity, user involvement is characterized by ‘direct contact with users’ during a design process (Kujala, 2003). Different approaches[1] to user involvement include, among others, User Centred Design (UCD), Human-Centred Design (HCD) and Participatory Design/Co-design. Each of these approaches is briefly explained in some detail underneath. UCD, HCD and Participatory Design have all been common approaches to the user involvement of people with intellectual disability in the design of technologies. A review of literature revealed that Participatory Design was the most used and HCD was the least commonly used in design activities with people with intellectual disability (Seale et al., 2020).

User Centred Design (UCD) which originates from the United States, is a term used to describe design processes in which end-users influence how a design is takes shape (Abras et al., 2004). Within UCD the main overarching focus and orientation is the usability of the product (Seale, Carrizosa, Rix, Sheehy, & Hayhoe, 2020). However, UCD also emphasizes involving the user in one way or another (Abras, Maloney-Krichmar, & Preece, 2004). For instance, the user can be consulted at specific times during the design process, often during the process of gathering requirements and usability testing (Abras et al., 2004). Still, the focus of the designer is to ensure that the user can use the product as intended, with little effort in learning how to use it.

While it is believed that UCD and Human-Centred Design (HCD) are the same approaches (Campese, Amaral, & Mascarenhas, 2020) and the terms are used interchangeably (van Velsen, Ludden, & Grünloh, 2022), HCD is rooted in fields such as ergonomics, computer science and artificial intelligence. HCD is an approach to systems design and development that focuses on the use of the

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[1] Approach: a way of doing something (Cambridge Dictionary, 2023)

system, human factors, and usability knowledge (Giacomin, 2014). The characteristics of HCD include an explicit understanding of users, multidisciplinary skills and perspectives, user-centred evaluation and involvement of users throughout the design and development process (Giacomin, 2014). In both UCD and HCD, user involvement can occur through *design for* (products designed on behalf of the user), *design with* (users reacting to proposed solutions), *design by* (users participate as part of the design team) and *adaptation by the individual user* (adapt a generic product and adapt it to their needs) (Campese et al., 2020). Scholars have however pointed out some differences between UCD and HCD. For instance, unlike HCD, within UCD the end-users are mainly involved as informants, usually early in the development cycle (Seale et al., 2020).

Participatory Design has roots and beginnings in various social and political movements of the 1960s and 70s and evolved in Scandinavia through collaborative work between academics, technology designers and people from trade and labour unions (Robertson & Simonsen, 2012; Steen, 2011). Participatory Design differs from other user involvement approaches such as UCD and HCD as it emphasises democratic participation, collaboration, and skill enhancement (Kujala, 2003; Robertson & Simonsen, 2012; Seale et al., 2020). A fundamental aspect of Participatory Design is to enable those who will use the technology to have a voice in the design process (Steen, 2011). Today, Participatory Design has a longstanding tradition, and its ideas and associated methods resonate with several other design approaches (Steen, 2011). Participatory Design differs from other user involvement approaches as it has little regard for involving users just as informants through for instance interviews or focus groups (Kensing & Greenbaum, 2012). In other words, approaches based on one-way data-gathering are not considered genuine participation within participatory design (Kensing & Greenbaum, 2012).

Participatory design has also been referred to as cooperative design or co-design due to the inclusion of various stakeholders, ranging in expertise and experience, in design activities (Robb et al., 2019). Being driven by interaction, cooperation and shared experimentation, co-design is often interchangeably referred to as participatory design. While Participatory Design and co-design have similar tenets, they have different historical roots. Steen (2011) writes that co-design can be thought of as a contemporary form of participatory design with tools and techniques added from other traditions. While the term *co-design* is often used to refer to the work of Sanders and other cooperating authors (Sanders, 2000; Steen, 2011), the term *co-creation* is also used (Sanders & Stappers, 2008; Steen, 2011). The roles in the co-design process are dynamic with the user being given the position of ‘expert’ and playing an important role in knowledge development, idea generation and the development of the concept (Sanders & Stappers, 2008). In this thesis, I will use the phrases Participatory Design and co-design interchangeably.

A variety of studies have reported that user involvement in digital technology design yields several benefits for designers - improved quality of the system, avoidance of costly features that users do not or cannot use, improved level of product or system acceptance, and a better understanding of the system resulting in more effective use (Kujala, 2003).

3.2.1 Core characteristics of user involvement in design

The field of user involvement and associated approaches is still an emerging interdisciplinary field where researchers use different terminology in slightly different ways. Despite the interdisciplinarity of user involvement in design, some core characteristics, which are rooted in inclusion, can be identified.

Participation. Participation is a core characteristic of user involvement. User involvement approaches such as HCD, UCD and Participatory Design all emphasise, recognise, and value the involvement of the users during the design process (Abras et al., 2004; Giacomin, 2014; Robertson & Simonsen, 2012). These approaches aim to enable participation through different methods and techniques of those who will, in the future, use or be affected by the results. While the emphasis on user involvement and the role of the user can differ between different user involvement approaches (Kujala, 2003), the goal is to involve and engage the end-user. The spectrum of user involvement ranges from being consulted, typically during usability testing, to being equal partners with the designer throughout the design process. For instance, in Participatory Design, ‘genuine’ participation means the transcendence of users’ roles from being informants to being acknowledged participants in the design process, is fundamental (Robertson & Simonsen, 2012).

User contribution. User contribution, having a say, or end-user influence all refer to not only expressing an opinion but also having an influence and affecting the outcome of the design (Abras et al., 2004; Giacomin, 2014; Marti & Bannon, 2009). This implies that the users need to be informed, given the chance to form and express their opinion, and given the power to influence decisions regarding design (Bratteteig et al., 2013). While some user involvement approaches aim to harvest user requirements and consult users at specific times during the design process (Abras et al., 2004), others generate knowledge by having a democratic approach (Bratteteig et al., 2013). For instance, in participatory design, while the design process includes a number of decisions, it is essential that users have their say about what problems should be solved and how to solve them (Bratteteig et al., 2013).

Growth of knowledge. Designers tend to know about the technical issues and the design processes, while users have knowledge of the domain. It is therefore important that both designers and users are involved in the design process and learn about each other, so they understand the different ways of reasoning and in that way gain mutual respect (Bratteteig et al., 2013). Interacting with users can amplify the designer's understanding of the intended purpose of the solution being designed. For instance, evaluations of a product can help identify usability criteria such as efficiency, safety or learnability, and the subjective satisfaction of the user (Abras et al., 2004). In participatory design, mutual learning is a core principle and a driving force in design projects. Mutual learning is viewed as an essential basis for shared decision-making, grounded in the fact that users are experts in their world (‘domain’ experts) (Hussain et al., 2012) and know most about the activities in which the designed system will be embedded (Bratteteig et al., 2013). This is characterized by a two-way learning in which the designers learn about the context of use from the users, and the users learn about the technical possibilities from the designers (Bratteteig et al., 2013). Mutual learning also involves finding common ground among the participants and building trust among participants (Bødker, Dindler, Iversen, & Smith, 2022).

Empowerment. User-involvement approaches are not only concerned with the extent user involvement can affect the designed solution; they are also motivated by the ethical and political dimension of user participation (Robb et al., 2019). User involvement empowers the participants through the willingness to share decision-making and gives users the opportunity to have a say. As the aim is to share power among participants, addressing power issues is important. Therefore, it is necessary to get to know each other’s expertise in order to recognise valid arguments in the decision-making process (Bratteteig et al., 2013).

The concept of empowerment incorporates processes and outcomes relating to issues of control, awareness, and participation (Zimmerman & Warschausky, 1998). The empowerment discourse is highly relevant due to attempts of balancing power, control and enhance the participation of marginalised groups. While empowerment "will look different in its manifest content for different people, organizations, and settings" (Rappaport, 1987 p. 122), it can be defined as actions and opportunities that support people to gain control and mastery over issues that concern them as well as to participate in decisions that affect their lives (Zimmerman & Warschausky, 1998). Empowerment can be both a process and an outcome. In empowering processes, people create or are given opportunities to gain control over their own lives and influence decisions that affect their lives (Zimmerman, 1995). Empowering processes can for instance include opportunities to develop skills, cooperate with others on a common goal and expand one's social support network (Zimmerman, 1995). On the other hand, empowerment outcomes refer to the consequences and results of empowering processes. Here, having a say, decision making and influencing the design are empowerment outcomes. Thus, user involvement of people with intellectual disability point to the possibilities of being an empowering process and having empowerment outcomes.

3.2.2 Tools and techniques to facilitate user involvement in design

Planning is a foundation for user involvement, and facilitators and designers are essential in helping and supporting participants. Sanders and Stappers (2008) state that facilitators have to "*acknowledge that different levels of creativity exist*" (p. 14) and provide the users with the necessary tools to facilitate idea generation. To effectively involve the user during design processes, several tools and techniques are often combined and adapted to support the participants in making, telling, and enacting aspects of the future design (Brandt et al., 2012). The aim of users 'having a say' affects how the design process is organised.

A design process is the sequence of activities in which a product or technology is developed and designed. The design process is not a linear process, instead, it is often iterative with designers and users moving between different stages and activities (Sanders & Stappers, 2008). To facilitate collaboration, workshops are widely used by designers in design processes. Sanders et al. (2010) state that workshops are an ideal and effective way to use participatory design tools and techniques to stimulate making, telling and enacting. Design teams and practitioners use various tools and techniques throughout the activities to develop ideas and concepts, test prototypes and come up with solutions. While toolkits (collection of tools) have been developed, designers can often cherry-pick, and use tools and techniques as needed during design processes. Design tools and techniques can be organised within three dimensions; *form* (the kind of action taking place, described as making, telling and enacting), *purpose* (why the tools and techniques are being used), and *context* (where and how the tools and techniques are used) (Sanders et al., 2010). Table 2 shows different examples of ways to involve users in design activities.

Table 2. Examples of ways to involve users in design (Abras et al., 2004; Campese et al., 2020; Maguire, 2001).

Purpose	**Example of technique**
Collect feedback and information	Interviews/Background interviews, Surveys/Questionnaires, Focus group/Group interviews, Photovoice, Personas, Shadowing, Journey mapping, Scenarios
Idea Generation/development of early design ideas, Evaluation of alternative designs, information about user needs	Card sorting techniques, Roleplaying, Walkthroughs, Simulations, Observations, Brainstorming, Video/VR scenarios, Stakeholder analysis, Role typing, Storyboard, User stories
Testing	Prototype testing, Paper prototyping, Controlled user testing, Post-experience interviews, Task/Function mapping, Usability testing/ Usability evaluation

3.2.3 Facilitators in technology design activities

While the different tools and techniques are important in involving users, facilitators also play an important role during design activities. Facilitators designated to help control the schedule, flow and communication are essential in securing successful design activities and workshops (Fuad-Luke, 2013). Fuad-Luke (2013, p. 179) states that the most important work of the facilitators revolves around the following basic principles:

- *Inclusion – getting everyone to voice their opinions;*

- *Listening – getting everyone to listen 'deeply', i.e., to the surface and underlying messages;*
- *Communicating, capturing, and disseminating information during the event;*
- *Allowing adequate time for tasks;*
- *Applying the most appropriate tools for the tasks; and*
- *Summing up and pointing to the next steps*.

In design activities with people with intellectual disability, facilitators from a range of different backgrounds are typically involved as facilitators (i.e., researchers, designers, specialists, practitioners, teaching staff, therapists, and care professionals) (Benton & Johnson, 2015). In addition, the design process generally includes a higher ratio of facilitators to users.

4 Related work

In this chapter, related prior work on technology design with people with intellectual disability is presented. This includes an overview of technologies designed with people with intellectual disability, the roles undertaken by people with intellectual disability, the roles of facilitators, reported impacts on people with intellectual disability, and lastly, research gaps are identified to provide a rationale for the research aim and questions of the thesis.

4.1 Designing with young adults and adults with intellectual disability

A variety of studies have described the involvement of people with disability in technology design research. However, earlier literature has largely focused on children with intellectual disability and other disabilities (see reviews of Benton & Johnson (2015) and Börjesson et al. (2015)). More recently, there has been a growing number of researchers involving young adults and adults with intellectual disability. These studies have described involvement in the design of a range of digital technologies including digital e-learning platforms (Murphy et al., 2022; Nash-Patel et al., 2022), virtual reality environments (Brown et al., 2016; Harris, Brown, Vyas, & Lewis, 2022), augmented reality (Koushik & Kane, 2022), serious games (Derks, Willemen, Wouda, Meekel, & Sterkenburg, 2022; Raman & French, 2021), applications (Bayor et al., 2021; Howard et al., 2021; Khan, Dunlop, Lennon, & Dubiel, 2021), tangible technologies (physical objects connected to the digital space) (Andradi, Bircanin, Sitbon, & Brereton, 2021; Bircanin et al., 2021; Neidlinger, Koenderink, & Truong, 2021), and websites (Kirijian, Myers, & Charland, 2007; Xu et al., 2014).

While the majority of earlier research has used Participatory Design and Co-Design (Bayor et al., 2021; Derks et al., 2022; Harris et al., 2022; Howard et al., 2021; Neidlinger et al., 2021), but researchers have also applied UCD (Augusto, Kramer, Alegre, Covaci, & Santokhee, 2016; Furberg et al., 2018; Lazar et al., 2018; Murphy et al., 2022) to involve young adults and adults with intellectual disability in technology design. Furthermore, specific methods have been developed within co-design and Participatory Design to particularly engage people with intellectual disability, including ‘design after design’ (Brereton, Sitbon, Abdullah, Vanderberg, & Koplick, 2015) and ‘method stories’ (Hendriks, Slegers, & Duysburgh, 2015). Elsewhere, several methods have been specifically designed to involve children with disabilities in design (Benton et al., 2012; Foss et al., 2013; Makhaeva et al., 2016).

4.1.2 User roles in technology design activities

People with intellectual disability have had various roles (i.e., testers, informants, design partners, co-designers) with various levels of involvement in technology design. Reported roles includes informants (advisors) and testers (Furberg et al., 2018; Harris et al., 2022; Howard et al., 2021; Khan et al., 2021; Nash-Patel et al., 2022). For instance, people with intellectual disability gave feedback on design concepts during the design of an application to help recognise abuse (Howard et al., 2021) and in Nash-Patel et al. (2022), students with intellectual disability were involved in a partnership with nursing students with the role of giving feedback (via parent communication) and providing their opinions on the format of the designed online programme.

People with intellectual disability have also been involved as co-designers (Andradi et al., 2021; Bayor et al., 2021; Dawe, 2007; Khan et al., 2021; Koushik & Kane, 2022). In Bayor et al. (2021), participants were involved in several phases of co-design activities including an exploration phase and an iterative design phase of the app. Elsewhere, participants with Down Syndrome, parents and caregivers were involved in exploring barriers to independent travel and app requirements in the process of developing a mobile app for independent travel for people with intellectual disability (Khan et al., 2021). In Koushik and Kane (2022), participants participated in developing the initial design idea, including describing visual and interactive elements in developing an augmented reality-based smart display (Koushik & Kane, 2022). Another example is Andradi (2021) who involved a non-verbal adult participant with an intellectual disability to develop a tangible device that provided entertainment and opportunities for social engagement. The participant contributed with input through being observed in interactions with people, sensory stimuli, and prototypes (Andradi et al., 2021).

People with intellectual disability have also been involved in technology design as experts by experience (Augusto et al., 2016; Murphy et al., 2022; Spencer González et al., 2020). This is exemplified in the work undertaken by Augusto et al. (2016) in which participants with Down Syndrome were involved to voice their needs, preferences and concerns regarding the developed products. Also in Spencer González et al. (2020) people with intellectual disability participated in the preparation phase, fieldwork phase, ideation phase, and validation phase in an inclusive design project conducted by a team of researchers. In Murphy et al. (2022), people with intellectual disability were involved in the design process as members of a Citizen Advisory Panel which co-created project material. The participants provided expert-by-experience prototype review work, user-tested the application, and shaped every critical project decision (Murphy et al., 2022).

Lastly, people with intellectual disability have also been involved in technology design as design partners (Derks et al., 2022). In Derks et al. (2022), participants with intellectual disability were involved in several roles during the preparation phase of the development process. Exploring user involvement through an involvement matrix, the participants had multiple roles such as listener, co-thinker, advisor, and partner. While the participants did not make final decisions, they contributed with insights about the needs and wishes of the target group (Derks et al., 2022).

The roles of young adults and adults with intellectual disability are defined and interpreted differently, as the above suggests. It has been difficult to explicitly identify the level of involvement and if their roles were redefined at different points in the design process (for example switching from tester to co-designer). Still, according to publications revisiting these roles, it is important to note that the roles are different and one role is not better than another (Benton & Johnson, 2015; Guha, Druin, & Fails, 2013).

4.1.3 Roles of facilitators in technology design activities

Facilitators from a wide range of backgrounds are involved to provide support in design activities. While details on the roles of facilitators varies, earlier research describes the involvement of teachers (Nash-Patel et al., 2022), teaching assistants (Harris et al., 2022), staff and therapists (Bayor et al., 2021), parents (Nash-Patel et al., 2022) and researchers (Andradi et al., 2021; Derks et al., 2022; Howard et al., 2021; Murphy et al., 2022; Neidlinger et al., 2021). For instance, in Derks et al (2022), the coordinating researcher supported involvement by simplifying language, making exercise material concrete, and structuring and simplifying the exercises. Another example is in Harris et al. (2022) where teaching assistants were involved as advisors during the design sessions. Similarly, in Bayor et al. (2021), staff and therapists in a Disability Support Centre were always present to offer facilitation support to researchers and replicated the workshops with participants who missed sessions. The staff also supported the participants during the design activities (Bayor et al., 2021). Elsewhere, in Nash-Patel et al (2022) teachers, parents and special arts and drama specialists provided support and facilitation during design activities. For instance, participants with intellectual disability communicated their ideas and feedback indirectly via parent communication. Moreover, storytelling and retelling approaches, facilitated by researchers and arts/drama specialists were used to help participants find their voice (Nash-Patel et al., 2022).

Furthermore, parents and caregivers have actively and directly contributed during the design sessions in addition to being involved as facilitators (Augusto et al., 2016; Khan et al., 2021; Neidlinger et al., 2021; Sitbon & Farhin, 2017). For instance, in Khan et al. (2021), participants participated with parents and carers in workshops and interviews and contributed to the development of the travel app (Khan et al., 2021). Similarly, in Sitbon and Farhin (2017), the participants and carers took part in the co-design sessions with both being active participants.

4.1.4 Impact of participation on users

The research on the impact of participating on young adults and adults with intellectual disability is limited. However, some individual benefits of participation, referred to as user gains (Benton & Johnson, 2015), have been identified in earlier research. In children with intellectual disabilities, reported benefits of participation in technology design activities include developing knowledge and skills, positive experience and positive emotions (Benton & Johnson, 2015). In young adults and adults with intellectual disability, Murphy et al. (2022), reported learning new digital skills, making friends, and learning from the experiences of others. Moreover, the participants received payment, which was beneficial regarding career development. Also, participation had a positive impact on their self-image and confidence. Elsewhere, by using a competency-based approach to co-design, participants developed their competencies (representative practical skills people develop from their participation in activities, in this case, mainstream technologies, such as social media and the internet), confidence and skills (Bayor et al., 2021). Young adults and adults with intellectual disability have also reported other positive experiences of participation in technology design such as learning and ownership (Raman & French, 2021). Regarding social factors, user gains such as making friends

(Raman & French, 2021) and enhanced inclusion amongst peers and recognition (Andradi et al., 2021) have been reported. Moreover, participation in co-design led to that the participant built social capital (Andradi et al., 2021). This shows that research reporting on social outcomes of participation in technology design activities for young adults and adults with intellectual disability is still limited.

While exploring the impact of participation in technology design is important, it is can also be difficult. Qualitative approaches are defined as most appropriate for exploring and measuring the impact of participation (Benton & Johnson, 2015). In qualitative studies, impact of participation on users is based on different sources including interviews (Murphy et al., 2022), discussions from meetings (Murphy et al., 2022), observations (Andradi et al., 2021; Bayor et al., 2021), short videos and participant enquiries (Bayor et al., 2021) and informally collected shared experiences (Raman & French, 2021). However, a large number of studies exploring user involvement of young adults and adults with intellectual disability in technology design does not explicitly report the impact of participation (e.g., Bircanin et al., 2021; Derks et al., 2022; Harris et al., 2022; Howard et al., 2021; Kirijian et al., 2007; Koushik & Kane, 2022; Nash-Patel et al., 2022; Neidlinger et al., 2021; Sitbon & Farhin, 2017).

4.2 Research gaps in the research base

The previous overview of the research on user involvement of young adults and adults with intellectual disability points to research gaps that researchers need to address. Firstly, there is little research on participation in digital technology design for young adults and adults with intellectual disability. The majority of existing research is concerned with the roles, methods, techniques, and impact of the resulting technology on children with intellectual disability, special educational needs, and autism (Benton, 2014; Benton & Johnson, 2015; Benton et al., 2012; Börjesson et al., 2015; Frauenberger, Good, & Alcorn, 2012; Frauenberger, Makhaeva, & Spiel, 2017; Parsons & Cobb, 2014). The limited focus on young adults and adults with intellectual disability is of concern. Relying on results and methods developed for children when designing with young adults and adults with intellectual disability is inappropriate and may impact the design process and research outcomes as there are essential differences between children and adults, regardless of whether the person has an intellectual disability. For instance, adults with intellectual disability may understand, experience, and interpret participation and outcomes of participation in digital technology design somewhat differently. This doctoral thesis expands research to include adults and young adults with intellectual disability.

Secondly, while there is evidence that people with intellectual disability are increasingly involved in digital technology design, the research on how such participation impacts people with intellectual disability remains fragmented and limited. Previous research on outcomes of participation in digital technology design activities has predominantly focused on describing the technological outcome such as artefacts, prototypes and interfaces (Hendriks et al., 2015). Thus, there is a need to further investigate the direct impact of user involvement on participants with intellectual disabilities. In line with the disability rights movement ‘Nothing About Us, Without Us’ (Rogers & Marsden, 2013; Stack & McDonald, 2014), there is a need to ask young adults and adults with intellectual disabilities directly. To date, the research exploring the impact of participation in digital technology design on young adults and adults with intellectual disability is largely informal. An example of this is the study carried out by Andradi et al. (2021) in which impact was explored though observations without researchers providing the methodological descriptions how the observations and insights were obtained. To provide insight into the impacts of participation, the experiences of people with intellectual disability participating in such activities are systematically and directly addressed in this doctoral thesis.

Thirdly, there is limited research and knowledge on *why* user gains occur (Benton & Johnson, 2015). To date, there is little research using existing theory to explore possible outcomes of participation in digital technology design for young adults and adults with intellectual disability. For instance, none of the above reviewed studies apply theory to explore participation or explain the identified user gains. To address this gap, this doctoral thesis explores and analyses experiences of participation in digital technology design using existing theory. Drawing on Dent-Spargo’s (2018) hypothesis, the self-determination theory is used as a lens to explore the motivation of young adults with intellectual disability participating in digital technology design activities.

Fourthly, research studies on the user involvement of people with intellectual disability show that facilitators from a range of backgrounds provide support during technology design activities. Facilitators are particularly important in technology design activities with people with intellectual disability as it is often necessary to adapt methods and techniques (Gibson, Dunlop, & Bouamrane, 2020). Facilitators in design activities also provide *in situ* adjustments and support to ensure and enable authentic participation (Hendriks et al., 2015). Still, the nature of facilitation (i.e., role, tasks, level of involvement, contributions to resulting technology) is rarely discussed in detail, making it difficult to identify how facilitators contribute during digital technology design activities with this population. As adjustments in practices and methods are often not the main focus, researchers struggle to learn from other researchers' efforts (Hendriks et al., 2015). While a growing body of research has focused on describing the roles of facilitators and their backgrounds, there is less research on their contribution and experiences during the design activities. This doctoral thesis provides insight and knowledge on *in situ* facilitation, adjustments made, and facilitators' experiences of supporting young adults and adults with intellectual disability during digital technology design activities.

Finally, today, social inclusion is a global aim, a central goal of welfare policies and legislation, and an important determinant of health and well-being (Grung et al., 2022). Still, only a limited number of strategies to improve social inclusion for persons with intellectual disabilities are identified in literature. Earlier studies have however reported social gains including making friends and inclusion among peers as user gains of participation in technology design activities (Andradi et al., 2021; Raman & French, 2021). Moreover, participation is a chore characteristic of both social inclusion and user involvement in design (Giacomin, 2014; Robertson & Simonsen, 2012; Simplican et al., 2015; Warschauer, 2004). While Andradi et al. (2021) suggest that participation in co-design can lead to social capital, inclusion and increased social relations, there is little research available on the social impact of participation in technology design on young adults and adults with intellectual disability. Consequently, given the importance of the social inclusion of people with intellectual disability, there is a need for research especially investigating participation in design as a possible strategy to improve social inclusion. This doctoral thesis addresses this gap and discusses how participation in digital technology design activities can support the social inclusion of young adults and adults with intellectual disability.

5 Theoretical background

The focus of this thesis is to explore how participation in the design of digital technology can contribute to the social inclusion of young adults with intellectual disability. In the first part of this chapter, the concept of social inclusion and a working definition is provided. Thereafter, in the second section of this chapter, self-determination and the Basic Psychological Needs Theory is presented.

5.1 Social inclusion

Social inclusion is defined differently by researchers, government institutions, and international organizations. While some definitions of social inclusion have a narrow scope, others have a broader scope. Narrow definitions of social inclusion view it as merely *access*, while broader interpretations regard social inclusion as *participation* or *empowerment* (Gidley, Hampson, Wheeler, & Bereded-Samuel, 2010). In defining social inclusion, Warshauer (2004) stresses the importance of participation, agency and self-determination and refers to social inclusion as "*the extent that individuals, families, and communities are able to fully participate in society and control their own destinies, taking into account a variety of factors related to economic resources, employment, health, education, housing, recreation, culture, and civic engagement"* (p. 8). The European Union (EU), on the other hand, highlights poverty and discrimination broadly describing social inclusion as *"a process which ensures that those at risk of poverty and social exclusion gain the opportunities and resources necessary to participate fully in economic, social and cultural life and to enjoy a standard of living and well-being that is considered normal in the society in which they live. It ensures that they have greater participation in decision making which affects their lives and access to their fundamental rights"* (EU, 2004, p. 10).

For people with intellectual disability, social inclusion can be defined as a complex process in which they can take part in society through being reciprocally active in its spaces (e.g., family, community), services (e.g., education, health, welfare), markets (e.g., employment,) and customs (e.g., arts) (Koller et al., 2018; Robinson et al., 2021). Overmars-Marx et al. (2014) emphasise the multidimensional character of social inclusion and identify five levels in which the inclusion of people with intellectual disabilities can be defined and conceptualized. These levels include informal networks, professional care, neighbourhood characteristics, and governmental policies (Overmars-Marx et al., 2014). There is however a recognition that social inclusion for people with intellectual disability is a product of complex interactions between environmental factors, opportunities, and competencies (Cobigo et al., 2012). Cobigo et al. (2012, p. 82) define social inclusion as “*(1) a series of complex interactions between environmental factors and personal characteristics that provide opportunities to (2) access public goods and services, (3) experience valued and expected social roles of one’s choosing based on his/her age, gender and culture, (4) be recognized as a competent individual and trusted to perform social roles in the community, and (5) belonging to a social network within which one receives and contributes support”.* This definition reflects a developmental perspective and reflects the notion that social inclusion occurs and improves through increased opportunities for interaction and participation in activities.

Social inclusion in communities contributes to a better life and is an established right for people with intellectual disability (McCausland et al., 2022). Social inclusion enhances a sense of belonging (Cobigo et al., 2012), leads to becoming a contributor to society (Overmars-Marx et al., 2014), and improves the quality of life and mental health (Forrester-Jones et al., 2006). However, a major obstacle to achieving these positive outcomes for people with intellectual disability is that the construct of social inclusion is multifaced, subjective (Koller et al., 2018) and still unclear (Simplican et al., 2015). The conceptual ambiguity of social inclusion can on one hand lead to conceptual open-endedness inviting researchers to take different approaches to social inclusion and how to promote it. On the other hand, the interchangeability of social inclusion can also lead to challenges such as confusion across stakeholders and conflicting measurements (Simplican et al., 2015).

Various concepts and theories have been used to explore social inclusion (Cobigo et al., 2012; Simplican et al., 2015). This includes concepts such as social networks, social interaction, independent living, and community participation (Amado et al., 2013; Cobigo et al., 2012; Rimmerman, 2013; Simplican et al., 2015). While these studies provide important insights, there are drawbacks to exploring social inclusion through these concepts. For instance, when defined through interpersonal relationships, social inclusion can be viewed as interchangeable with social interaction or social networks causing a narrow perspective. As argued by Simplican et al. (2015, p. 21), “*one of the main problems of defining social inclusion as social interaction is that social interaction is an interpersonal concept without any community dimension*”.

Elsewhere, social inclusion can overlap with expansive definitions of community participation. An example of such a definition is Verdonschot et al. (2009, p. 304), who define community participation as "*the performance of people in actual activities in social life domains through interaction with others in the context in which they live"*. While this definition incorporates both domestic and interpersonal life, the distinction between the person's social network and involvement in the community is blurred (Simplican et al., 2015).

In an attempt to provide a clear and accessible definition of social inclusion of people with intellectual disability, Simplican et al. (2015) define social inclusion as the interaction between interpersonal relationships and community participation. Both interpersonal relationships and community participation are reoccurring themes in social inclusion literature and are also core domains of quality of life (Simplican et al., 2015). Simplican et al. (2015) describe social inclusion within an ecological model, where both disability and social inclusion are a product of individual, environmental and social factors. This is in line with the multi-dimensional understanding of disability in this thesis (Schalock et al., 2021b; Shakespeare, 2018; World Health Organization, 2001).

5.1.2 Working definition and model of social inclusion

As mentioned, the literature on social inclusion for people with intellectual disability has been inconsistent and lacked conceptual clarity. For conceptual clarity, I adopt the concept of social inclusion as presented by Simplican et al. (2015) as it provides a thorough and comprehensive model for the complex and broad variety of elements that influence the two domains of social inclusion. Figure 2 provides an overview of the two domains of social inclusion as per Simplican et al (2015).

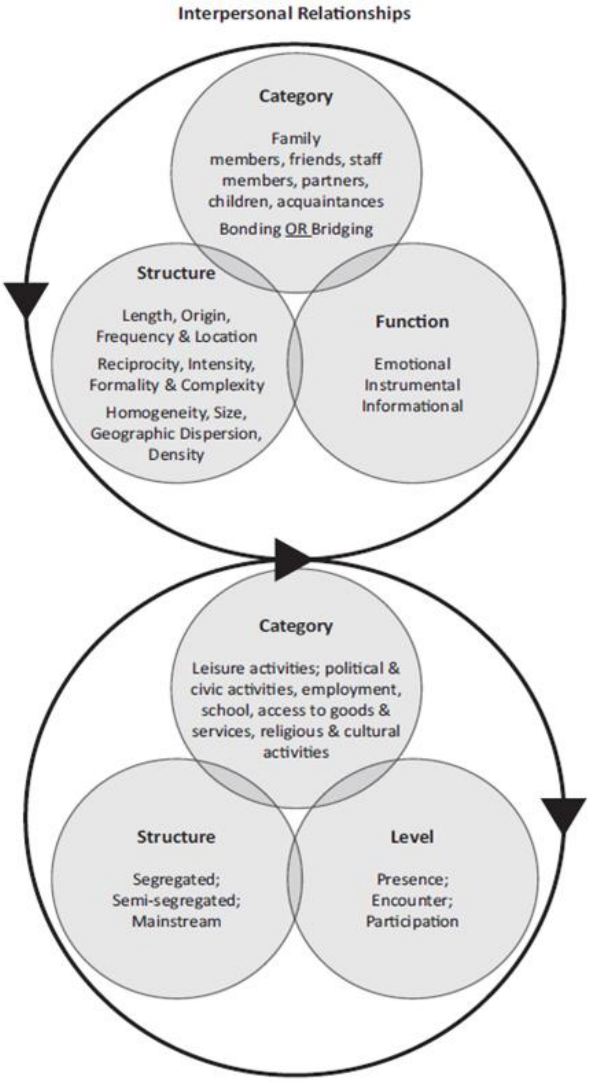


Figure 2. The model of social inclusion (Simplican et al. 2015, p. 23).

The two domains, interpersonal relationships and community participation overlap and mutually support one another. For instance, increased participation in community activities may result in new and more diverse interpersonal relationships which may then lead to further potential community participation. Within each of the two domains, important categories are defined to capture structural and functional components regarding social inclusion (Figure 2).

As shown in figure 2, the domain of ***interpersonal relationships*** contains three characteristics which include category, structure and function (Simplican et al., 2015). The first characteristic, *category*, refers to the people in the person's social network. These interpersonal relationships function as means for boding or bridging. Bonding happens between people who share a common bond and bridging is forging contact between diverse people. The second characteristic, *structure*, refers to structural components of interpersonal relationships and includes factors such as the length and origin of the relationship, frequency of contact, as well as the dimension of the location in which the social interaction takes place (e.g., if the contact occurs at home, the community or online). The third characteristic, *function of the relationships,* is divided into three categories of social support: emotional, instrumental and informational (Simplican et al., 2015). The function aspect refers to the types of support within an interpersonal relationship one seeks or obtains.

The domain of ***community participation*** captures involvement in community activities that promote and lead to the development of personal relationships (Simplican et al., 2015). This domain is divided into three characteristics; category, structure, and level of involvement. The first characteristic, *category*, refers to community activities including leisure activities, political and civil activities/organisations, productive activities, access to services, and religious and cultural activities in which a person is involved (Simplican et al., 2015). The second characteristic, *structure*, refers to the framework of the settings in which the activity is situated or in which the social interaction takes place and includes segregated, semi-segregated or integrated settings. The third characteristic of community participation is the *level of involvement* in the community which is conceptualized as presence, encounter, and participation.

The distinction between the different domains provided in this model shows recognition that there is a spectrum of *interpersonal relationships* and *community participation* that can promote the social inclusion of people with intellectual disability. The model and definition of social inclusion provided by Simplican et al. (2015) has been utilised in several studies with people with intellectual disabilities (Hanson et al., 2021; Martin et al., 2021; McCausland et al., 2022; Werner & Hochman, 2017; Wilson et al., 2017). It has also been used to analyse social inclusion in contexts outside of the disability studies field, including the military (Werner & Hochman, 2017), technology (Martin et al., 2021), sports (Corazza & Dyer, 2017), and volunteer work (Kruithof et al., 2021).

5.2 Self-determination

Over the past decades promoting and enhancing the self-determination of people with intellectual disability has become best practice. The earliest use of the term self-determination concerning people with intellectual disability was applied in 1972 by Bengt Nirje (as cited in Shogren et al., 2017). Nirje highlighted the importance of self-determination in his writing on the Normalisation Principle and argued that people with disabilities deserve to be treated with respect, have access to their communities, opportunities to make decisions and assert themselves over their lives. Despite this early effort, self-determination for people with intellectual disabilities first received significant attention in the 1990s when it became a critical focus in the self-advocacy movement (Shogren et al., 2017). Later, the focus on empowerment within the self-advocacy movement highlighted the importance of people with intellectual disabilities directing their lives (Shogren et al., 2017).

Shogren et al. (2015, p. 258) define self-determination as a "*dispositional characteristic manifested as acting as the causal agent in one's life. Self-determined people (i.e., causal agents) act in service to freely chosen goals. Self-determined actions function to enable a person to be the causal agent is his or her life*". This definition points to three essential characteristics of self-determined actions: volitional action (e.g., making conscious choices based one's own preferences), agentic action (e.g., self-directed action to enable progress towards freely chosen goals or aims) and action-control beliefs (e.g., a sense of personal empowerment) (Shogren et al., 2015).

Self-determination, which focuses on autonomy, self-regulation and personal control, has been identified as a possible key factor in enhancing the social inclusion of people with intellectual disability (Soresi, Nota, & Wehmeyer, 2011). The interaction between self-determination and social inclusion may be reciprocal. For instance, people with disabilities living in inclusive environments are more self-determined than those living in segregated settings, and moving from restrictive settings to the community results in enhanced self-determination (Soresi et al., 2011). Several earlier studies have established a link between the self-determination of people with intellectual disabilities and for instance positive employment outcomes (Shogren et al., 2015; Wehmeyer & Bolding, 2001), participation in recreational activities (McGuire & McDonnell, 2008), independent living (Shogren & Shaw, 2016), increased community participation (Nota et al., 2007; Wehmeyer & Palmer, 2003), increased quality of life (Lachapelle et al., 2005; Nota et al., 2007), and general wellbeing (Shogren et al., 2006).

Regardless of the acknowledgement and consensus that self-determination is important for children, adolescents and adults with intellectual disability (Wehmeyer & Bolding, 2001), and an important developmental outcome for people with intellectual disabilities (Garrels & Granlund, 2017), research indicates that people with intellectual disabilities are less self-determined than their peers without intellectual disability (Garrels & Granlund, 2017). They often find themselves in segregated settings and living environments in which opportunities for choice-making and practicing self-determination skills may be limited (Björnsdóttir et al., 2015; Hughes et al., 2013). While self-determination can be enhanced by supporting the development of factors related to self-determined action such as decision-making, goal-setting and problem-solving skills (Dean et al., 2019), the potential for self-determination among people with intellectual disability is defined by the interplay between the individual and environmental factors (e.g., education, family, friends, institutional setting) (Vaucher, Cudré-Mauroux, & Piérart, 2020).

This background acknowledges self-determination to be an important factor in the social inclusion of people with intellectual disability, where involvement in contexts which provide opportunities for practicing self-determination skills is essential. Thus, self-determination has been chosen as a lens for exploring social inclusion and deserves attention within a variety of contexts that provides opportunities for decision making, including digital technology design activities.

5.2.1 The Basic Psychological Needs Theory

The self-determination construct has been conceptualised in different ways and several theories explain the construct. Examples of the most influential self-determination theories are the functional theory of self-determination (Wehmeyer et al., 1996), Causal Agency Theory (Shogren et al., 2015) and Self-Determination Theory (Deci & Ryan, 2000). The Self-determination theory is a psychological macro-theory aiming to explain human motivation (Deci & Ryan, 2002), and consists of six different mini-theories including Cognitive Evaluation Theory, Causality Orientations Theory, Organismic Integration Theory, Goal Content Theory, Relationships Motivation Theory and Basic Psychological Needs Theory. These mini theories each explain a specific set of observed motivation phenomena in several different domains. While a more detailed look at self-determination theory is beyond its scope, this thesis employs the Basic Psychological Needs Theory, which is presented below.

According to the Self-Determination Theory, humans have three basic psychological needs; autonomy, competence, and relatedness (Deci & Ryan, 2000, 2002). A psychological need is defined as psychological nutrients that are essential for a person's integrity and growth (Ryan, 1995). To qualify as a basic psychological need, a desire or need must be essential to people's well-being when satisfied and increase the risk of passivity and ill-being when not satisfied (Vansteenkiste, Ryan, & Soenens, 2020). The Self-Determination Theory suggests that people are driven to engage in actions to fulfil their psychological need for autonomy, relatedness and competence. The satisfaction of these needs leads to intrinsic motivation, which is highly autonomous and refers to doing activities for their own sake, out of interest. As Deci and Ryan (2008, p. 21) state, "*autonomous motivation has been found to be more in evidence when people experience satisfaction of their basic psychological needs for competence, relatedness, and autonomy".*

Basic psychological needs are universal, meaning they are evident in all cultures, ages (in all developmental periods), and genders. As such, when possible, humans gravitate towards situations that provide and nurture the fulfilment of these needs. Ryan and Deci (2002) state that social environments that allow the satisfaction of the needs for autonomy, relatedness and competence are predicted to support healthy functioning and well-being, whereas factors that thwart these needs are predicted to be antagonistic. All three basic psychological needs are essential for growth and development (Deci & Ryan, 2002) and play a role in wellness, both in general terms and in specific contexts (Ryan et al., 2010).

The first basic need, *autonomy*, is defined as "*being the perceived origin or source of one's own behavior*" (Ryan & Deci, 2002, p. 8). The need for autonomy is fulfilled when a person experiences self-endorsement or volition in behaviour (Ryan et al., 2010). When the need for autonomy is satisfied one experiences a sense of integrity as one's actions and thoughts are authentic (Vansteenkiste et al., 2020). On the other hand, when frustrated, the person experiences a feeling of being pushed in an unwanted direction (Vansteenkiste et al., 2020).

The second basic need, *competence*, refers to "*feeling effective in one's ongoing interactions with the social environment and experiencing opportunities* *to exercise and express one's capacities"* (Ryan & Deci, 2002 p. 7). The need for competence leads individuals to seek optimal challenges that are fitting for their capacities and skills, with the aim of maintaining and enhancing those skills through activity. However, it is important to note that the need for competence is not an attained skill, but rather a sense of confidence (Deci & Ryan, 2002). Therefore, the need for competence is closely linked or related to the concept of self-efficacy. When the need for competence is frustrated, people experience a sense of ineffectiveness or failure (Vansteenkiste et al., 2020).

The third basic need, *relatedness*, refers to *"feeling connected to others, to caring for and being cared for by those others, to having a sense of belongingness both with other individuals and with one's community"* (Ryan & Deci, 2002 p. 7). The need for relatedness concerns the tendency to connect with and being accepted by others, as well as a sense of being with others (Deci & Ryan, 2002). Thus, the need for relatedness refers to something beyond simply being present or around other people (Ryan et al., 2010). When satisfied, people experience bonding and care. When frustrated, people experience a sense of exclusion and loneliness (Vansteenkiste et al., 2020).

The Self-Determination Theory has been used in the disability field, although in a limited fashion, to focus on the creation of autonomy-supportive environments (Shogren et al., 2017). Moreover, research and theory related to people with intellectual disability could benefit from using the same perspectives and principles as those used for all (Deci & Chandler, 1986). All people need to feel competence, autonomous and belong (Deci & Chandler, 1986). Elsewhere, in disability studies, the Self-Determination Theory has been used as a lens to study health, social development and wellbeing (Ryan & Deci, 2000), autonomy support and needs satisfaction (Frielink et al., 2018), education (Katz & Cohen, 2014) and employment (Garrels & Sigstad, 2019). The Self-Determination Theory and participation in design have been linked to each other in earlier work, which also hypothesised that participation in such activities may be able to support the satisfaction of the three basic psychological needs and self-determined action (Dent-Spargo, 2018). This link has however not been explored yet.

With this overview of social inclusion, self-determination, and the basic psychological needs theory, I point to a) the importance of social inclusion for people with intellectual disability, b) self-determination as an essential factor for the social inclusion of people with intellectual disability, and c) self-determination being a lens to explore both motivation and wellbeing through the needs for autonomy, competence, and relatedness. While they are all important concepts and theories, they may also be essential factors in understanding possible outcomes of participation in digital technology design activities with people with intellectual disabilities.

6 Context

In this chapter I present the context of this PhD thesis and the included papers. First the innovation project InnArbeid is presented. Thereafter, an overview of Action Design Research, the methodological approach used in the design project, is given. Lastly, an overview of the design activities and the designed technology (Self-reflective career tool and Transport support tool) is presented.

6.1 The InnArbeid project

The papers I-IV of this thesis are based on the digital technology design activities conducted during the development of two of the digital services (see section 6.1.2 and 6.14). These digital services were developed through user involvement with the intended end users (young adults and adults with intellectual disability, teachers and employers).

According to Guha et al (2010), technology design teams should not be artificially created for the sole purpose of studying the impact and effects of participation. The InnArbeid project was chosen as the context of this thesis. The InnArbeid project (2017-2022) was a need-based innovation project that aimed to develop services and applications that enable people with disabilities to find, gain and retain work. The result of the project was four digital services to support people with disabilities during the transition from school to work and for further participation in working life. To develop digital services, the project identified barriers and needs related to the transition from school to working life. The project involved stakeholders in the transition between upper secondary school and work including young adults and adults with intellectual disability, next-of-kins, teachers, professionals from housing services, the Norwegian Association for People with Intellectual Disabilities, NAV (Norwegian Labour and Welfare Administration) and enterprises organised through the Norwegian employers' organisation.

6.1.2 Action Design Research

The activities in the InnArbeid project followed the principles of Action design research (ADR). ADR is a methodology that emphasises user involvement, proposed by Sein, Henfridsson, Purao, Rossi and Lindgren (2011, p. 40) and blends activities of action research (AR) and design science research (DSR).

> *ADR is a research method for generating prescriptive design knowledge through building and evaluating ensemble IT artifacts in an*

> *organizational setting. It deals with two seemingly disparate challenges: (1) addressing a problem situation encountered in a specific organizational setting by intervening and evaluating; and (2) constructing and evaluating an IT artifact that addresses the class of problems typified by the encountered situation.*

ADR consists of four stages, 1) problem formulation, 2) building, intervention and evaluation and 3) reflection and learning and 4) formalisation of learning (Sein et al., 2011). The stages in action design research are based on certain principles and tasks. An overview of the ADR process is presented in figure 3.

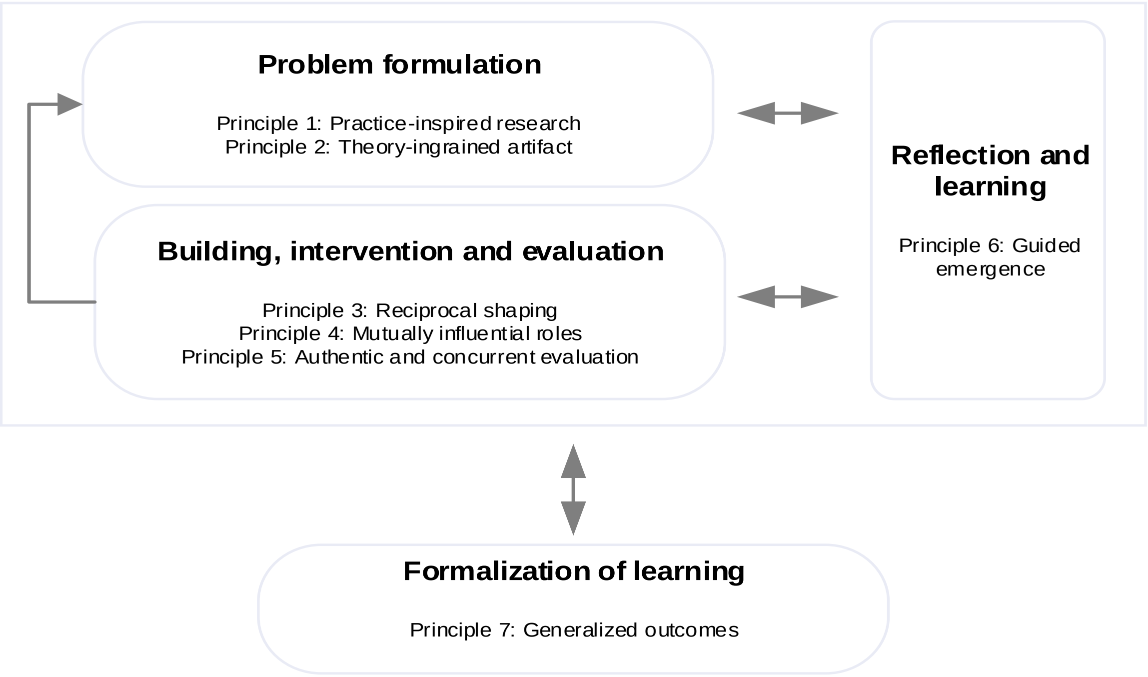
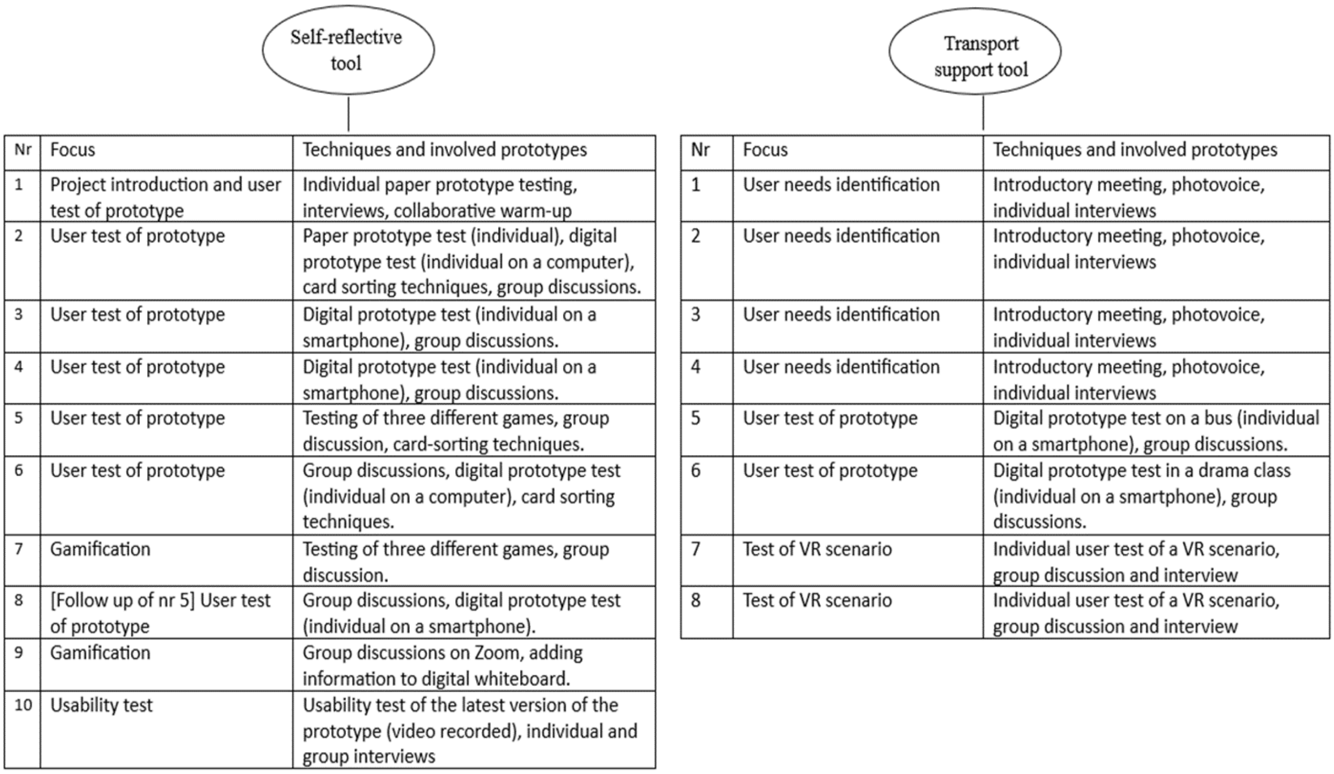


Figure 3. Action design research methodology: Stages and principles. From Sein et al. (2011, p. 41).

The first stage is *problem formulation* (Sein et al., 2011). Here a practice-inspired problem situation is explored and formulated, supported by existing theories and technologies (Sein et al., 2011). The second stage, *building, intervention, and evaluation*, uses the problem framing and theoretical premises from stage one to generate an initial design of the IT artefact. The IT artefact is further shaped by testing and subsequent design cycles (Sein et al., 2011). The second stage is the stage in which most of the user involvement occurs. In stage three, which is a continuous stage and parallels the first two stages, the *reflection and learning* stage moves from building a solution for a particular problem to applying that learning to a broader class of problems (Sein et al., 2011). In stage four, *formalization of learning*, the situated learning from the ADR project should be developed further into general solution concepts (Sein et al., 2011).

6.1.3 Design activities

The papers I-IV are based on the following digital technology design activities (Figure 4). The aim of the design activities included user needs identification, user testing of prototypes, gamification workshops and usability testing.



Self-reflective tool

Nr	Focus	Techniques and involved prototypes
1	Project introduction and user test of prototype	Individual paper prototype testing, interviews, collaborative warm-up
2	User test of prototype	Paper prototype test (individual), digital prototype test (individual on a computer), card sorting techniques, group discussions.
3	User test of prototype	Digital prototype test (individual on a smartphone), group discussions.
4	User test of prototype	Digital prototype test (individual on a smartphone), group discussions.
5	User test of prototype	Testing of three different games, group discussion, card-sorting techniques.
6	User test of prototype	Group discussions, digital prototype test (individual on a computer), card sorting techniques.
7	Gamification	Testing of three different games, group discussion.
8	[Follow up of nr 5] User test of prototype	Group discussions, digital prototype test (individual on a smartphone).
9	Gamification	Group discussions on Zoom, adding information to digital whiteboard.
10	Usability test	Usability test of the latest version of the prototype (video recorded), individual and group interviews

Transport support tool

Nr	Focus	Techniques and involved prototypes
1	User needs identification	Introductory meeting, photovoice, individual interviews
2	User needs identification	Introductory meeting, photovoice, individual interviews
3	User needs identification	Introductory meeting, photovoice, individual interviews
4	User needs identification	Introductory meeting, photovoice, individual interviews
5	User test of prototype	Digital prototype test on a bus (individual on a smartphone), group discussions.
6	User test of prototype	Digital prototype test in a drama class (individual on a smartphone), group discussions.
7	Test of VR scenario	Individual user test of a VR scenario, group discussion and interview
8	Test of VR scenario	Individual user test of a VR scenario, group discussion and interview

Figure 4. Overview of design activities explored in this thesis.

6.1.4 Self-reflective career tool and transport support tool

The respondents in papers II and III participated in design activities connected to a ***self-reflective career tool***. The self-reflective career tool was designed iteratively with young adults with intellectual disability to support users in the transitions into work by mapping their skills, abilities, interests and needs. The concept included six main elements: (1) login and user details, (2) mapping of skills and abilities, (3) mapping of interests, (4) goal setting, (5) progress evaluation and (6) generating a CV. During the project, the design ideas transformed from paper prototypes to a digital tool that could be used on smartphones, tablets and computers. The mapping of interests was based on swiping and skills and abilities were graded using smiley faces. Drawing on TV and gaming, the user is on a road on which to progress, the user must solve tasks to proceed to the next level.[2]

Dette er du god på

Nå skal du med smileys beskrive hva du synes du er god på

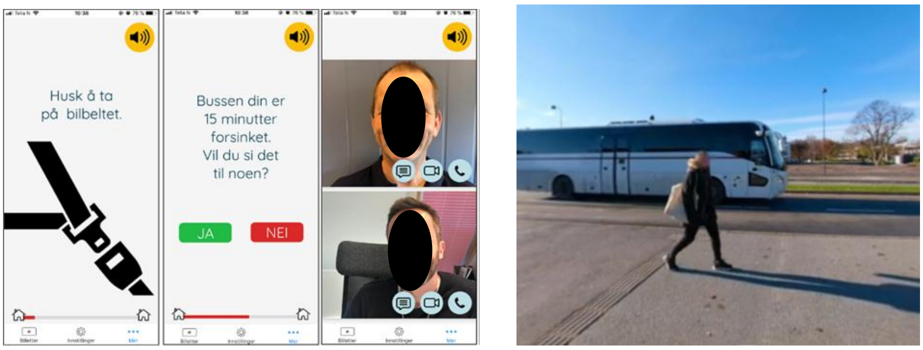
Høres det bra ut?

VELG DINE INTERESSER
KATEGORI: UNDERHOLDNING

Du har kommet så langt:

Figure 5. Screencasts of the self-reflective tool

The respondents in papers I, III, and IV participated in the design of a digital ***transport support tool*** with the aim of supporting people with intellectual disability in public transportation. The transport support tool set out to support users in identifying the correct bus, time management, reminders, and social interaction. A high-fidelity prototype that included reminders and different modes of communication during unforeseen events was developed. As a second step, a 360-video scenario was developed to explore how scenarios could assist in learning how to manage unforeseen events during transport.



Husk å ta på bilbeltet.

Bussen din er 15 minutter forsinket. Vil du si det til noen?

Figure 6. Screencasts of the prototype of the transport support tool and the VR scenario

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[2] For more information about the prototype of the self-reflective and transport support tool see Wass et al. (2020).

An overview of the relationship between the included papers and the digital technology developed in the InnArbeid innovation project is provided in Table 3.

Table 3. Relations between papers and innovations in the InnArbeid project.

Paper	Innovation I	Innovation II
Paper I - ‘I Got To Answer the Way I Wanted To’: Intellectual Disabilities and Participation in Technology Design Activities		X
Paper II - Motivation of people with intellectual disabilities in technology design activities: the role of autonomy, competence, and relatedness	X	
Paper III - Supporting people with intellectual disabilities during co-design of technology: Perspectives of facilitators	X	X
Paper IV - Photovoice—Towards Engaging and Empowering People with Intellectual Disabilities in Innovation		X

7 Methods

In this chapter I first discuss the research philosophy and the theoretical underpinnings of this research. Then, an overview of the research design and used methods is presented. Thereafter, I present the practical steps taken to explore the research questions and the data analysis. Lastly, ethical considerations, including details on the complex process of undertaking research with people with intellectual disability are discussed.

7.1 Research philosophy

In this section, I will briefly present the ontological and epistemological underpinnings of the thesis. Metatheoretical foundations, which are theoretical perspectives about science itself, carry assumptions about the data, the world and the nature of ‘reality’. It is therefore essential that researchers state their ontological and epistemological position. Ontology refers to the *objects* of knowledge (what exists/what is reality) and epistemology concerns the *conditions* for knowledge (the study of knowledge/our knowledge of reality) (Bhaskar & Danermark, 2006). The researchers’ ontological and epistemological stances are ‘guidelines’ when approaching the real world to do science. For instance, based on ontology, different research questions can be asked, which will have consequences for *what* is being studied, and *how* it is studied. In the field of disability, Critical Realism has been put forward as a way to understand the different facets of disability (Bhaskar & Danermark, 2006). Moreover, critical realism is viewed as an alternative to both positivism and constructivism and a viable philosophical paradigm for conducting social science (Wynn & Williams, 2012).

Critical realism is a philosophy of science, rooted in realist ontology and a constructivist epistemology, predominantly shaped and associated with the work of Roy Bhaskar (1975). Similar to other philosophies of science, critical realism is concerned with both ontology and epistemology. According to critical realism, *“reality exists independently of our concepts and knowledge of it”* (Danermark et al., 2019 p. 24). In other words, what exists is independent of human knowledge. Confounding ontology with epistemology is within critical realism described as *epistemic fallacy*. Danermark et al. (2019, p. 7) state that in critical realism *“there exists both an external world independently of human consciousness (the intransitive dimension), and at the same time a dimension that includes our* *socially influenced knowledge about reality (the transitive dimension)"*. The entities in the world are part of the *intransitive dimension*, which operate independently of humans and their ability to perceive it (Wynn & Williams, 2012). However, our knowledge of these entities, generated by for instance research, is part of the *transitive dimension* (Wynn & Williams, 2012). The transitive dimension, including critical realism, is therefore constantly subject to revision.

Despite the theories we have about the world, the world itself does not necessarily change because our understanding evolves or changes. Neither the transitive dimension nor the intransitive dimension can be wholly reduced into the other. For instance, Wise (2016) gives the example of Down Syndrome to illustrate the intransitive and transitive dimensions. Down Syndrome has always been caused by an extra 21st chromosome, whether or not humans knew of the condition or their cultural beliefs about the condition (Wise, 2016). In the case of Down Syndrome, the condition was believed to be rooted in for instance ethnicity before the true cause was discovered in 1959 by John Down. Today the cause of Down Syndrome is well known. While the name and beliefs used about Down Syndrome have changed over time (transitive), the aetiology and physical determinants did not change (intransitive) (Wise, 2016). This reality exists regardless of the people's beliefs. The transitive and intransitive dimensions of reality can be of the essence in disability studies and for disability discourse. People with intellectual disability may be perceived in varying ways by researchers, parents and support workers who know them (transitive epistemology), however, they also exist partly independently of these varying views (intransitive ontology) even if they are influenced and interact with the perceptions on several levels.

In Critical Realism, the point of departure is that the world is *structured, differentiated, stratified and changing* (Danermark et al., 2019). A key aspect is the differentiation and stratification of reality into a model of three different ontological domains used to explain the world. The domain of *the real, the actual and the empirical* (see Danermark et al., 2019). These three levels can be summarised as follows: The first level is the domain of *the real* that includes structures and mechanisms. These structures and mechanisms exist regardless of whether they produce an event or not. When the mechanisms produce a factual event, whether we observe it or not, falls under the domain of *the actual*. When such an event is experienced, it enters the domain of *the empirical* and becomes an empirical fact. In other words, the empirical domain consists of what we actually observe and experience of physical and social objects and events, the actual domain includes objects and events that can be observed and experienced and those that cannot, and the real domain encompasses the first two domains and generative causal mechanisms (entities that exist whether or not people know of them or can observe their effects) (Wise, 2016). Regarding how to attain knowledge, critical realism maintains, due to the structures of reality that;

> *a scientific method necessarily involves observation of events, but due to the structures of reality it cannot be reduced to observation of phenomena at the empirical level. To acquire usable knowledge it is essential that we know the mechanisms that produce the empirical events, and they are seldom directly visible. The knowledge we do attain is, however, always fallible, and its usefulness varies under different conditions"* (Danermark et al., 2019 p. 26).

The reality is stratified within critical realism, meaning that mechanisms belong to different strata of reality (i.e., biological, social, and psychological strata). The tenet of stratification is the idea that reality consists of hierarchical levels. For instance, to analyse disability research, Bhaskar and Danermark (2006) use seven levels: physical, biological, psychological, psychosocial, socioeconomic, sociocultural and normative (Bhaskar & Danermark, 2006; Wise, 2016). These levels are meant to be case specific. In disability studies, the stratification of reality proposes and allows a non-reductionist perspective of disability taking into account the different multiple layers that make up a *disabled experience* (Frauenberger, 2015).

This approach opens for an interactional approach to disability. For people with intellectual disability, their experience is a result of an interplay between intrinsic factors to the individual, and extrinsic factors which emerge from the environmental context (Shakespeare, 2014). Intrinsic factors may include the nature and severity of the intellectual disability, motivation, personality and personal abilities. Examples of possible extrinsic factors include the attitudes of others, the extent to which the environment is enabling, and cultural and social issues relevant to the disability (Shakespeare, 2014). This approach to disability is based on the argument that "*people are disabled by society and by their bodies"* (Shakespeare, 2014 p. 75). This holistic approach to disability is similar to the perspective of the ICF (see Section 2.1)(Frauenberger, 2015). A strength of the critical realist approach is that by being non-reductionist, it accounts for the range of differences and the diversity of the experiences of people with intellectual disability. Moreover, it recognises both the different individual and contextual factors that are associated with intellectual disability.

7.1.1 What critical realism adds to this research

Firstly, the differentiation and stratification of reality mean that according to the critical realist view of the world, the reality that scientists study and explore is larger than the empirical domain. The critical realist approach has been viewed as a promising perspective from which to illuminate the experiences of people with disability (Bhaskar & Danermark, 2006; Wise, 2016), designing technology for people with disability (Frauenberger, 2015), and a straightforward way of understating the social word as it allows for complexity (Shakespeare, 2014). A critical realist approach provides a useful approach as it recognises the complexity of both social inclusion and user involvement of people with intellectual disability, including the various underlying and interacting factors. Within critical realism, social causes, such as social inclusion, work in complex, interacting open systems that cannot be directly attributed to one single determining cause. With this approach, I, for instance, recognise that there are several different ways in which the social inclusion of people with intellectual disability can be increased. This includes both ‘evidence’ as in empirical effects that can be seen, and in unseen social causes.

Secondly, critical realism provides a balanced view of disability and the challenges people with intellectual disability may face. Critical realism allows for a realistic view of both the individual and contextual experiences of people with intellectual disabilities. In doing so, it recognises the complexity of both disability and the context in which the person is involved. In addition, critical realism stresses the need for mechanisms to be researched. In the case of this thesis, the interactional approach within critical realism makes room for the social inclusion of people with intellectual disability to be addressed on several levels, including individual and structural levels.

Thirdly, as critical realism views the world as complex and multi-layered with structures and mechanisms, both intensive and extensive designs can be applied in research. Reality is composed of several different structures, each with different emergent properties and powers, which require different methods and perspectives to develop knowledge about them (Wynn & Williams, 2012). This means that the methods used can vary according to the needs of the study

(Danermark et al., 2019). This opens up the use of triangulation and multi-methods, hence collecting data from varying sources. In critical realism, the aim is not repeated confirmation, but to increase the understanding of causal factors and relationships (Wynn & Williams, 2012). Still, critical realism recognises that all knowledge is fallible and rooted in the context, including historical, social, and political contexts.

7.2 Research design

The aims of the studies formed the selection of the design and methods. For this PhD project, a qualitative design was selected as the research questions lie within a qualitative paradigm. Qualitative research is an approach that allows for the exploration of people's experiences in detail (Hennink, Hutter, & Bailey, 2020). To examine experiences, qualitative research uses several research methods such as in-depth interviews, focus group discussions, observation, content analysis, and visual methods (Hennink et al., 2020). One of the most distinctive features of qualitative research is that it allows for the identification of issues and topics from the perspective of the study participant (Hennink et al., 2020). While qualitative research can be used for a wide range of applications, in this doctorate research it was used to explore the experiences of participating in digital technology design activities.

7.2.1 Overview of research design, methods, and analysis

Papers I, II, and IV focus on the experiences of participation in digital technology design activities for people with intellectual disability while paper III focuses on the experiences and recommendations of facilitators in the same context. The main reason for conducting three studies on the experiences of people with intellectual disability is that they themselves are best placed and prepared to speak about the meaning and experiences of participation in digital technology design activities. With this in mind, I avoid the assumption that 1) someone else will speak for them, and 2) that it is easier to ask the person without a disability (Brereton et al., 2015). Furthermore, in line with the focus on user perspectives and empowerment, there is a need to obtain data from the users themselves.

I used a range of different methods including individual and focus group interviews, participant observation, reflective notes, photovoice, and a Smileyometer Likert scale (see Table 4). Thematic analysis was used to analyse the collected data for all studies. Table 4 provides an overview of the used methods in the included papers (Papers I-IV).

Table 4. Overview of the methods used in the papers included in the thesis.

	Paper I	Paper II	Paper III	Paper IV
Design	Qualitative design (Empirical paper)	Qualitative design (Empirical paper; Single case embedded design)	Qualitative design (Empirical paper)	Qualitative design (Empirical paper)
Sample characteristics ¤	Young adults and adults with intellectual disability	Young adults with intellectual disability and facilitators	Design facilitators (i.e., researchers, teachers, social educators)	Adults with intellectual disability
Sample size	13 respondents (male 3, female 10)	7 respondents with intellectual disability (male 3, female 4) and 8 facilitators (7 male, 1 female)	11 respondents (male 5, female 6)	9 respondents (male 7, female 2)
Setting	User needs identification, Design workshops, User tests	Design workshops, User tests	Design workshops, User tests	User needs identification
Methods	Individual qualitative interviews, participant observations, photovoice, Smileyometer Likert Scale	Reoccurring qualitative individual and focus group interviews, participant observations, reflective notes	Individual qualitative interviews (on Zoom *), participant observations	Photovoice interviews
Analysis	Inductive thematic analysis	Inductive-Deductive thematic analysis	Inductive thematic analysis	Inductive thematic analysis

Note. * Zoom is an online communication platform that allows users to connect via video, audio, and chat. ¤ Young adults refers to participants who were high school students (under 22 years, Adults refers to participants who were older than 22 and worked in sheltered workshops.

7.3 Research sample and recruitment

The respondents in the studies included in this thesis were all recruited from the InnArbeid project and had participated in the digital technology design activities (see Figure 4). In selecting a sample, all participants in the InnArbeid design activities were invited to participate as respondents in the papers. In papers I, II, and IV, people with intellectual disability were included as respondents. Facilitators and support workers/staff, without an intellectual disability, were included as respondents in papers II and III. Table 5 provides an overview of the sample characteristics of the participants and facilitators in papers I-IV.

Table 5. Overview of sample characteristics

Role: Participants	Total	N = **29**
Age	18-22	N = 15
	22-30	N = 11
	30-40	N = 3
Sex	Male	N = 20
	Female	N = 9
Role: Facilitators *	Total	**N= 15**
Sex	Male	N = 9
	Female	N = 6

Note. * 4 Facilitators participated as respondents in both paper II (reflective notes) and Paper III (interviews).

The participants in the InnArbeid project who were interested in participating as respondents were invited to meet the researchers before the design activities at a place and time that was convenient for them. For example, for the respondents who were students at a high school, a quiet room was booked for the initial meeting. The purpose of this meeting was to present the research project and answer any questions that the respondents had. Moreover, the initial meeting was an opportunity to assess the respondents' level of expressive language and level of understanding. The initial meeting was also an opportunity to map and assess whether the respondents needed adjustments in the individual and focus group interviews. The researchers used the initial meeting to build trust and get to know the preferences of the respondents.

The respondents were given information about the research projects' purpose and aim. They were then given time to reflect on if they wished to participate. Once verbal consent was given, all respondents with an intellectual disability signed an adapted voluntary informed consent form (see appendix - attachment 3 & 4). In addition, their parents or guardians were informed and asked to consent (see appendix - attachment 4B). Respondents who participated as facilitators also signed a consent form (see appendix - attachment 4C). Two participants did not wish to be recorded (paper II) and all interviews in paper III were conducted on Zoom (online due to the Covid-19 pandemic).

7.4 Data collection and analysis

In the following section the data collection methods used for this research and thematic analysis, including a detailed description of the analytic process, is presented.

7.4.1 Individual and focus group interviews (Paper I, II, III, IV)

Qualitative research methods offer valuable insights into the lives of people with intellectual disability (Beail & Williams, 2014). Sigstad and Garrels (2018) argue that it is desirable to include people with intellectual disability in qualitative research due to three main reasons: 1) self-reports, such as interviews, from people with intellectual disability may be more reliable than proxy reports when investigating complex subjective matters, 2) excluding people with intellectual disability from research may be against the principle of non-maleficence and contributes to segregation, 3) people with intellectual disability want to be heard and participate in research to make a difference. Qualitative research methods such as interviews can inform us about experiences and increase the research participation of people who have an intellectual disability. Qualitative interviews form an efficient tool when in the quest to access the subjective experiences of a person (Sigstad & Garrels, 2018). For people with intellectual disability, interviews can provide an appreciated opportunity to discuss their lives and make important contributions as research participants (Corby et al., 2015).

However, qualitative interviewing of people with intellectual disability can pose methodological and ethical challenges. People with intellectual disability can have cognitive challenges and experience difficulties with communication such as difficulties in understanding complex grammatical structures and concepts (Finlay & Lyons, 2001; Sigstad, 2014). To facilitate qualitative interviews, three different communication techniques from counselling practices can be suitable for enhancing conversation (Sigstad & Garrels, 2018); 1) silence and encouraging prompts, 2) rephrasing questions and 3) repeating, paraphrasing and summarising responses. As a learning disability nurse (*Vernepleier in Norwegian*), I drew upon the different communication techniques (Sigstad & Garrels, 2018) and previous experiences with people with intellectual disability to inform the interviewing situation and techniques to obtain the best possible data for the papers.

Semi-structured interviews provide an opportunity to both follow a framework of core questions that focus on key topics chosen by the researchers, as well as the opportunity to follow-up with a series of probing questions (Dalen, 2011). In semi-structured interviews, the aim is to encourage the interviewee to share information and experiences in the person's own words. In addition, understanding the experiences of people with intellectual disability, and hearing and obtaining their views through interviews is important and preferred rather than depending on proxies. In this thesis, I used face-to-face semi-structured interviews in studies I and II. In study III semi-structured interviews were conducted online with design facilitators due to the Covid-19 pandemic (see appendix attachments 5, 5B & 6).

Focus group interviews were also undertaken as a method of data collection (Paper II). An advantage of employing this method is that the participants might feel less anxious about expressing their views (Thorogood & Green, 2018). Also, in a group interview, the researcher can access the interaction between the respondents and provides a ‘naturalistic’ setting that resembles the interactions people have in their everyday lives (Thorogood & Green, 2018). Focus group interviews capture some of the advantages of ethnographic research (Thorogood & Green, 2018). Both individual and focus group interviews are flexible methods in which the researcher does not have to follow the exact order of questions and not every question has to be asked in the same way for every participant. This can be essential in interviews with people with intellectual disability as they can often require a more flexible approach that fits their needs (see Sigstad and Garrels, 2018).

For paper II, to explore the experiences of the participants, I conducted reoccurring individual and focus group interviews with the purpose of understating the individuals’ experiences over time. The advantage of such an approach is that it can provide and can add depth and understanding of the respondents' experiences (Grossoehme & Lipstein, 2016). Moreover, reoccurring interviews can enable researchers to discover change and enable participants to get to know the researcher, build trust, and provide information at their own pace.

7.4.2 Participant observation (Paper I, II, III)

Participant observation is a commonly used method in ethnography where long-term engagement is needed to investigate a group of people or behaviour. Using observational methods as part of qualitative research is useful in contexts in which there is little knowledge about the topic (Johnson, Douglas, Bigby, & Iacono, 2011). Participant observation is defined as “*process of learning through exposure to or involvement within the day-to-day routine activities of participants in the research setting*” (Schensul et al., 1999, p. 91 in Johnson et al. 2011 p. 267). The involvement of the researcher may vary during the data collection and ranges from being situated as an observer to other times being actively engaged with the participants (Johnson et al., 2011). In participant observation, the most usual roles are participant-as-observer and observer-as-participant as they open the opportunity for either detachment or engagement with participants. The researcher’s role during participant observation is to gather all relevant impressions of the context. These insights are then recorded as field notes (Johnson et al., 2011).

In studies with people with intellectual disability, a combination of participant observation over time and qualitative interviews is a suitable approach (Kittelsaa, 2008). Through participant observation, the researcher can explore interaction and relationships, while in the interviews the researcher can gain in-depth knowledge, reflections and clarifications (Kittelsaa, 2014). This approach, in which participant observation and interviews are complementary, is recommended in studies with people with intellectual disability since such participation can create trust and communication (Sigstad, 2014; Sundet, 2010).

A main advantage of participant observation in studies with people with intellectual disability is that it does not require the participants to have good language or communication skills. As people with intellectual disability can have challenges in verbal expression (Finlay & Lyons, 2001), participant observation can increase the depth and richness of the data material as the researcher can observe gestures and body language (i.e., facial expressions) which in some situations can be a substitute for, or complementary to verbal communication and language. Participant observation can also support the researcher in describing what respondents say and do in the natural context. This knowledge is acquired by being present and getting close to the reality of the respondents. In the context of this thesis, as I was present, I was able to observe conversations and how they were initiated. These observations gave good insight into how the respondents experienced participation. In papers I, II, and III participant observations and field notes were collected as part of the data. See appendix attachment 7 for the used field notes template.

7.4.3 Photovoice (Paper I, IV)

Photovoice is a research method where participants are actively involved in the research process (Povee, Bishop, & Roberts, 2014). The method was developed by Wang and Burris (1994, 1997) and was traditionally used as a means of conducting participatory needs assessments and evaluations. In photovoice, the participants take photographs that document various aspects of their lives, which are later used, as input in qualitative interviews, to encourage reflections on feelings and experiences (Wang & Burris, 1997). Povee et al. (2014) point out that photovoice aims to capture the reality of people’s lives. In addition, Booth and Booth (2003) describe photovoice as a means of accessing other people’s worlds and making those worlds accessible to others.

Povee et al. (2013) state that photovoice offers an interesting way to engage individuals with an intellectual disability in research. Photovoice can facilitate the inclusion of people with intellectual disability in research processes as it does not require the ability to read and write (Wang & Burris, 1997; Booth & Booth, 2003). Whereas methods for including people with intellectual disability in participatory research have tended to be limited to interviews (Jurkowski, 2008; Povee et al., 2014), photovoice offers a means of concretizing in a manner that corresponds closely to the reasoning of the participants. Photovoice, in addition to providing respondents with a way to express themselves, can empower them to advocate for changes in their environment (Overmars-Marx, Thomése, & Moonen, 2018). Photovoice has been utilized as a method with people with intellectual disability across a range of contexts and topics (Overmars-Marx et al., 2014).

In this thesis, photovoice was used to collect insight in paper I. In paper I, the respondents were asked to take photographs related to their experience of participating in the digital technology design activities. During the workshops, the respondents could take pictures at three prearranged breaks lasting between three to five minutes. The respondents were provided with a mobile phone with which they could take pictures with and they were given additional instructions (see appendix attachment 9 & 9B). As a reminder, each participant was given a paper card with these instructions: Take a photograph of 1) something important when participating; 2) something that makes you happy during participation; and 3) something that describes the activity you have participated in.

7.4.4 Smileyometer Likert Scale (Paper I)

In paper I, a Smileyometer derived from the Fun Toolkit was used to explore the experience of participation (see appendix attachment 8). The Smileyometer is based on a widely used question format called Visual Analogue Scales. A Visual Analogue Scale uses pictorial representations (emoticons) to identify feelings or opinions (Read & MacFarlane, 2006). The aim of using faces/emoticons in the scale is to support communication and memory. The Smileyometer scale has also been used in earlier studies to establish participants' overall opinions of participating in a design process (Benton, 2014).

In the case of paper I, I asked: *How did you experience participating?*, which the participants answered on a 5-point Smileyometer Likert scale (*Awful, Not very good, Good, Really good, Brilliant*). See appendix 8.

7.4.5 Reflective notes/Log

In paper II, reflective notes/logs were collected to explore the experiences of the facilitators (see appendix attachment 10). Reflective notes, including journals, logs, critical incidents analyses and reflective reviews, are self-reflective written accounts and are a well-established data source in qualitative research (Jasper, 2005). Reflective notes are a tool that allows for both learning and critical reflection (Honold, 2006). While reflective notes are a starting point for learning, they can also enable a step outside actions and enable a critical look at the how, what, why and when of an experience (O'Connell & Dyment, 2011). Also, such notes may provide a venue for potential solutions to problems or challenges (O'Connell & Dyment, 2011).

The included studies in this PhD thesis are a result of the collected data material summarised in table 6.

Table 6. Overview of collected data material.

Data collection method	Outcomes
Individual interviews and focus group interviews	37 individual interviews and 7 group interviews with respondents with intellectual disability (audio recorded except 1); between 20-35 minutes in duration. 10 online interviews with facilitators (audio-recorded); between 25-45 minutes in duration.
Participant observations Field notes	I participated in and observed 32 workshops. 1 notebook with handwritten field notes from all participant observations (40+ A4 pages of field notes).
Reflective notes/Log	19 reflective notes/log collected from facilitators (Paper II).
Pictures (including photovoice pictures)	In total 45 photos were taken by participants.

7.4.6 Thematic analysis (Paper I, II, III, IV)

Thematic analysis (TA) is widely used in qualitative research to identify, analyse, and report patterns within collected data (Braun & Clarke, 2006, 2013, 2022). While qualitative methods have different ontological and epistemological standpoints, one of the key advantages of TA is that it is not wedded to a single pre-existing theoretical framework (Braun & Clarke, 2006, 2022). TA can therefore be used within a variety of different theoretical frameworks. TA fits well within the frame of critical realism as it can be used to analyse different types of data and allows for social and psychological interpretations of data (Braun & Clarke, 2006). It is however important that the theoretical analysis is made clear as any theoretical framework carries a number of assumptions about the nature of the collected data and what they represent in terms of reality (Braun & Clarke, 2006). For a clarification regarding this thesis see sections 7.1 and 7.1.1. By undertaking a critical realist approach (Bhaskar & Danermark, 2006; Danermark et al., 2019) to TA, I recognise that the data does not provide a clear representation of reality. Instead, the researcher accesses the respondent's perception of their reality which is shaped by and embedded in their cultural context.

Braun and Clarke (2006. 2022) provide a six-phase process for carrying out TA. The first phase of TA is *familiarising yourself with the dataset.* This phase involves reading and re-reading the data and, if working with audio data, listening to the data. The researcher should become familiar with the depth and breadth of the data material and start making brief notes about any insights or ideas related to each data item and the dataset. Once the researcher is familiar with the data, in phase two a rigorous and systematic *coding* process is undertaken. Potentially interesting, relevant and meaningful segments of data that are identified and fitting codes (analytically meaningful descriptions) are applied. Phase tree involves *generating initial themes*. As the researcher has coded and compiled relevant segments of data for each code, the researcher now starts to identify shared patterned meaning across the data material. Theme development is an active process in which the researcher construct themes based on the data, research questions, and the researchers' insights. While codes capture a specific meaning, themes describe broader meanings. Once themes are identified and relevant coded data is collated to each theme, the next phase is *developing and reviewing the themes*.

In phase four, the initial fit of the themes to the data is assessed and the researcher checks if the themes make sense in regard to the coded data and the full dataset. In this phase, it is common to have major revisions and certain themes maybe be merged together or split into new themes. The relationship between the themes, existing research, and practice is also considered. Phase five involves *refining, defining and naming themes*. In this phase, the analysis is fine-tuned, and ensuring that the themes are developed around a strong core concept. The main practical activity in phase five is writing a brief outline and summary and naming each theme. However, if needed the themes can still be refined and further developed. The sixth and final phase is *writing up*. Writing is an important phase of the analytic process. While formal writing often starts earlier in the process, in writing up, the analytic narrative and vivid data extracts are weaved together to tell the reader a coherent story about the collected data material. Writing up also involves developing and producing other parts of the research report such as the introduction, method, and conclusion sections.

In this thesis, TA (Braun & Clarke, 2006, 2022) was used to analyse the collected data in papers I, II, III, and IV. TA was a fitting method to explore the views and experiences of the respondents in the included papers. The rationale for utilizing TA is that it offered the possibility of both inductively oriented analysis and deductive developed analysis. The flexibility of TA allowed for analysis that could be informed by existing theories (Paper II) and inductively developed analysis (Papers I, III and IV). Moreover, TA allows for highlighting similarities and differences across the collected data in each study and opens for offering 'thick descriptions' of the data set (Braun & Clarke, 2006). Also, Braun and Clarke (2006) recommended TA as a useful method when exploring under-researched areas or working with respondents whose views on the topic are not well known. Note that the language used to describe the phases, particularly phases four and five in papers I, II, III, and IV reflect the original phase names (Braun & Clarke, 2006), which have since been revised (Braun & Clarke, 2022). The data analysis process for each paper is presented in sections 7.4.1 to 7.4.4 and can also be found in the respective papers (see papers I-IX in the Appendix).

The analytic process – A detailed methodological write up. The data analytic process presented in the papers are a short description of the data analysis process. The papers included a summarised description of the analysis due to the word limit of the journals. While the processes differed slightly across the papers, I will here provide the specifics of what the analytic process looked like in practice as recommended by Braun and Clarke (2022). The data material utilised in all the papers was collected by me. Most of the data was collected and generated gradually over the space of two years. The analytic approach in all papers was guided by the six phases recommended by Braun and Clarke (2006, 2022). The six phases were used as guidelines, rather than rules during the analytic process to explore patterns across the datasets. During the analysis, the process of TA was not linear, it was more of a recursive process. Therefore, my co-authors and I moved back and forth between the phases. In addition, some of the data analysis stages were done individually by me, however, in other phases of the process my co-authors and I met physically or digitally (due to Covid-19) to discuss the analysis.

As soon as the data was collected, I entered the familiarisation process, which is the first step of analysis (Braun & Clarke, 2022). Since I collected different types of data, including fieldnotes, interviews, group interviews and photovoice, the noting of initial ideas started during the data collection. For instance, I marked interesting observations with a star in my field notes and noted down interesting experiences on paper during the interviews. As part of familiarising myself with the data, I transcribed the collected audio from the interviews. Initial ideas and interesting quotes were also noted down during the transcription process. As the papers aimed to explore experiences of participating in digital technology design activities, the initial analytic observations and interpretations were primarily inductive and latent. During this phase, I was aware of my earlier experiences working as a learning disability nurse, and how some of the data resonated with my earlier experiences. Therefore, I tried to be mindful of the influence of my subjectivities. For instance, when analysing respondents' experiences of boredom or challenges during participation, I was mindful of focusing on their experiences and not my subjective opinion of the difficulty or possible ways to support or solve the challenges.

In the next phase, I moved into a more systematic and rigorous stage of analysis. I coded the data both digitally and on paper. The use of different forms of data (digital and on paper) prompted new insights and reflections during the analysis. In the process of coding the data, usually, the analysis contained both latent and semantic codes and the data was often a mixture of experiences, wishes, recommendations, emotions and sometimes associations. The process of coding was therefore often difficult as I wished to capture the complexity of the respondent's experiences in a coherent manner. In this phase, my co-authors were also involved in independently coding the data and we created initial inductive themes independently before discussing and reaching a consensus. An exception was in paper II, where another round of coding took place, and we deductively analysed the experiences of the respondents based on the three basic needs in the self-determination theory. In producing and developing the final themes, we were conscious of staying close to the experiences described by the participants.

In phases four and five, in which we developed the themes and refined, defined and named the themes (Braun & Clarke, 2022), the process was iterative. We moved back and forth within these phases. I initially collated relevant data and extracts, including thick descriptions before all authors discussed and refined the themes to reach a consensus. However, this was a process that overlapped in phases four, five and six. During the process of constructing the themes, the field notes were used as supporting material in papers II and III. In paper I, the field notes were used directly as part of the main data material. In paper I, pictures taken by participants as part of Photovoice, were also analysed, coded and collated to the developed themes. Lastly, in papers I, II and III, I defined, and named the themes and wrote up the analysis presented in this thesis and in the individual papers with supervision from my supervisors (co-authors). In paper IV, my co-author and I wrote the report together.

In terms of analysing data across the datasets, it's important to state that after completing the analysis in Paper I (first analysis during my PhD studies), we had general discussions on how and in what ways the participants described similar experiences across the datasets. Onwards, we were conscious and focused on analysing each dataset independently regardless of earlier analysis processes and results. Regarding physical environments, I worked with the analysis in quiet spaces such as at my desk in the office at the university and home office. During the analysis with co-authors, the meetings were held in a meeting room at the university or on Zoom.

7.5 Summary of sample, methods, data collection, and analysis in Papers I-IV

7.5.1 Paper I

This study aimed to understand how young adults and adults with intellectual disability experience participation in digital technology design activities. The study's respondents were involved in two phases of the design process and included 13 respondents with intellectual disability. The respondents were between 18 and 40 years old, including 3 females and 10 males, and all were able to verbally express themselves. A triangulation of methods was used, including semi-structured qualitative interviews, participant observations, photovoice interviews and a Smileyometer Likert scale. The interviews lasted for approximately 20 minutes and were recorded and transcribed. An inductive thematic analysis was used to analyse the data. As guidance, the six phases of thematic analysis recommended by Braun and Clarke (2006) were used.

7.5.2 Paper II

This study employed a single-case embedded design (Yin, 2017) to explore how participants with intellectual disability experience the fulfilment of the basic psychological needs for autonomy, competence, and relatedness during digital technology design activities. Seven respondents between 16 and 22 years old participated. To collect data, a triangulation of methods consisting of reoccurring individual and group interviews, participant observations and reflective notes were used. The interviews lasted between 20 and 35 minutes each (24 interviews in total). The interviews were recorded and transcribed. To analyse the data, thematic analysis (Braun & Clarke, 2006) was used. In this study, first, an inductive data-driven process was conducted, then a deductive process using the three basic psychological needs from the self-determination theory (2002). The six recommended phases of thematic analysis as per Braun and Clarke (2006) were used as guidance.

7.5.3 Paper III

In this study, the experiences of facilitators supporting people with intellectual disability during digital technology design activities were explored. The respondents were facilitators (having a relationship with the users prior to the design activities), supporting facilitators (part of the design team), and lead facilitators (leaders in the InnArbeid project). In total 11 respondents participated in this study; five males and six females. The data was collected through individual qualitative interviews on Zoom due to the Covid-19 pandemic. The interviews lasted between 25 and 45 minutes each and were audio recorded and later transcribed. The data material was analysed using thematic analysis (Braun & Clarke, 2006), supported by prior collected participant observation notes. The six steps recommended by Braun and Clarke (2006) were followed as guidance. One section of the data concerned recommendations that the facilitators shared based on their experiences of facilitating the design activities. These recommendations were grouped into codes and themes and then categorized as dealing with the individual or the structural levels. Recommendations were then mapped to themes describing the respondents' overall experiences.

7.5.4 Paper IV

This study aimed to reflect on the process of using photovoice in a digital technology design process. The respondents in this study participated in the design process by providing user insights and identification of user needs for transportation support. In total 9 respondents with intellectual disability; seven males and two females, participated. The interviews took place at their workplaces shortly after taking the photovoice pictures and were thereafter transcribed. In this study, the data presented stems from the material focusing on the respondents’ experiences of using photovoice. The data regarding the respondents' experiences of using photovoice was analysed using thematic analysis, following the recommended steps presented by Braun and Clarke (2006).

7.6 Ethical considerations

Ethical approval for the research was granted by the University of Agder Ethics Committee and the Norwegian Centre for Research Data (648227). Detailed information was given to all participants, including information about the study, data protection and their right to withdraw from the study at any time. Information about consent was given throughout the project. The respondents were also given contact information and given the opportunity to ask questions throughout the project. Parents and guardians were informed and asked to observe whether the respondents showed any signs of negative outcomes or a wish to withdraw from the project. To ensure confidentiality, all names and citations were anonymised in the data and also in the presented results.

8 Results

This section presents the three published papers and the one submitted paper as part of this PhD thesis. The full papers are attached in the appendix (Papers I-IV). Papers I and II, investigated how young adults and adults with intellectual disability experienced participation in the design of digital technology, and papers III and IV explore how young adults and adults with intellectual disability can be supported to enable participation in the design of digital technology.

8.1 Research question 1 – User experiences of participation (Paper I & II)

Paper I

‘I Got To Answer the Way I Wanted To’: Intellectual Disabilities and Participation in Technology Design Activities.

Aim

This study aimed to explore the experiences of people with intellectual disability participating in the design of new technologies and to understand how user involvement affects participants by asking them directly. The following research question guided the study: How do young adults and adults with intellectual disabilities experience participation in technology design activities?

Results

The results showed that for young adults and adults with intellectual disability, participating in technology design activities can initiate positive emotions, encourage positive behaviours and support the development of new skills. Still, adverse experiences such as boredom may occur.

Participation in technology design led to a *sense of pride and ownership*. The sense of pride and ownership the respondents experienced was developed by being engaged in the design activities, and their interest in the design process and the designed technology. Moreover, the respondents experienced being acknowledged through being an essential part of the design activities and being regarded as experts. The respondents emphasised that they accepted the invitation to participate in the design activities as they were contributing to something important and meaningful. Still, while the participants enjoyed the activities and described them as fun and pleasurable, feelings of boredom during certain activities occurred.

According to the respondents, participation in the technology design activities also led to an *experience of socialisation*. The technology design activities provided a social context that contributed to social interaction in which the respondents had conversations with peers, teachers and researchers. While the respondents reported asking questions and talking about hobbies and leisure activities, they also interacted with each other to ask for support and assistance. For them, the opportunity to communicate and express themselves without interruptions and the opportunity to communicate verbally, via text and through pictures was essential. Furthermore, the respondents described forming new relationships that differed from their existing relationships. In addition, they also reported collaborating with peers and researchers as an important part of participating.

Finally, active involvement in the design activities led to a *sense of empowerment*. The respondents cited that a sense of autonomy, developed through the ability to influence the activities, as an important element throughout the design activities. The respondents also reported experiencing coping and enjoying the opportunity to demonstrate their skills. For them, participation in technology design was in itself to cope with something new. And while some tasks were challenging, other tasks were familiar. Within the theme of empowerment, the respondents also described feelings of competence. This feeling was fostered by the combination of performing known and mastered tasks and acquiring new skills and knowledge. The respondents also talked about participation leading to more knowledge about technology and design activities. Using a Smileyometer-scale, the respondents rated their experience of participating as *brilliant*, *really good* and *good*.

Paper II

Motivation of people with intellectual disabilities in technology design activities: the role of autonomy, competence, and relatedness.

Aim

This study used Ryan and Deci’s (2002) Self-Determination Theory as a theoretical framework to explore what motivates young adults with intellectual disabilities to participate in technology design activities. The following research question was addressed: How do respondents experience that participation in design activities contributes to the fulfilment of the needs for autonomy, competence, and relatedness during technology design activities?

Results

The results of the analysis showed that autonomy, competence, and relatedness are important motivational factors for young adults with intellectual disabilities participating in technology design activities.

Autonomy**.** Within the category of autonomy, the respondents reported experiencing influencing the designed technology and the design activity. It was important for the respondents that their contribution was incorporated in the technology design and that they actively took part in decision-making situations. The respondents talked about the importance of their feedback being included in the design and being acknowledged during the activities. However, the respondents also mentioned the importance of influencing the design workshops and being able to choose in what ways they participated.

Competence**.** Within the category of competence, the respondents talked about enhancing skills and knowledge and experiencing a sense of self-efficacy. The respondents described enhanced knowledge about the technology (i.e., using tablets, navigating in applications, searching online) and knowledge about the technology design process (i.e., knowledge of how applications are made). For the respondents, participating in technology design activities also led to a sense of self-efficacy as they could use many of the same skills as in school. Thus, leading to feelings of predictability and security. For them, participation led to feelings of confidence as they were viewed as experts and listened to. Moreover, the respondents received support and help in cases in which they did not master or understand given tasks.

Relatedness. Within the category of relatedness, developing social relationships and experiencing a sense of meaningfulness were described as essential elements. The respondents reported developing new relationships with the researchers and the design team. Throughout the design activities, social relationships were built, and respondents described having social interactions that differed from their interactions in other settings. It was essential that the relationships were built over time consequently leading to trust. The social relationships between the respondents also developed due to the collaborative nature of the technology design activities. Another essential element of participation was that it was meaningful. The respondents felt that participating was meaningful as the technology had the potential to help other people with intellectual disability.

Enjoyment**.** The respondents also described experiencing a sense of enjoyment. This finding was categorised as an additional theme outside the three categories of the basic psychological needs of the self-determination theory. Participating in the technology design activities was reported to be an enjoyable experience because they were in line with their interests and preferences. Tasks such as for instance trying new games and testing technology, were defined as enjoyable.

8.2 Research question 2 - Support in design activities (Paper III & IV)

Paper III

Supporting people with intellectual disabilities during co-design of technology: Perspectives of facilitators

Aim

This study aimed to explore facilitators' experiences of supporting adults and young adults with intellectual disabilities during technology design activities. In addition, the paper provides recommendations for guiding facilitators, considering both structural and individual needs.

Results

The results showed that the facilitators experienced a need to *adapting the activities to individual needs*. Firstly, the respondents described the need to understand and identify the support needs of the participants. However, this process was challenging as some participants were unable to communicate their needs. In addition, distinguishing whether the support needs were due to the lack of skills or motivation was described as a particular challenge. Secondly, the respondents reported the need to adapt tasks and support to each individual user. The given support necessitated the use of different techniques such as modelling and prompting. Thirdly, the respondents described building relationships with the participants with the aim of fostering trust. The one-on-one nature of the activities allowed the development of connections and relationships which was important in adapting and identifying the participants' support needs.

The respondents experienced a process of *personal development*, which included professional development and the development of design-related skills. For the participants, taking part in the technology design activities enhanced their development in their field of work. Professional development was linked to knowledge and experiences of cooperating with people with intellectual disability. They reported being better prepared to work and support people with intellectual disability after participating in technology design activities. According to the respondents, supporting people with intellectual disability also led to a correction of assumptions related to people with intellectual disability. Furthermore, respondents reported that technology design activities allowed them to develop design-related skills including techniques and tools. They highlighted the intent to use their new skills in their daily practice after the project. Moreover, the respondents talked about developing transferable skills in communication, organising activities, and teamwork.

The participants talked about their experiences of participation as a process of *learning by doing* in which they experienced managing uncertainty and balancing between commitments. They described challenges with being fully prepared as unforeseen situations occurred despite planning well beforehand. However, the respondents reported that it was important not to dwell on the tasks or activities that did not work out as intended. Rather, they adopted a flexible approach (i.e., omitting the task). Furthermore, the respondents described challenges with balancing commitments regarding the design activities and commitments linked to their other tasks. While some respondents had enough resources to solely focus on the design activities, others had other tasks simultaneously.

Recommendations for guiding facilitators

Recommendations to support facilitators during technology design activities with people with intellectual disability were developed on a structural and individual level. While recommendations on the individual level aim to guide facilitators directly in their practice, on the structural level, they aim to support leaders and organizers of the design process or the design project. The recommendations are not exhaustive. However, 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.

Adapting to individual needs. On a structural level, we recommend that technology design projects establish a facilitator-supportive environment. On an individual level, we recommend facilitators build relations with participants to enable individualized facilitation during design sessions.

Process of personal development. On a structural level, we recommend that technology design projects conduct strategic recruitment of facilitators. On an individual level, we recommend facilitators to stay open to learning as the design sessions unfold.

Learning by doing. On a structural level, we recommend technology design projects to value and use input and feedback from facilitators to adapt the design sessions. On an individual level, we recommend facilitators to adapt to emergent challenges and difficulties.

Paper IV

Photovoice—Towards Engaging and Empowering People with Intellectual Disabilities in Innovation

Aim

This study aimed to report and reflect on the process of using photovoice to understand user needs and as a way to empower participants with intellectual disability in digital technology design. The following research question was addressed: How can photovoice empower participants with intellectual disabilities when participating in an innovation process?

Results

The respondents reported that using photovoice led to the *experience of coping* in which they experienced mastery. Most respondents described using photovoice as fun, natural and that they were able to take the pictures they wished to take. Also, the respondents stated that the pictures taken were an adequate representation of their experiences. Moreover, they were also able to describe the reasoning behind the pictures taken. Still, environmental and cognitive challenges were reported. The environmental challenges difficulties included the quality of the photos and difficulties connected to taking photos. These difficulties were mostly practical such as the setting being too dark, people being in the way, and the weather. On the other hand, cognitive challenges did occur. The cognitive challenges included factors such as respondents being too tired to engage in the activity and forgetting to take photos.

For the participants, using photovoice led to a sense of *self-determination* (when using photovoice) during digital technology design. As photovoice allows for a user-led process, the respondents described experiencing their participation as open and with few boundaries. They reported freedom of choice when taking pictures and they could contribute with both contextual and individual information. In terms of contextual insights, the respondents provided general insights on their experiences with travel to and from work. The respondents also shared individual insights, including individual information about themselves.

The respondents talked about the *sense of ownership* that was developed during the use of photovoice. Characterised by engagement and meaningfulness, the respondents reported that they experienced an ownership of the process. They were engaged, interested, and motivated when using photovoice. The respondents were interested in further participation and taking pictures, as well as they valued the opportunity to participate in a new activity. Through photovoice, it was reported that the participants felt being part of something meaningful and important.

9 Discussion

The overall aim of this PhD thesis was to explore how participation in the design of digital technology can contribute to the social inclusion of young adults and adults with intellectual disability. The aim was addressed through two research questions; 1) How do young adults and adults with intellectual disability experience participation in the design of digital technology? and 2) How can young adults and adults with intellectual disability be supported to enable participation in the design of digital technology?

This discussion chapter is structured in five parts and explores the relevance and meaning of the key findings in papers I-IV. The first part focuses on the involvement of people with intellectual disability in the design of digital technology and captures the participants' experiences of participating in technology design. The second part focuses on facilitation during digital technology design and captures the experiences of participants, facilitators and staff. The third part discusses if participation in digital technology design can be a catalyst for social inclusion by using Simplican et al.'s (2015) model of social inclusion as a lens. The fourth part discusses the methodological considerations.

9.1 Involvement in digital technology design

There is a growing amount of literature on the involvement of people with intellectual disability in technology design (Benton & Johnson, 2015), still there is limited evidence, based on data collected directly from people with intellectual disability, on how such participation impacts them. A core characteristic of user involvement is empowerment (Robb et al., 2019; Robertson & Simonsen, 2012), which can be both a process and an outcome. While empowering processes include opportunities to develop skills, cooperate with others on a common goal and expand one's social support network, empowerment outcomes refer to the consequences and results of empowering processes (Zimmerman, 1995). In accordance with previous research that points to benefits such as learning new digital skills (Murphy et al., 2022), enhanced competencies (Bayor et al., 2021) and ownership (Raman & French, 2021), in papers I, II and IV, the participants described having a positive experience (i.e., enjoyment), experiencing positive emotions (i.e., sense of acknowledgement, belonging, coping), showing positive behaviours (i.e., engagement, contribution, supporting peers) and developing skills and abilities (i.e., learning about digital technology use and design). These findings suggest that participation in digital technology design activities can be an empowering process and, consequently, have empowerment outcomes.

The findings in papers I, II and IV show that autonomy and self-determination was an important experience during participation in design. This is emphasised in Paper II that suggests the participants were motivated by influencing both the design activities and the designed technology. These experiences seem to be related to user contribution which is a chore characteristic of user involvement in design. User contribution refers to end-users both expressing their opinion and affecting the outcome of the design (Abras et al., 2004; Giacomin, 2014). User contribution has similarities to empowering processes and self-determination. In empowering processes, people are given opportunities to gain control and influence decisions that affect their lives (Zimmerman, 1995; Zimmerman & Warschausky, 1998). Similarly, self-determination focuses on autonomy and personal control (Nota et al., 2007; Wehmeyer, 2001; Wehmeyer et al., 1996). As an example, in Paper I and II, participants describe having the opportunity to influence both the activities and the designed technology as well as being viewed as an expert and expressing themselves. Our results suggest that due to the emphasis on user contribution, participation design activities may possibly facilitate an empowering process and support self-determination. These findings are important as promoting and enhancing the self-determination of people with intellectual disability has become best practice in disability services (Soresi et al., 2011). Furthermore, participation in digital technology design may therefore be an exciting and important context for people with intellectual disability as they often find themselves in environments with few opportunities for practising self-determination skills (Björnsdóttir et al., 2015).

While participation in design was largely a positive experience (Paper I), it should be noted that negative outcomes such as boredom and non-engagement were reported. These findings are in line with earlier literature suggesting that participation in design activities can also foster adverse experiences (Benton & Johnson, 2015). To mitigate adverse experiences, findings in paper IV and II suggest two possible approaches. Firstly, the use of creative methods such as photovoice seems to contribute to positive experiences and strengthen the individual’s capacity to cope with the demands of participating (Paper IV). Secondly, findings in paper II show that the fulfilment of basic psychological needs can mitigate possible adverse effects of participation. The results in Paper

II showed that participation in digital technology design can lead to the fulfilment of the need for autonomy, competence, and relatedness. Consequently, the satisfaction of these needs may lead to a sense of enjoyment and contribute to motivation during the design activities (Paper II). The fulfilment of the basic psychological needs also suggests that participation in digital technology design may be an important context for people with intellectual disability as it can support intrinsic motivation and well-being. This is supported by Deci and Ryan (2002) who found that the fulfilment of the basic psychological needs supports healthy functioning and wellbeing in social environments.

In papers I and II, the findings show that the participants experienced being part of decision-making and were listened to. Being listened to and shared decision-making accords with mutual learning. Mutual learning is grounded in the fact that users are experts in their world (Hussain et al., 2012) and know most about the activities in which the designed system will be embedded (Bratteteig et al., 2013). This finding is important as it is in line with the disability rights movement (Rogers & Marsden, 2013; Stack & McDonald, 2014). Being part of decision making is particularly important for people with intellectual disability as they have previously been overlooked in the design of technology and treated in a third-person sense (Brereton et al., 2015; Rogers & Marsden, 2013). However, in line with earlier literature on Participatory Design (Kensing & Greenbaum, 2012), our findings suggest that involvement beyond being informants is important in promoting both user contributions and mutual learning. Findings show participants gave feedback, elaborated on ideas, and shaped the designed technology (paper I, II, IV), suggesting that they had roles as either co-designers or design partners (Benton & Johnson, 2015). These findings support the notion of ‘genuine’ participation being the transcendence of users’ roles beyond being informants (Robertson & Simonsen, 2012). Thus, in paper I, we argue that participants should be able to independently switch between roles rather than being given a particular role. Derks et al. (2022) used a similar approach defining users as design partners (changing roles throughout the design process). Allowing participants to influence both the design activities and the designed technology may open up for user contributions and mutual learning. As found in Paper II, autonomy and influencing the design activity itself seems to be important for the participants. The possibility of influencing the design activities and one’s own role seems to support authentic participation. Authentic participation concerns the opportunities that participants have to impact the outcome of the design (Robb et al., 2019). For example, in paper II, participants highlighted the importance being able to choose between writing and drawing when communicating and elaborating on their design ideas. Elsewhere, in paper IV, the participants pointed out the importance of few boundaries and freedom when using photovoice to provide their desired contextual insights.

Still, a note of caution is due here since it is difficult to pinpoint how particular roles, techniques, or activities lead to the specific experiences or user gains (Paper I). In sum, the findings in paper I, II, and IV suggest that the participants experienced, and were able to achieve, inclusion and impact the outcome of the digital technology design activities.

9.2 Facilitating participation in digital technology design

The design process is a sequence of activities, often iterative, moving between different stages and activities (Sanders & Stappers, 2008) and involving users and facilitators. Design activities with people with intellectual disabilities are complex due to additional needs, and a range of facilitators from different backgrounds are often involved (Benton & Johnson, 2015). Facilitators are therefore essential in securing successful design activities and workshops (Fuad-Luke, 2013) and contribute with facilitating communication (Derks et al., 2022; Nash-Patel et al., 2022), giving advice (Harris et al., 2022), and managing and adapting tasks (Bayor et al., 2021; Nash-Patel et al., 2022).

In paper III, the facilitators[3] reported the importance of identifying facilitations needs and providing individual support. These findings are consistent with the description of the responsibilities of facilitators which includes supporting participants in communicating, voicing their opinions and applying the appropriate tools for the tasks (Fuad-Luke, 2013). In paper I and III, it is noted that enabling a positive experience and ensuring beneficence was also an important part of facilitating the activities for people with intellectual disability. However, facilitators expressed difficulties on structural and individual levels when supporting participants with intellectual disability (Paper III). Structural difficulties included managing uncertainty and balancing commitments, and individual difficulties included identifying needs and ethically providing support. While these findings are interesting as there has been a limited

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[3] Note that facilitators in paper II included staff (social educators, teachers), researchers, designers and other facilitators such as psychologists and university students.

discussion of the roles of facilitators in design literature in general (Benton & Johnson, 2015), they also suggest that facilitating design activities with people with intellectual disability can be difficult and challenging. Consequently, to mitigate these challenges, in paper III we recommend that facilitators seek guidance and supervision from an established support group, have enough resources to cope with unexpected events, and that their additional tasks outside the design project are minimised.

On the other hand, while facilitators experienced the difficulties described above, a finding that stands out is that they reported several gains for facilitators as a result of participating (Paper III). The facilitators reported both professional development and developing design-related skills. A possible explanation for this might be that the design activities provided an opportunity to collaborate and develop social relationships with people with intellectual disability, and in addition to gain knowledge about design techniques and technology. These findings are important as they suggest that there are possible gains of participation in design beyond user gains and technological artefacts. The development of these skills may be important in preparing support workers to provide quality daily support for people with intellectual disability (Topping, Douglas, & Winkler, 2022) and facilitating the participation people with intellectual disability in other inclusive contexts. Given the history of marginalisation, segregation and abuse (Tøssebro, 2016), providing people with intellectual disability adequate support and services is essential in ensuring their human rights. In paper III, the facilitators also described getting to know the participants better and correcting their assumptions about people with intellectual disability. This suggest that participation in design can also support relationship-building and function as a context for facilitators to practice relationship-building skills. Good relationships in supporting people with intellectual disability are important and can be beneficial for both groups and reduce staff burnout (Fish & Morgan, 2021; Mersin, İbrahimoğlu, Çağlar, & Akyol, 2020). The gains described by facilitators suggest that earlier experience as a facilitator may be valuable in ensuring quality support during digital technology design activities.

Design activities with people with intellectual disability can range from one-off activities to extended periods of time (up to years) (Benton & Johnson, 2015). Interestingly, findings in paper I-III suggest that participation over time is important in ensuring user gains and beneficence. For instance, participation over time was essential if participation in digital technology design activities is to fulfil the basic psychological needs for autonomy, competence and relatedness (paper II). A possible explanation is that in-depth knowledge of the participants' abilities was crucial in facilitating the fulfilment of these basic psychological needs. Furthermore, repeated interactions and frequent contact with the same people was essential (Paper II). Several factors could explain this finding. Firstly, it takes time to form and develop social relationships. Secondly, participating over time allows participants to witness their ideas being incorporated into the designed technology. To further support the importance of participation over time, in paper III, the facilitators recommend building a relationship with the users to enable individualised facilitation during design sessions. Also, to adapt to emergent challenges, it is important to ensure continuity and predictability. These findings are in line with Bratteteig et al. (2013) who state that it is necessary to get to know each other during design activities. Growth of knowledge and learning about each other can help facilitate understanding the different ways of reasoning and in that way lead to mutual respect (Bratteteig et al., 2013). In addition, collaborating with users can amplify the designer's understanding of the intended purpose of the solution being designed. This is particularly important when designing with people with intellectual disability as due to a different cognitive, and sensory experience of the world, designers have little experience to see the world from their perspective (Brereton et al., 2015). This growth of knowledge about each other can help identify important usability aspects and criteria such as safety, learnability, and support subjective user satisfaction (Abras et al., 2014).

On the other hand, in paper IV, findings show that participation in design activities over a short period of time and one-off activities can also foster positive outcomes (i.e., sense of ownership, sense of self-determination and coping). One-off activities can for instance provide important information on user needs including contextual and individual insights (paper IV). These findings suggest that while participation over time and relationship building is essential (papers I-III), design activities can also lead to user gains even if the participants are only involved in a limited number of activities. A possible explanation for these findings might be that photovoice offered an alternative approach to understanding user needs, and an exciting way to involve users in design activities (Paper IV). However, it is worth noting that the photovoice activities in paper IV was tailored to participants with certain abilities, and it is likely that the participants were more skilled and capable of using technology than other people with intellectual disabilities. Still, when undertaking design activities over a short period of time, we recommend a flexible approach regarding the roles, methods, and techniques. This is in line with the idea that designers can cherry-pick tools and techniques as needed during design processes (Fuad-Luke, 2013). To facilitate one-off activities that are meaningful, findings show that 1) facilitators should use creative and empowering methods such as photovoice, 2) participants should be offered the opportunity to make decisions and exert control over their participation, 3) facilitators should use accessible methods and techniques that correspond well with the participants abilities.

In Paper IV, we suggest that a relational approach to disability, striving to reduce or remove barriers (NOU 2016; Shakespeare, 2018; World Health Organization, 2001), is important when facilitating design activities for people with intellectual disability. Echoed in paper III, facilitators focused on adapting the design activities to individual needs and recommend flexible tasks and activities that enable facilitators to customize and differentiate difficulty. These findings and recommendations are in line with a relational approach to disability in which disability exists within a gap between the person's strengths and capabilities and the demands of the context (Wehmeyer & Shogren, 2016). However, in adapting the activities, the tasks must not be too easy as they become boring, and not too difficult as they might cause frustration (Paper II and III). Researchers must therefore find a balance when facilitating as too much support can lead to dependency and learned helplessness. Thus, findings in papers II and III suggest involving facilitators that are able to differentiate the support needs of the participants and are knowledgeable about the person's ability. A possible solution is including staff or stakeholders with prior knowledge of the users (paper III). This is in line with earlier studies which have emphasised the importance and value of proxies as partners in design activities (Brereton et al., 2015; Francis, Balbo, & Firth, 2009). A possible drawback is that these different stakeholders can have a significant influence on the power structures during the design process. For example, staff or other proxies may typically make decisions on behalf of the participant with intellectual disability and consequently influence the potential of empowerment (Benton & Johnson, 2015) and user contribution. Supported by Bircanin et al. (2021), relying on the contribution of proxies or staff can strengthen the power differentials that already exist between designers and adults with disabilities, ultimately leading to disempowerment. However, it is not unusual that people with intellectual disability are accompanied by a staff member or take part in activities with co-residents (Verdonschot et al., 2009). This is supported by findings in Paper III, which show that staff accompanied and supported participants with intellectual disability during the design sessions. It is also important to note that in paper I participants stated that it was important that people they had a prior relationship to were present during the design sessions. Nevertheless, researchers need to be mindful of possible influences that may hinder the self-determination of the participants.

While facilitating participation is a key part of the role of facilitators, they are also often encouraged to actively and directly contribute to the designed technology (Gibson et al., 2020). What is surprising is that findings in paper III show that the facilitators and staff were duty and task-oriented towards facilitation, suggesting they were solely focused on supporting the users during the design activities. This finding differs from earlier studies that have reported parents and staff both supporting participants and actively contributing during design sessions (Augusto et al., 2016; Khan et al., 2021; Neidlinger et al., 2021; Sitbon & Farhin, 2017; Xu et al., 2014). There are several possible explanations for this finding. Firstly, the amount of support needed, and given to the participants, can influence to which degree facilitators can directly contribute during design. Secondly, the focus on solely supporting the users may be a result of a misunderstanding or lack of clarification of expectations. Thirdly, facilitators may be focused on avoiding a third-person perspective, thus consequently solely focusing on direct user-contributions. While promoting direct user-contributions and user perspectives is important, findings in paper III suggest that this can result in missing “psychological and pedagogical insights” from facilitators. To solve this challenge, we suggest establishing a consulting group to discuss and provide guidance for facilitators, to clarify expectations before the design activities and conduct training sessions to prepare facilitators for participation prior to design activities (Paper III).

The abovementioned recommendations, along with the additional recommendations provided in Paper III meet the research gap identified in earlier literature showing that adjustments in practices and methods are often not the main focus of researchers and therefore researchers struggle to learning from earlier efforts (Hendriks et al., 2015). By exploring the nature of facilitation, experiences of facilitators, and providing *in situ* and structural recommendations, the results in paper III can support and inform researchers and practitioners in designing with this population. Still, note that design sessions with people with intellectual disability are complex, seldom straightforward, and directly impact both facilitators and participants with intellectual disability (Paper III).

9.3 Participation in digital technology design and social inclusion

Social inclusion is complex and can be understood in different manners (see section 3.1). According to Simplican et al., (2015), social inclusion is characterised by two domains – interpersonal relationships and community participation (Simplican et al., 2015). By evaluating interpersonal relationships and community participation, an in-depth understanding can be given of how young people with intellectual disability view and experience their social involvement and interaction with others (Louw, Kirkpatrick, & Leader, 2020).

Figure 7 summarizes the results of participation in digital technology design activities based on the model by Simplican et al. (2015).

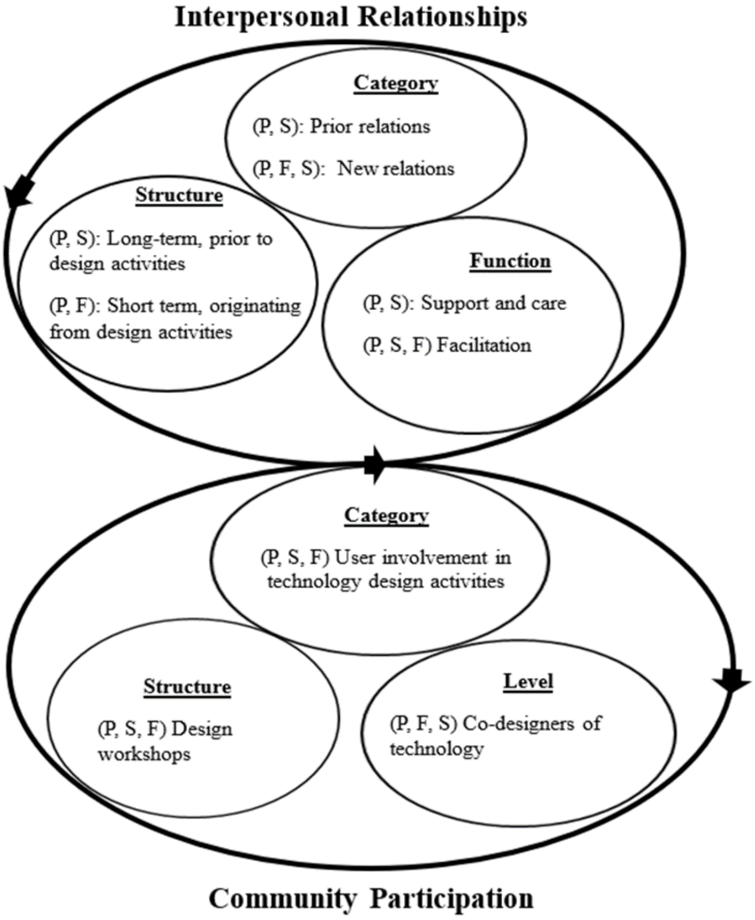

Figure 7. Model for social inclusion in digital technology design activities. Note. P=Participants with intellectual disability, S-Staff with prior relations with

participants, F=Facilitators including researchers and designers without prior relations with participations.

In this PhD thesis, based on the results from papers I-IV, I argue that participation in digital technology design activities can facilitate the social inclusion of people with intellectual disability as it supports interpersonal relationships and promotes access to participation in community activities (i.e., design workshops, user testing in different contexts and usability testing at the university). Participation in digital technology design activities can support dynamic interactions between participants, facilitators, and staff. For instance, papers I-III show that these interactions included conversations about a range of subjects and themes, facilitation and support during workshops and eating lunch together. Papers I-III confirm that participation in digital technology design is associated with social gains such as inclusion among peers and increased social relations (Andradi et al., 2021). In papers I and III, findings revealed that participation can be beneficial for the interpersonal relationships of both participants with intellectual disability as well as others involved (i.e., facilitators and staff). In line with Simplican et al (2015), the findings in this thesis suggest that participation in a community activity (i.e., digital technology design) can result in new and more diverse interpersonal relationships (i.e., person with intellectual disability – designers/ person with intellectual disability – staff/ person with intellectual disability – researchers/ staff – designers/ designers – researchers). Unsurprisingly, in line with Dindler and Iversen (2014), findings in papers I and III show that the relationship building is also important to the success of the design project.

In the following section, I describe the results concerning interpersonal relationships, and later those concerning community participation.

9.3.1 Interpersonal relationships in digital technology design activities

Categories of relationships. The categories of relationships refers to the kinds of people in the social network (Simplican et al., 2015). The design activities studied as part of this thesis involved *participants* (people with intellectual disability), *staff* (social educators, teachers) and *facilitators* (researchers, designers and other facilitators such as psychologists and university students). Compared to the facilitators, the staff had prior knowledge and relations with the participants. Together, these stakeholders composed the social network of the participants. This is in line with earlier research that has pointed out that facilitators from various backgrounds are often involved in technology design activities with people with intellectual disability (Benton & Johnson, 2015).

Papers I-III showed that the participants reported experiencing participation in digital technology design activities as an opportunity to develop and build new relationships and socially interact with others. This is consistent with Murphy et al. (2022), who indicated that participating in technology design can support the formation of new friendships and expand the persons' immediate personal network. Interestingly, in paper I, the respondents revealed that the new relationships with the facilitators differed from their existing relationships. One possible reason to why these relationships differed is that people with intellectual disability have fewer opportunities to meet people and have limited social networks (Bigby, 2008; Simplican et al., 2015). Another possible explanation is that people with intellectual disability often experience more restrictions when trying to develop new relationships (Hall, 2017).

Interpersonal relationships can facilitate bonding (relationships between people who share a common bond) (Simplican et al., 2015) which can offer opportunities to build trust and confidence (Hall, 2009; Simplican et al., 2015). As demonstrated by the findings in papers I-III, participation in digital technology design can support the bonding of relations between people with intellectual disability and staff. For instance, while participants with intellectual disabilities helped each other with solving difficult tasks, they were also supported by staff during the design activities. The presence and participation of facilitators and researchers can also facilitate the bridging of relationships. Simplican et al. (2015) define bridging relationships as putting diverse people in contact. In paper I and II, findings reveal that the participants developed relationships with the researchers during the course of the project. They talked about leisure activities, ate lunch together, and got to know each other (i.e., interests, preferences, past experiences). The bridging of relationships during digital technology design activities may support the expansion of the person's social network, which is particularly important for people with intellectual disability as they have relatively small social networks often consisting of mostly peers with intellectual disability (Verdonschot et al., 2009).

Structure of relationships. The structure component of interpersonal relationships includes elements such as the length of the relationship, the origin of the relationship, and the frequency of contact (Simplican et al., 2015). In addition, there are four structural characteristics: reciprocity (level of mutual support), intensity (level of emotional closeness), formality (source of relationships), and complexity (number of functions a relationship serves) (Simplican et al., 2015). The findings in papers I-III show that participation in digital technology design facilitates different structures relating to the interpersonal relations of people with intellectual disability during digital technology design activities.

In papers II and III, the relations between participants with intellectual disability and facilitators were mostly formal, had a low level of intensity and little complexity, meaning they did not have high levels of emotional closeness and the relationship served mostly one function, facilitating the respondents during the design activities. Interestingly, these relations changed over time as the participants and facilitators established a relationship (paper II). The findings in paper II suggest that over the course of the design project the relations with the facilitators and researchers became more flexible and had higher intensity. A possible explanation for this is that the frequency and consistency of design workshops allowed for these relations to form and develop. Consistent with Kelly and Wagstaff (2022), it takes time to build trust in a relationship and relationships change over time (i.e. structured relationships turning into friendships). Supported by results in papers I and II, these relations led to confidence and trust between facilitators and participants. Nevertheless, the results in papers I-IV do not indicate that the relationships formed between participants with intellectual disability and facilitators extended beyond the project. These results are in agreement with those of previous studies that show that while people with intellectual disability consider staff as their friends (van Asselt-Goverts, Embregts, & Hendriks, 2015), there is no evidence that people with intellectual disability and staff stay in touch beyond the actual context (Bigby, 2008).

Regardless that the relations may be short-term, this PhD thesis suggests participation in digital technology design activities can facilitate collaboration and relationship building. Such opportunities for interaction may be particularly important for people with intellectual disability as they are one of the most socially excluded groups in society (Bredewold, 2021; Howarth, Morris, Newlin, & Webber, 2016; Xu et al., 2014). Indeed, earlier research shows that people with intellectual disability regard co-workers and support workers as friends, and these friendships are often formed within structured and formal settings (Callus,

2017) similar to digital technology design activities. On the other hand, participation in digital technology design also presents a great opportunity for facilitators and researchers without intellectual disability to extend their relationships to people with intellectual disability.

Unlike the relations with facilitators and researchers, the relations with the staff had a different structure. These relations were long-term relations originating from other contexts. In paper III, findings showed that staff had prior knowledge of the needs of the participants with intellectual disability and that these relationships served several functions. For instance, the teacher coordinated when participation could occur during the participants' daily school schedule, had classes with the students before or after the design activities, and facilitated during the design workshops. This finding is in line with earlier research that shows that to increase participation in meaningful activities, people with intellectual disability need support and assistance (i.e., planning, coordinating, and travel support) (Wilson et al., 2017). However, findings in study III suggest that the complexity of the relationship with staff, meaning the number of functions a relationship serves, can be particularly difficult to balance during participation in digital technology design projects. For instance, participation in design activities might be time-consuming and therefore staff must postpone other tasks and responsibilities (paper III). Therefore, as recommended in paper III, providing staff with enough resources, and minimising their additional demands and tasks may be important in facilitating community participation.

Lastly, participants had relations with peers with intellectual disability also participating in the digital technology design activities. Some of the participants had been classmates for several years. The findings in papers I and II revealed that the participants with intellectual disability had long-term relations with each other and that these relations were reciprocal. This finding is not surprising and seems to be consistent with other research which shows that the friendships and social relationships of people with intellectual disability are often largely restricted to peers with similar disabilities, paid staff and family (Bigby & Knox, 2009; Gilmore & Cuskelly, 2014). Still, these relationships are very important and should not be devalued as they are experienced as "equal" by people with intellectual disability (McVilly et al., 2006b). Earlier research suggests that the reciprocity seen in relationships between people with intellectual disability may be missing in relationships with peers without disabilities (Friedman & Rizzolo, 2018). To further illustrate the importance of these relations, findings in papers I and II reveal that participating with peers with intellectual disability was important in motivating the participants. Furthermore, in study I, the participants noted the importance of participating with peers (i.e., friends, classmates) rather than participating with facilitators, staff and researchers only, suggesting that these relations were particularly meaningful. This finding is in line with Callus (2017) who reported that the relationships people with intellectual disability regarded as more meaningful is when the friendships are built on an equal basis emphasising the importance of reciprocity and mutual respect.

Function of relationships. Simplican et al. (2015) divide the function of relationships into three categories including emotional, instrumental, and informational support. The findings in papers I-III show that the participants received various types of support from different stakeholders during the digital technology design activities. The function of the relations with facilitators was mainly addressed in paper III which showed that they were mostly focused on providing instrumental and informational support such as adapting the design activities and supporting communication. This finding is reassuring since the role of facilitating includes informational and instrumental tasks such as disseminating information, applying appropriate tools for tasks, and allowing time for tasks (Fuad-Luke, 2013). On the other hand, in paper I, the findings suggest that the relations between the participants with intellectual disability had an emotional function. Supported by findings in paper II, the participants with intellectual disability supported each other through encouragement and care. A possible explanation for this might be that participants with intellectual disability had close relations and friendships before the design activities and were in a relatable situation. The function of the staff was however multifaced with results in papers I-III suggesting they provided emotional, instrumental and informational support. Such support is essential as people with intellectual disability can have a range of different support needs. In line with earlier studies, participants with intellectual disability can be reliant on support to appropriately contribute during design activities (Benton & Johnson, 2015). While findings in papers I-III revealed different functions of relations, it is also evident that they were all important for the participants. This supports previous research reporting that people with intellectual disability can experience a sense of belonging to a network when they have different people fulfilling different needs (McVilly et al., 2006a).

9.3.2 Digital technology design as a community activity

Category of digital technology design activities. Community participation is central to a person’s quality of life and necessary for social inclusion (Simplican et al., 2015). Community activities includes several types of activities including leisure activities, political and civic activities, productive activities and religious and cultural activities (Simplican et al., 2015). In this thesis, participation in digital technology design activities can be categorized as a productive activity or as access to goods and services. Still, people with intellectual disability have previously been overlooked in digital technology design. However, the findings in this PhD thesis suggest that participating in digital technology design can be role-valorising (Paper I, II and IV) and impact perceptions of the social roles that people with intellectual disability can have and perform in the community. Role-valorising is enhancing the perceived value of the social roles of a person or group and can be done through the enhancement of the person or group's competencies and the enhancement of people’s social image in the eyes of others (Osburn, 2006).

Results from papers I and II show that participants contributed to the design project and technology by providing insights and shaping the technology during the digital technology design activities. Findings in papers I and III suggest that their contributions led to a change in perception within staff and facilitators, and the participants were viewed as experts and valuable contributors. These findings suggest that the participants had a valued social role during the design activities. Having a valued social role is particularly important for people with intellectual disability as they have been a devalued and stigmatised group (Gilmore & Cuskelly, 2014; Pelleboer-Gunnink, Van Oorsouw, Van Weeghel, & Embregts, 2017). Thus, enhancing the perceived value of the social role of people with intellectual disability is essential as while devalued groups are likely to be treated badly, people with valued social roles are likely to be treated better (Osburn, 2006). Also, the enhancement of people’s competencies is important in social role valorisation (Osburn, 2006). As people with intellectual disability can enhance their competence and knowledge further supports participation in digital technology design as role-valorising. Together these findings suggest participation in digital technology design can be an inclusive and productive way to participate in the community. While the involvement in productivity roles is associated with enhanced physical and mental health (Lysaght, Ouellette-Kuntz, & Morrison, 2009), it also supports social inclusion as the person is perceived as competent to perform social roles that are valued. Interestingly, in study I and II, the participants expressed participation in digital technology design as being part of something important and experienced being acknowledged. In accordance with the present findings, previous studies have demonstrated that people with intellectual disability want to feel part of "something" (an activity or group) and be paid attention to (Rojas-Pernia et al., 2020).

Structure of digital technology design activities. The structure of community activity for people with intellectual disability can be classified as segregated, semi-segregated, and integrated (Simplican et al., 2015). According to Simplican (2015), semi-segregated settings include activities that take place in segregated settings but include community members, such as volunteers and researchers. The design activities in the InnArbeid project fit the definition of a semi-segregated community activity (see section 6). While the majority of design activities in papers I-IV took place in segregated classes and classrooms, community members, including researchers and designers, participated in and facilitated the workshops. As earlier literature points out, it is not unusual for people with intellectual disability to participate in semi-segregated settings (Simplican et al., 2015). Still, results in papers I and II showed that participation in such a setting was important for people with intellectual disability regardless. By taking part in these activities, the participants developed a sense of acknowledgement and pride for taking an active part in society. In paper II, the participants preferred collaborating within this structure as it offered continuity and predictability.

In paper I, the results showed that the participants described the digital technology design activities as something different from their usual activities and that they valued the participation. A possible explanation is that people with intellectual disability still have restricted engagement with their community (Verdonschot et al., 2009). Similarly, in paper IV, although the participants contributed individually, they described participation as empowering, fun, and exciting. While the activities took place in semi-segregated settings, our findings suggest that the participants had a positive and empowering experience and experienced a sense of acknowledgement and a sense of belonging. It is however important to note that the participants took photovoice pictures in integrated settings (paper IV). As opportunities for participating in integrated settings are scarce for people with intellectual disability, the flexibility that photovoice provides may be an opportunity to extend technology design activities beyond segregated or semi-segregated settings. Still, the findings in this PhD thesis seem to be consistent with those of Hall (2013) who stated that semi-segregated activities can offer people opportunities for developing belonging. According to Hall (2013), such activities can in turn support the person's ability to transition to integrated settings.

Level of involvement in digital technology design activities. The different levels of community involvement are conceptualised as presence, encounter, and participation. Presence includes merely being physically present, encounter includes meetings and interactions between strangers in community settings, and participation includes involvement in activities that promote the development of interpersonal relationships (Simplican et al., 2015). According to Simplican et al. (2015), participation that promotes the development of interpersonal relationships is the deepest level of involvement.

Overall, in papers I-IV, the findings show that digital technology design activities facilitated participation and involvement. The participants were engaged in decision-making and a range of different activities. Moreover, findings in papers I-IV show that they participated beyond presence, meaning being involved in meetings and conversations, and consequently, developed interpersonal relationships with researchers, facilitators, and staff. For deeper reflections on the level of involvement, see section 9.2.

9.4 Methodological considerations

This section discusses the methodological considerations and the quality of research undertaken in this PhD thesis. Qualitative research relies on a rigorous approach. In this research, I used the terminology and strategies described by Lincoln and Guba (1985) to account for a rigorous approach. Lincoln and Guba (1985) propose evaluating *credibility*, *transferability*, *dependability,* and *confirmability* in the pursuit of trustworthiness. These constructs correspond to the criteria of internal validity, external validity, construct validity and reliability employed in quantitative research (Riege, 2003). The concept of trustworthiness, including the four criteria presented above, is widely accepted by qualitative researchers (Connelly, 2016; Cope, 2014; Kvale & Brinkmann, 2009; Shenton, 2004) and an appropriate way of assessing the quality of qualitative research (Cope, 2014; Korstjens & Moser, 2018; Shenton, 2004). Threats to trustworthiness, including credibility, transferability, dependability and confirmability are unavoidable in research. However, note that communicative difficulties and cognitive limitations may pose additional methodological challenges when undertaking qualitative research with people with intellectual disability (see Sigstad & Garrels, 2018, Sigstad, 2014 and Beail & Williams, 2014 for discussions in detail). While there is no study with a complete absence of bias, in the next sections I try to report possible threats to trustworthiness so that the readers can independently assess the quality of the study. Thus, the four criteria and how they are addressed in this PhD thesis are explained in detail below.

Credibility is concerned with the aspect of truth-value and whether the findings are a correct interpretation of the participants' views (Kortjens and Moser 2018, p. 121, based on Lincoln and Guba, 1985). Credibility is similar to the concept of internal validity in quantitative research (Korstjens & Moser, 2018; Riege, 2003). Credibility can be ensured through strategies such as *prolonged engagement, persistent observation, triangulation and member check* (Korstjens & Moser, 2018). Prolonged engagement is a lasting engagement with the participants in the field to become familiar with the setting/context to build trust and to test for misinformation (Korstjens & Moser, 2018). This is particularly important in research with people with intellectual disability due to cognitive and communicative difficulties.

To ensure *prolonged engagement,* I interviewed the participants on several occasions after design activities in different contexts (paper I & II). Moreover, participants were asked several different questions about their experiences, and they were encouraged to provide examples to support their statements. In that way, I was able to gain insight and collect relevant information. Follow-up questions were also asked to confirm and clarify statements. The development of an early familiarity with the participants is also suggested to promote credibility (Shenton, 2004). Thus, I visited the participants before the interviews through preliminary visits. These visits provided me with information and insight about the participants, and how to approach them, and facilitated the mapping of possible ethical issues. In addition, before the interviews, I participated in the digital technology design activities and conducted participant observations which provided me with the opportunity to collaborate with the participants and gain an understanding of the design activities and their experiences and to build a relationship. As I participated in all design activities, I was able to continually develop familiarisation with the context, culture, and participants throughout the design and research process. Still, it is important to note that while getting to know the participants is essential, prolonged engagement may create a relationship between the researchers and the interviewee which may pose a reflexive threat (Yin, 2017). Thus, the relationship with the participants was constantly reflected upon with the other researchers involved in the research process.

Persistent observation is identifying relevant characteristics and factors in the context that are likely to be most relevant to the issue or topic being explored or investigated (Korstjens & Moser, 2018). Persistent observation was achieved by maintaining contact with the participants throughout the research process (Paper I-IV). Moreover, by conducting participant observations, I was able to maintain communication with the participants (Paper I-III). For instance, I was able to talk to and observe the participants before each interview (Paper I-V). The observations could then be used as input and prompts during the interviews. Another important factor is that I ensured that all participants had participated in the digital technology design activities and could provide insight into their experiences of participating. Also, I could use observations notes to supplement the interviews (Paper I-IV).

Triangulation refers to using different sources of data and methods of data collection. Triangulation includes data triangulation (using multiple sources of data in time: different times of day/year, space: same phenomenon in different sites, and person: data from different people i.e., individuals, family members, staff), investigator triangulation (two or more researchers involved in coding and analysis) and method triangulation (using multiple methods). In papers I-III, methodological triangulation was ensured by gathering data through different data collection methods including individual and group interviews, participant observations, photovoice and a Smileyometer Likert Scale. Investigator triangulation was applied by involving two other researchers in the research process (paper I-IV). In addition, one of the researchers was present during the participatory observations of all the design activities. The data in papers I-III was analysed by three different researchers, whereas the data in paper IV was analysed by two researchers. See section 7.4 for a more detailed description of the analysis process. In addition to methodological and investigator triangulation, triangulation of data was also employed. For instance, various data sets were collected by using reoccurring and follow-up interviews with the same participants (papers I-III). In line with Yin (2017), follow-up interviews can serve as a set of multiple sources of evidence. Also, interviewing the participants at different points can be useful in checking the consistency of their statements.

Member check is feeding data, analysis and conclusions to those groups from whom the data was obtained (Korstjens & Moser, 2018). While member checks are important for establishing credibility (Lincoln & Guba, 1985), it was not applied in this PhD thesis. However, to ensure that the participants' words matched what they intended, we followed up by asking probing questions if their response or answer was unclear. Moreover, we used techniques described by Sigstad and Garrels (2018), including repeating, paraphrasing and summarising responses. During the interviews, I paraphrased and summarized the responses of the participants to offer them an opportunity to hear their responses, reflect on their responses, give a correction, and possibly complement the statement or answer. According to Sigstad and Garrels (2018), paraphrasing may fill the role of member checking in facilitated interviews with people with intellectual disability.

In addition to the strategies described above I also made the following provisions to promote credibility (Provisions described by Shenton, 2004). To *ensure honesty in informants*, in this current thesis, the participants were free to participate and offer data as they wished. Moreover, the participants were informed that they could withdraw at any given time and encouraged to be honest (i.e., told that no there were no wrong or right answers) (see appendix attachment 5B and 9 which describes a short introduction given prior to all interviews). All participants were also given a choice to participate in interviews with or without a proxy present. Also, to promote credibility, I and my co-researchers had *frequent debriefing sessions* and supervisions to discuss different approaches and the use of the different methods. The debriefing sessions were a context in which different ideas and interpretations of data were discussed and helped in recognising possible biases. In addition, to receive *peer scrutiny of the research project*, I presented preliminary findings of papers I-III in a research dissemination course and in a conference about doing research during the pandemic time. These presentations allowed me to receive feedback about the project and the initial research findings. Moreover, findings were presented at a conference in which the participants in papers I-III attended. To ensure *reflexivity*, I documented discussions during supervision with my advisors and recorded initial thoughts during both participant observation and the data analysis process. Moreover, before supervision, I documented and sent notes which included questions and reflections on the research process.

Transferability refers to the aspect of applicability and concerns whether the findings and the acquired knowledge can be applied to other settings, contexts or groups (Kortjens & Moser 2018, based on Lincoln and Guba, 1985). Transferability is the parallel construct to external validity in quantitative research (Riege, 2003; Shenton, 2004). A strategy to ensure transferability is providing a thick description of the phenomena under study and sufficient information about the participants, context, methods and analysis so that research findings are meaningful to an outsider or transferable to fit other contexts. In the present PhD thesis, thick descriptions of the study context, data collection, analysis and findings are presented in detail in sections 6, 7, and 8 to allow readers to assess the potential of transferability to similar settings or similar populations. In papers I-IV, quotations have been included to back up the analysis and provide the reader with enough information and context to judge the interpretation. However, limitations include the homogeneity of the participants. While ranging in age (between 18 and 50), the participants were all Norwegian and lived in two cities in southern Norway. This may create limited transferability to other geographical areas and cultures. Another limitation of this PhD thesis is related to the small sample size. However, the number of participants is reasonable for qualitative research and particularly when interviewed over time. Still, transferability is enhanced through analytic generalisation including the use of Ryan and Deci’s Self-determination Theory (2000, 2002) and Simplican’s Model of Social Inclusion (2015), and the findings are also supported by earlier empirical research (see section 9).

Dependability refers to the consistency and continuity of the data over time (Kortjens and Moser 2018, p. 121, based on Lincoln and Guba, 1985) and in similar conditions (Cope, 2014). Dependability is similar to the notion of reliability in quantitative research (Riege, 2003; Shenton, 2004). According to Lincoln and Guba, in Shenton (2004), there are close ties between credibility and dependability, and in practice, a demonstration of credibility goes some distance in ensuring dependability. Thus, in this PhD thesis, in addition to ensuring credibility as described earlier, dependability was ensured through the use of Thematic Analysis as a method of data analysis. The data analysis process followed the recommendations provided by Braun and Clarke (2006, 2022). Moreover, the analytic process is described in papers I-IV and a detailed write-up is provided in section 7.4.5. In addition, I conducted and transcribed all the interviews, participant observations and analyses and the methods used, and the research process is thoroughly described in papers I-IV and section 7.

Confirmability concerns the aspect of neutrality in the research process and objectivity (Kortjens and Moser 2018, p. 121, based on Lincoln and Guba, 1985). Conformability corresponds to construct validity in quantitative research and concerns the findings and if the interpretation of data is drawn in an unprejudiced manner (Riege, 2003). A way to ensure dependability and confirmability is to provide an audit trail. An audit trail is transparently describing the research from start to end including keeping the records of the research path throughout the study (Korstjens & Moser, 2018). To establish a chain of evidence, interviews were recorded, field notes, and observations were documented and stored throughout the whole research process. The data obtained, including transcribed interviews, was anonymised and saved in a storage cloud provided by the University. An overview of the data collected as part of this PhD thesis is presented in section 7.4.5. Moreover, in addition to triangulation and a detailed methodological description, the results in papers I-IV include rich quotations and an example of a thematic analysis. However, during the data collection, a semi-structured approach was undertaken. While the emphasis was placed on participants being free to speak, the researcher may still influence the participants. Moreover, during the interviews, I facilitated the interviews for respondents with intellectual disability as recommended by Sigstad and Garrels (2018) which may also be a threat to confirmability. Therefore, during the interviews, I actively used the same language and vocabulary as the participants when paraphrasing or summarising to avoid putting words in their mouth.

10 Conclusion

In the next section, I present the conclusion of this PhD thesis and research contributions which point to both practical and theoretical contributions. Lastly, I present some reflections for further research.

This PhD thesis investigated how participation in the design of digital technology can contribute to the social inclusion of young adults and adults with intellectual disability. To address the overall aim, I have raised two research questions:
I. How do young adults and adults with intellectual disability experience participation in the design of digital technology?
II. How can young adults and adults with intellectual disability be supported to enable participation in the design of digital technology?

Using Simplican's (2015) model of social inclusion where social inclusion is characterised by two domains – interpersonal relationships and community participation, I have argued, based on findings from Papers I-IV, that participation in digital technology design activities can potentially enable and support the social inclusion of people with intellectual disability. I have concluded with the following: participation in digital technology design activities can facilitate the social inclusion of people with intellectual disability as it can both support dynamic interactions with different stakeholders and promote access to participation in community activities.

Regarding experiences of participation, the findings suggest that participation in digital technology design activities can initiate positive emotions, encourage positive behaviours, and foster the development of new skills for young adults and adults with intellectual disability. Overall, and consistent with other literature (see section 4), findings in this PhD thesis show that participation in digital technology design can have a positive impact on both participants with intellectual disability, facilitators and staff.

Concerning facilitation of technology design activities for people with intellectual disability, I have found that creative methods, such as photovoice, can strengthen the participants' ability to cope with the demands of participating in digital technology design activities. Moreover, I found that while supporting people with intellectual disability can be difficult and complex, facilitators can also enhance their competence and skills during such activities. Facilitators in design activities need both individual and structural support when supporting people with intellectual disability in such activities.

Furthermore, the interactions between different stakeholders in digital technology design activities can have broader impacts in terms of a shift in perceptions of marginalised groups. With people with intellectual disability being segregated, having negative images attached to them, and being cast into negative social roles (Tøssebro, 2015, 2016), participation and collaboration in technology may enhance the perception of people with intellectual disability in the eyes of others.

In the following paragraphs, I summarize the contributions of my research. I have grouped the contributions into theoretical contributions and practical contributions.

10.1 Contribution to theory

This PhD thesis makes three main theoretical contributions. The theoretical contributions are related to social inclusion, Self-determination Theory and participatory design/co-design.

The findings in this PhD thesis build upon the social inclusion model as per Simplican et al. (2015) by applying it as a theoretical lens to explore the context of digital design activities. I demonstrate that both the domain of interpersonal relations and community inclusion are important domains for understanding and exploring the social implications of participation in digital technology design activities for people with intellectual disability. Thus, this PhD thesis advances the literature on social inclusion by bringing a new perspective on potential social gains of participation in digital technology design activities. This is important because while there has been a need for strategies to increase the social inclusion of people with intellectual disability (McCausland et al., 2022; Grung et al., 2020), social gains of participation in digital technology activities have seldom been systematically explored (see sections 4.1.4 & 4.2).

Regarding self-determination, the current thesis expands the Self-determination Theory (Deci & Ryan, 2000, 2002) by testing Dent-Spargo’s (2018) hypothesis showing that the Self-determination Theory can be utilised to explore the motivation of people with intellectual disability in the context of digital technology design. As the findings show, the three basic psychological needs are important elements for understanding motivation in design activities with people with intellectual disability. The use of Self-determination Theory advances the theory by demonstrating that the fulfilment of the basic psychological needs can help mitigate possible negative experiences and support enjoyment in digital design activities with people with intellectual disability.

Lastly, the findings in this PhD thesis also expand the literature on user involvement in participatory design/co-design (See section 3 & 4; Benton & Johnson, 2015) by offering insight in facilitators' experiences and the use of photovoice as a method to facilitate the participation of people with intellectual disability in such activities. I argue that facilitation applying a relational view (NOU 2016) or a person-environment fit model (Wehmeyer & Shogren, 2016) of disability is important when facilitating participation for people with intellectual disability. Moreover, while the majority of research has focused on children with intellectual disability (see Benton & Johnson, 2015; Börjesson et al., 2015), this PhD thesis contributes with insight and an understanding of the experiences of young adults and adults with intellectual disability.

10.2 Contributions and recommendations to practice

The user involvement of people with intellectual disability in digital technology design is essential as it can enhance the quality of the designed technology and have positive impact on the participants. Moreover, in line with Nothing About Us Without Us movement (Stack & McDonald, 2014), users are considered best placed to voice their needs and wants (see section 3.2). The findings in this PhD thesis show the potential benefits of participation in digital technology design activities for young adults and adults with intellectual disability. Thus, this research contributes with insights that can support researchers, designers, teachers, social workers, and others in promoting empowering user involvement of people with intellectual disability in design processes. Still, it cannot be said that participation in such activities will benefit all adults and young adults with intellectual disability, however there is a potential that they could benefit depending on the person, personal characteristics, their skills, and interests.

Also, this thesis contributes with an understanding of potential social benefits of participation in digital technology activities. For instance, participating with both people with a prior relationship and without may be important in forming new interpersonal relations. Moreover, facilitating participation in both semi-segregated and intergraded settings can be essential in promoting community participation.

Practically, in digital technology design activities, the findings suggest engaging participants in digital technology design activities over time seems important if such activities are to foster some of the described user gains. An example is that forming relations takes time, thus I recommend planning technology design activities that are not one-off when designing digital technology with people with intellectual disability.

In efforts to ensure beneficence of participation in digital technology design activities I recommend the fulfilment of the needs for autonomy, competence and relatedness. For example, it seems that participants are motivated by influencing the design activities and designed technology and participating with other participants (i.e., peers, staff, and researchers) rather than alone. Moreover, the tasks during the design activities should not be too easy, or too difficult. In doing so, potential negative experiences such as boredom or frustration can be mitigated.

Given the importance of facilitation in digital technology design activities, a contribution of this PhD thesis is a set of recommendations to support facilitators involving young adults and adults with intellectual disability. As the efforts of participants and the nature of facilitation is rarely reported, I systematically provide recommendations, insights in adjustments, and experiences of facilitators supporting adults and young adults with intellectual disability. This knowledge and insight can further inform other researchers' efforts in participatory design activities with people with intellectual disability. Ensuring facilitators have the resources needed to provide individual strength-based approaches (see recommendations in paper III) seems critical if participation in digital technology design is to foster user gains. For instance, facilitators should be given enough resources to be able to solely focus on facilitation rather than balancing several commitments (i.e., other work tasks) parallelly. Also, the developed recommendations are an important contribution to designers and facilitators as earlier research efforts have largely focused on results and methods designed for children.

10.3 Recommendations for future research

For future research, I find the following directions relevant. Firstly, the current research explored digital design activities with people with intellectual disability in a semi segregated context. Thus, there is a need for more research on how participation in integrated contexts with other stakeholders can impact factors relating to the social inclusion of people with intellectual disability. Such research may provide valuable knowledge on how to ensure positive social impacts of participation in digital technology design activities for people with intellectual disability, as well as other stakeholders.

Secondly, the findings in this PhD thesis suggest that the interpersonal relations formed during the design activities did not last beyond the design project. Thus, there is a need for more research regarding the relations formed in such contexts. In sum, there is a need for more research on how to raise awareness regarding the boundaries for these relations and a need for more knowledge on how these relations can be strengthened to last beyond the design project.

Thirdly, further research is also needed on self-determination and the involvement of other stakeholders. For instance, exploring how the self-determination of people with intellectual disability is impacted when participating in technology design activities with stakeholders such as parents, siblings, and volunteers. Future research should therefore explore how these different roles impact power structures, and consequently the empowerment of this population in digital technology design activities. In doing so, such research may shed light on how to promote self-determination during technology design activities with people with intellectual disability and other marginalised populations. This may be particularly important in design activities with a longitudinal approach as power-relations and balance may change over time.

Fourthly, in the explored design project, and this PhD thesis, the design activities were planned by researchers and designers without intellectual disability. Also, participants with intellectual disability were practically facilitated by researchers, staff and other facilitators without an intellectual disability. Thus, there is a need for more research on how co-design/participatory design activities themselves can be designed with and by people with intellectual disability.

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Appendices

Paper I
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Paper I

Safari, Mugula Chris., Sofie, Wass., & Elin Thygesen. (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. DOI: https://doi.org/10.16993/sjdr.798.

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RESEARCH

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

Mugula Chris Safari, Sofie Wass and Elin Thygesen
University of Agder, NO
Corresponding author: Mugula Chris Safari (chris.safari@uia.no)

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.

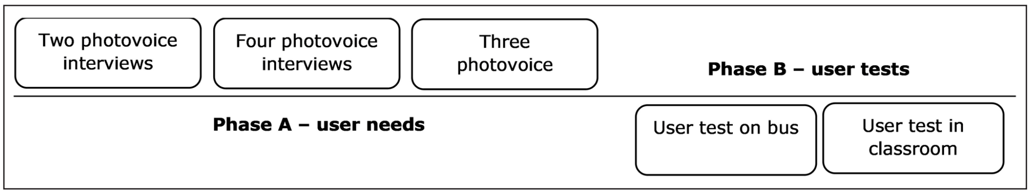

Figure 1: An overview of the research activities in the design project.

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.

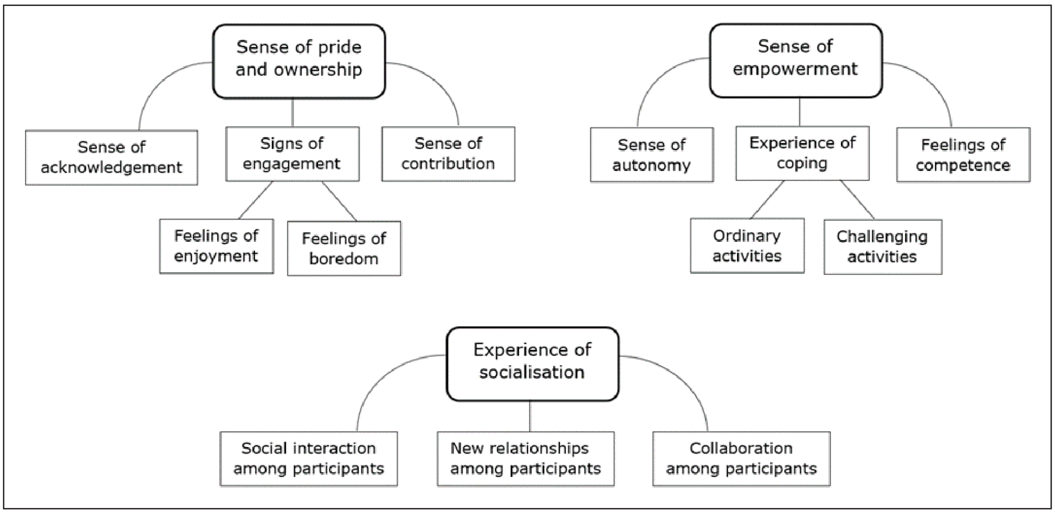

Figure 2: Thematic map showing the three main themes, nine subthemes, and four subcategories.

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

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Contribution to design

The participants in Phase A contributed to the design project by providing insights on contextual and individual needs. The insights gathered highlighted important elements of independent transport such as time management, punctuality of public transport, stress management, and communication. For instance, the participants provided insight on how challenges with identifying the correct bus for users with vision impairment or with limited literacy impacts independent transport. For example, when the bus is not on time, the user may not be able to identify the correct bus based on the bus table or route name. This insight informs the design by pointing out the need to assist the user in identifying the correct bus. Other insights such as handling the lack of seating and avoiding social interaction were also mapped. The design was informed by the need for support in navigating social situations during independent transport.

The participants in Phase B contributed to the design project by highlighting the need for customizable solutions that support understanding of time, locations, notifications, and language. For instance, the participants gave insights on the need for customizable and simple instructions as the users are heterogeneous. Another example of an insight was the need for assistance with visualising time and supporting alternative understandings of time. For instance, visualising how long till the bus arrives, or how much time the user has spent on the bus. Moreover, the users' insights provided descriptions of requirements such as the need for text-to-speech, different modes of communication when in need for support (SMS, voice call or prewritten SMS) and supporting adjustment of font size for users with vision impairment.

The contributions from the participants in both phases were vital in shaping the artifact and informing the design.

Paper II

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Motivation of people with intellectual disabilities in technology design activities: the role of autonomy, competence, and relatedness

Mugula Chris Safari [a], Sofie Wass [b] and Elin Thygesen [c]

[a]Department of Psychosocial Health, University of Agder, Grimstad, Norway; [b]Centre for eHealth, University of Agder, Grimstad, Norway; [c]Department of Health and Nursing Science, University of Agder, Grimstad, Norway

ABSTRACT
While people from marginalised groups are increasingly involved in design processes, research is scarce on the reasons why people with intellectual disabilities participate in such activities. Drawing on Self-Determination Theory, we explore what motivates young adults with intellectual disabilities to participate in technology design activities. This case study is based on reoccurring interviews and focus groups interviews with seven young adults with intellectual disabilities who participated in design activities. We also gathered reflective notes from eight support staff and conducted participant observations of the activities. An inductive thematic data analysis revealed six themes that contribute to motivation. These themes were deductively analysed with a focus on the three basic psychological needs in Ryan and Deci's (2002) Self-Determination Theory: autonomy, competence, and relatedness. Our study shows that a sense of enjoyment, influencing the designed technology and the design activity, enhancing skills and knowledge, experiencing a sense of self-efficacy, developing social relationships, and experiencing a sense of meaningfulness can lead to the fulfilment of the need for autonomy, competence, and relatedness. The results suggest that participation over time is essential to understand participants' needs for autonomy, competence, relatedness and to facilitate enjoyable design activities that motivate participants with intellectual disabilities.

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Intellectual disabilities; user involvement; design activities; technology design; motivation; self-determination theory

1. Introduction

Technology is increasingly used to support activities of people with intellectual disabilities such as independent travel and wayfinding (Mechling and Seid 2011; Lancioni et al. 2010; García-Catalá, Rodríguez-Sánchez, and Martín-Barroso 2020), social networking (Caton and Chapman 2016), time management (Green, Hughes, and Ryan 2011), employment tasks (Collins et al. 2014), communication (Murphy and Cameron 2008; Saturno et al. 2015), completion of daily tasks (Mechling 2007), and engagement in daily and leisure activities (Lancioni et al. 2020). Intellectual disability is characterised by significant limitations in both intellectual functioning and in adaptive behaviour, including many social and practical skills (Schalock, Luckasson, and Tassé 2021). Given the positive impact that technology can have on the lives of people with intellectual disabilities, providing them with an opportunity to participate in technology design is essential (Benton and Johnson 2015; Mankoff, Hayes, and Kasnitz 2010; Ghanouni et al. 2020). Today there is an increasing body of research on user involvement of people with intellectual disabilities (Benton and Johnson 2015; Wilson et al. 2016; Sitbon 2018; Wass, Hansen, and Safari 2020; Safari, Wass, and Thygesen 2021; Bayor et al. 2021; Raman and French 2021).

User involvement, described as direct contact with users during design activities, ranges from being observed to having an active role in providing information and making decisions (Kujala 2003). The core idea is that the future user should have an opportunity to influence the design (Robb et al. 2021). User involvement can reduce the cost of developing solutions, increase users' well-being (Steen, Manschot, and De Koning 2011), and positively impact user satisfaction, system performance, and quality (Cinquin, Guitton, and Sauzéon 2020; Bano and Zowghi 2015; Baroudi, Olson, and Ives 1986). Previous research shows that involvement of people with disabilities in design activities not only increases the usability of the technology but can also empower participants (Robb et al. 2021), increase their self-confidence, lead to feelings of enjoyment and ownership (Benton and Johnson 2014; Benton et al. 2012). While the positive outcomes of user involvement in technology design processes are well established, user involvement of people

CONTACT Mugula Chris Safari chris.safari@uia.no

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with intellectual disabilities in design activities can be complex due to additional support needs (Benton and Johnson 2015) and requires the use of different methods and techniques, such as workshops, photo-elicitation, prototyping, interviews, and observations (Muller 2012; Sanders, Brandt, and Binder 2010).

Studies show that participants are motivated to contribute to design activities by factors such as interest in technology, cooperation, and of being endorsed as experts (Hansen and Iversen 2013). According to Iversen, Dindler, and Hansen (2013), 'democracy' and self-determination in design activities are closely linked to motivation for participation. However, the responsibility of motivating users to engage in the design process lies with the design team. While several studies have focused on technology and design processes (Benton and Johnson 2015), less is known about how users can be motivated in design activities (Hansen and Iversen 2013). Self-Determination Theory is a theory of motivation that accounts for how the psychological needs of autonomy, competence and relatedness motivates behaviour (Ryan and Deci 2000). Previous research in disability studies has shown the relevance of the Self-Determination Theory and used it as a lens to study well-being and health (Ryan and Deci 2000), autonomy support (Frielink, Schuengel, and Embregts 2018), education (Deci et al. 1992; Katz and Cohen 2014) and employment (Garrels and Sigstad 2019). Although the basic psychological needs in the Self-Determination Theory are universally important, regardless of the level of intellectual functioning (Frielink, Schuengel, and Embregts 2018; Ryan and Deci 2000), research utilising this theoretical framework within the context of technology design activities has, to date, been scarce.

Given the importance of the three basic psychological needs and their role in motivation (Deci and Ryan 2002), we use Ryan and Deci's Self-Determination Theory as a theoretical framework to explore what motivates young adults with intellectual disabilities to participate in technology design activities. In particular, we investigate how participants experience that participation in design activities contributes to the fulfilment of the needs for autonomy, competence, and relatedness during technology design activities. A case study approach (Yin 2017) was taken throughout this study.

2. Related work

2.1. User involvement of people with intellectual disabilities in design activities

User involvement includes approaches such as participatory design, co-design, user-centred design, ethnography, and contextual design. Such approaches and engagement are particularly important as designers have little experience to see the world from the perspective of participants with intellectual disabilities (Brereton et al. 2015). However, while people with disabilities have previously been overlooked in the development of technological solutions, in recent years the number of studies engaging people with intellectual disabilities in design activities has been growing (see literature reviews: Börjesson et al. 2015; Benton and Johnson 2015). Newer examples include design of technological solutions such as a transport support tool (Wass, Hansen, and Safari 2020), a mobile goal-setting application (Wilson et al. 2016), a web application (Sitbon 2018; Bayor et al. 2021), a game-based learning tool (Raman and French 2021), and multisensory wearables (Neidlinger, Koenderink, and Truong 2021).

User involvement of people with intellectual disabilities can be challenging as commonly used design methods and tools draw on multiple cognitive and sensory abilities (Benton and Johnson 2015; Raman and French 2021). However, methodological frameworks, approaches and principles have been suggested to engage and facilitate participation (Raman and French 2021). For instance, the 'Handlungsspielraum' or 'Action-Play-Space' which provides a theoretical lens combined with practical tools for co-design activities with children with different abilities (Makhaeva, Frauenberger, and Spiel 2016) and the 'Who-what-when-where-how' framework for planning and organising co-design activities with children (Mazzone, Read, and Russell 2011). Other approaches include the method stories, which advocates for a highly individual approach towards adjusting co-design techniques (Hendriks, Slegers, and Duysburgh 2015) and an approach based on principles underpinned by a rights-based ethos (Raman and French 2021). However, only a few of the existing frameworks focus specifically on people with intellectual disabilities in co-design (Raman and French 2021).

2.2. Self-determination and motivation

While self-determination is important in technology design activities (Dent-Spargo 2018), promoting and enhancing the self-determination of people with intellectual disabilities has also become best practice (Soresi, Nota, and Wehmeyer 2011) and an essential focus of disability services (Wehmeyer and Bolding 2001). There is a consensus that self-determination is vital for children, adolescents, and adults with intellectual disabilities (Wehmeyer and Bolding 2001). Wehmeyer (2005, 117) describes self-determined people as 'causal agents in their lives'. While intellectual capacity is not considered a significant contributor to self-determination, the freedom and ability to make choices is thought to enhance self-determination and autonomy (Wehmeyer and Garner 2003). Self-determination of people with intellectual disabilities has been linked to several positive outcomes such as employment, social integration, community access, and financial independence (Shogren et al. 2015; Wehmeyer and Palmer 2003; Nota et al. 2007). Still, people with intellectual disabilities experience limited self-determination, and few or limited opportunities to express preferences and make choices (Wehmeyer and Palmer 2003).

The notion of self-determination is broadened through the lens of the Self-Determination Theory as a means to understand why people are motivated to act in ways that are autonomous (Deci and Ryan 2000). The self-determination framework considers people to be actively searching for optimal challenges and new experiences to master, cope, and integrate (Deci and Ryan 1991). According to Deci and Ryan (1985), *amotivation, extrinsic motivation, and intrinsic motivation* lie on a continuum of self-determination and account for reasons why people engage in activities or not. The most self-determined type of motivation is intrinsic motivation, which is highly autonomous (Deci and Ryan 2000), and refers to doing activities for their own sake, out of interest, without the need for external rewards (Deci and Ryan 2002).

The Self-Determination Theory identifies three basic psychological needs – autonomy, competence, and relatedness – that support healthy functioning, well-being, and motivation in social environments (Deci and Ryan 2002). When the need for autonomy, competence, and relatedness are fulfilled, individuals experience intrinsic motivation and are likely to function and develop optimally (Ryan and Deci 2017). According to Ryan and Deci (2017), the conditions that thwart basic psychological needs undermine intrinsic motivation. The Self-Determination Theory proposes that people are driven to engage in actions to fulfil the basic psychological needs of autonomy, relatedness, and competence, furthermore, the environments that support the fulfilment of these needs enable the person to be engaged and energised about achieving goals (Deci and Ryan 2012).

2.3. Autonomy, competence, and relatedness in design activities

Autonomy is defined as 'being the perceived origin or source of one's own behaviour'. Autonomy is the need to feel ownership of one's behaviour and to act based on one's interest (Deci and Ryan 2002, 8). An environment or situation is autonomy-supportive when the individual experiences being in control of their actions. According to Niemiec and Ryan (2009), having a voice and a choice can support the need for autonomy. Design activities may provide people with intellectual disabilities an autonomy-supportive environment, as users are encouraged to take control and make decisions based on their own experiences and preferences (Robb et al. 2021; Sanders and Stappers 2008). Indeed, research shows that design activities can lead to a sense of ownership for people with disabilities (Frauenberger, Good, and Alcorn 2012; Benton et al. 2012). Furthermore, design activities provide opportunities for people with intellectual disability to be recognised and listened to (Benton and Johnson 2015).

The second basic psychological need is the need for competence and refers to experiencing mastery and producing desired outcomes in a social environment (Deci and Ryan 2002). The need for competence leads people to seek challenges that are optimal for their abilities and skills, with the goal of maintaining and enhancing those skills. According to Deci and Ryan (2002), competence is not a skill or capability, but a felt sense of confidence in action or during an activity. Design activities can lead to the development of creative skills, teamwork, and social skills for people with disabilities (Benton et al. 2012; Benton and Johnson 2014). Design activities may also offer opportunities for mutual learning and outcomes that can be sustainable beyond the design project (Benton and Johnson 2015). Dent-Spargo (2018) states that design activities can facilitate a sense of competence when they challenge a person's capabilities. Indeed, previous studies have reported participants in technology design activities experiencing a sense of mastery, coping and competence (Safari, Wass, and Thygesen 2021). Moreover, design activities can be an opportunity for young adults and adults with intellectual disabilities to learn and increase competence (Safari, Wass, and Thygesen 2021). Bayor et al. (2021) state that a competency-based approach to co-design technologies with people with intellectual disabilities is empowering and provides room for enhancing skills.

The third basic psychological need is relatedness, described as the need to relate and connect to others (Deci and Ryan 2002). Relatedness is a feeling of caring for and belonging to others (Deci and Ryan 2002); it is a sense of security or unity. As people with intellectual disabilities are among the most socially excluded groups (Xu et al. 2014), design activities can provide an opportunity participate in new activities (Benton and Johnson 2015). Building a relationship with the participants to help them feel comfortable in design activities is essential (Piper et al. 2006). This is supported by Benton and Johnson (2015) who point out that design activities offer an opportunity to develop and practice social skills and teamwork. Furthermore, the environment should be facilitated to mediate social interaction where needed and enforce social rules (e.g. turn-taking and listening to others) (Benton et al. 2012). Internal, external, and contextual factors influence the fulfilment of autonomy, competence, and relatedness, which, when satisfied, lead to enhanced self-motivation (Ryan and Deci 2000).

3. Methods

3.1. Context

One should not artificially create a technology design team for the sole purpose of studying the effects of participation. Preferably, the research is conducted in parallel to other research activities performed by a design team (Guha, Druin, and Fails 2010). Thus, this study was conducted in collaboration with an action design research project (see Table 1 for overview of design activities). Action design research combines action research and design science research and allows researchers to solve a practice-inspired problem through the design and development of theory-ingrained artifacts (Sein et al. 2011). It outlines a 'method for generating prescriptive design knowledge through building and evaluating ensemble IT artifacts' (Sein et al. 2011, 4). This research approach stresses the need to involve the end-user in the design process to design and develop useful services (Sein et al. 2011) and was therefore a relevant context to explore motivation of participation.

The action design research project aimed to design and develop a self-reflective career tool to support the transition of people with intellectual disabilities from school into work (Figures 1 and 2). The concept consisted of six main parts: (1) login and user details, (2) mapping of skills and abilities, (3) mapping of interests, (4) goal setting, (5) progress evaluation, and (6) generating a CV. Through the design process, that served as a context for this paper, the prototype was designed to enable and inspire the user to map their skills, abilities, interests and needs (Figure 2). This included features such as mapping of interests based on swiping, grading of skills and abilities using smileys, goal setting and an overview of registered information. Drawing on TV and mobile games, the user is on a 'road' on which the user has to solve tasks in order to get to the next level (Figure 1 centre) and included aspects of gamification and positive feedback.

The action design research project and development of the self-reflective tool is iterative. However, the project is still ongoing, and the intention is to redesign

Table 1. Overview of design activities in the action design research project.

	Timeframe	Session (s) Duration	Focus of design activity	Techniques and involved prototypes
Group 1	Week 1	Session 1 2 hours	Introducing the aim of the project and testing the first paper prototype. Feedback on mapping information such as schools, favourite subjects, previous internships, work tasks and characteristics.	Paper prototype test (individual) Interviews, collaborative warm-up.
	Week 12	Session 2 1.5 hours	Feedback on the first prototype and insights on possible ways to visualise grading of skills and abilities, and interest mapping.	Paper prototype test (individual), digital prototype test (individual on a computer), card sorting techniques, group discussions.
	Week 19	Session 3 1.5 hours	Focusing on design elements and feedback on the use of icons and wording. Insight on ways to map adjustments needed in work settings.	Digital prototype test (individual on a smartphone), group discussions.
	Week 20	Session 4 1.5 hours	Feedback on design elements, and insight on user login and ways to map interests.	Digital prototype test (individual on a smartphone), group discussions.
	Week 23	Session 5 1.5 hours	Feedback on gamification elements and insight on motivation in games.	Testing of three different games, group discussion.
	Week 36	Session 6 1.5 hours	Following up session 5 and to gain insights on progress and rewards in games. Feedback on login and mapping (interests, skills and abilities) features.	Group discussions, digital prototype test (individual on a smartphone).
	Week 52	Session 7 2 hours	Usability test of the self-reflective tool in lab. Test of features including log in, mapping skills and abilities, interests, adjustments needed in work settings and an overview of registered information	Usability test of the latest version of the prototype (video recorded), interviews, SUS.
Group 2	Week 22	Session 1 1.5 hours	Introducing the aim of the project and giving feedback on design elements and the use of icons. Feedback on gamification elements, games and insight on motivation in games.	Testing of three different games, group discussion, card-sorting techniques.
	Week 23	Session 2 1.5 hours	Insight on ways to map and categorise interests.	Group discussions, digital prototype test (individual on a computer), card sorting techniques.
	Week36	Session 3 1 hour	Insight on progress and rewards in games. (This session was digital du to restrictions connected to the Covid-19 pandemic)	Group discussions on Zoom, adding information to digital whiteboard.

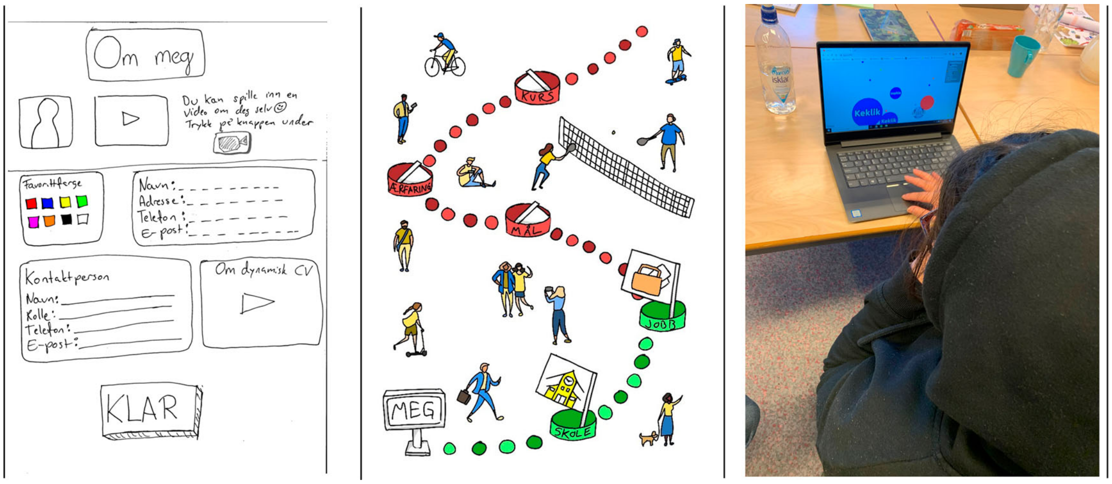


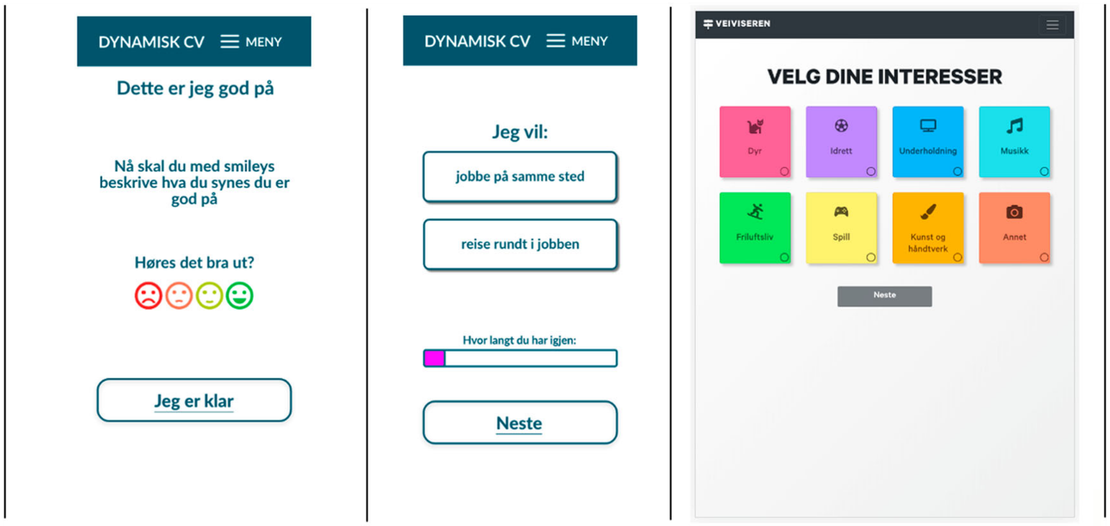
Figure 1. Left: Paper prototype used in design activities on mapping user details (session 1 and 3). Centre: Paper prototype sketch on visualising progress ('road') in the artifact (session 1 and 3). Right: Test of games in gamification workshop (session 5).

and evaluate the artifact in real settings. At the time of this study, features of the prototype had been tested on smartphones, tablets and computers and a usability test in a lab had been performed (Table 1). Figure 2 shows screencasts of the latest version of the prototype used in session 7 (Group 1).

The participants contributed to the designed technology by providing insights on possible ways to map abilities, skills, interests, and setting goals. The participants also contributed with insights on the need for customisable solutions, wording, figures, and colours. For instance, the participants provided insights on the need for and how to visualise how much of a task that is done. Other insights include the need for text to speech, using a smiley face rating and adjustment of font sizes. The participants also contributed with insight on how gamification elements and how rewards could be incorporated to motivate the users of the self-reflective tool. For instance, a suggestion that a trophy should appear whenever a task is completed.

3.2. Study design

A single-case embedded design was employed to investigate how participants in two different groups experience the fulfilment of the needs for autonomy, competence, and relatedness during technology design activities. Case study research provides the opportunity to combine multiple sources of evidence to in-depth investigate contemporary phenomena (the 'case') within



Dette er jeg god på

Nå skal du med smileys beskrive hva du synes du er god på

Høres det bra ut?

Jeg vil:

jobbe på samme sted

reise rundt i jobben

Hvor langt du har igjen:

VELG DINE INTERESSER

Dyr
Idrett
Underholdning
Musikk
Friluftsliv
Spill
Kunst og håndverk
Annet

Figure 2. Left: Version of mapping skills and abilities (Smiley faces combined with colours to grade personal skills and abilities). Centre: Version of mapping abilities and preferences (User chooses what he/she dislikes or prefers, the bar below visualises task progress). Left: Version of mapping interest (User chooses which interests he/she has).

real-world contexts, especially when the boundaries between the case and context may not be clear (Baxter and Jack 2008; Yin 2017). Moreover, in a case study the contextual conditions are most likely relevant to understanding the case (Yin 2017). According to Yin (2017) case study research is suitable to answer questions of 'how" and 'why' through the use of more than one data collection technique. We used a triangulation of techniques to gather data (Yin 2017), consisting of individual and group interviews, participant observations, and reflective notes. These techniques were selected since short and repeated qualitative interviews combined with participant observations are recommended in studies with people with intellectual disability (Kittelsaa 2014). Moreover, participant observations allow the researcher to experience the activity (Spradley 2016) and observe verbal and nonverbal communication (Fangen 2010; Kittelsaa 2014).

3.3. Participants

Participants were recruited through the action design research project, in which they were already involved (Figure 2). The project included young adults with intellectual disability from two different high schools. The participants attended two separate school classes (not integrated into the mainstream curriculum) and were divided into two groups throughout the design project and research process. All participants in the action design project were invited to take part in this study. In addition, a supplementary sample consisted of the designers, teachers, university students, and other support staff who worked closely with the young adults during the design process. None of the participants had prior experience in design activities. The participants are anonymised for name, gender, and school.

3.3.1. The first participant group

The first group participated in seven design activities that lasted between one to two hours each (Table 1). During the first activity (1), the aim of the project was introduced to the group and a first paper prototype of the tool was tested . In design activities 2–6, the group participated in prototype testing on paper, computer, and smartphone. Individual interviews were conducted after the test sessions. The final design activity (7) was a usability test in a usability lab at the University. During this design activity, participants tested the latest version of the prototype on a computer and two of the tests were video recorded. The session finished with a lunch and playing Nintendo Switch together. During tests, participants gave feedback on how elements such as gamification, interest mapping, use of icons, wording, mapping of skills and abilities, log in functions, and progress could be incorporated into the solution. All design activities except the final one took place in a classroom at a high school. All participants and support staff had lunch or a snack together before, during or after every design activity depending on the time of the activity. The following participants took part (Table 2):

3.3.2. The second participant group

The second group participated in three (1–3) design activities, which lasted one hour each. The aim of the project was introduced to the group during a lecture, and as a first step the design elements and the use of icons were discussed (1). During the second activity (2), the group participated in a prototype testing session on a computer. Participants gave feedback on mapping of interests. In the final design activity (3), the participants took part in a digital design activity using Zoom and Miro (due to the Covid-19 pandemic). The participants gave feedback on how elements of progress, gamification and rewards could be incorporated into the tool. All design activities took place in a classroom at the high school. The following participants took part (Table 3):

The following support staff participated in the design project and this study (Table 4):

The first and second author participated in all design activities with both groups. The first author participated as an observer and the second author participated as a facilitator. As some design techniques can draw upon cognitive and sensory abilities that may not be including when designing with people with intellectual disabilities, modifying the techniques beforehand and in situ facilitation was important throughout the design activities (Raman and French 2021). Therefore, the first and

Table 2. Overview of participants in the first participant group.

Name	Age	Gender	Number of design activities	Number of interviews	Relevant characteristics	Technology experience
Eric	18–22	Male	6 (1-4 and 6-7)	5 interviews	Can write and read. Prefers drawing and being creative.	Has a smartphone and computer. Plays computer games.
Hege	18–22	Female	7 (1-7)	6 interviews	Can write. Has trouble reading.	Has a smartphone and computer. Plays games on a console and used YouTube regularly.
Beate	18–22	Female	7 (1-7)	6 interviews	Can read and write. Well spoken.	Has a smartphone and computer. Active on social media.

Table 3. Overview of participants in the second participant group.

Name	Age	Gender	Number of design activities	Number of interviews	Relevant characteristics	Technology experience
Andreas	16–20	Male	3 (1-3)	2 interviews	Can read and write. Likes drawing.	Has a smartphone and computer. Plays games on the computer and uses YouTube.
Tom	16–20	Male	3 (1-3)	2 interviews	Can read and write. Does not like drawing.	Has a smartphone and computer. Plays games on a console and uses YouTube regularly.
Marit	16–20	Female	3 (1-3)	2 interviews *	Can read and write.	Has a smartphone and computer. Active on social media and uses YouTube regularly.
Andrine	16–20	Female	3 (1-3)	2 interviews *	Can read and write.	Has a smartphone and computer. Active on social media. Did not play games.

Note: *Did not wish to be recorded.

second authors were involved in planning, coordinating, structuring, and facilitating the sessions. During the design activities we provided explanations, clarified ideas and opinions, facilitated consensus, and enabled the design progress. The university students, who participated as support staff, were Bachelor students in IT and Information Systems at the University and were involved in the design activities to map and test how gamification elements could be incorporated in the self-reflection tool. The participants' teachers had a purely supportive and observational role throughout the design activities.

3.4. Data collection

The data collection took place where the design activities were held, either at the groups' school or at the university. All participants had the opportunity to have a proxy or teacher present during the interviews and design activities. During the interviews, participants were asked to evaluate their experience of the participation. The questions were open-ended to allow for in-depth exploration. For instance, participants were asked which activities they liked, in what ways, if any tasks were challenging, and how they could be improved. Sigstad and Garrels (2018) recommendations such as repeating, rephrasing questions, silence and encouraging prompts, and summarising responses were used to facilitate and improve the quality of the interviews. The interviews lasted for between 20 and 35 minutes each. The interviews were audio-recorded and later transcribed by the first author. For two participants who did not want to be recorded, handwritten notes were taken during the interviews. The observation of participants focused on descriptions of the context, their behaviour, nonverbal communication, and the interaction between facilitators and group members. A field note template was used to record and structure the field notes during and shortly after the observations.

Table 4. Overview of support staff.

Support staff	Role	Number of reflective notes	Participated in activities
Tor	Designer	4	Group 1, activity 1–4 & 6-7. Group 2, activity 3
Mina ¤	Teacher	5	Group 1, activity 1–7
Martin ¤	Teacher	3	Group 2, activity 1–3
Ole	Facilitator	2	Group 2, activity 1 & 2
Joakim	University student*	2	Group 1, activity 5. Group 2, activity 1
Jaran	University student*	1	Group 1, activity 5. Group 2, activity 1
Per	University student*	1	Group 2, activity 1
Marius	University student*	1	Group 2, activity 1

Note. *Role of a university student focusing on gamification ¤ The school teachers of the participants in The first and Second participant groups.

The researchers also collected reflective notes from participating teachers, facilitators, and the designer. These notes were sent via e-mail to the first author directly after the design activities. Reflective notes were used to collect information about the tasks during the workshops, and the teachers', facilitators', and designers' perceptions and experiences of the design activities.

3.5. Data analysis

Thematic analysis (Braun and Clarke 2006) was used to analyse individual and group interviews, notes from the participant observations, and reflective notes from the supplementary sample. Thematic analysis supported flexibility and assisted to identify, organise, and report patterns in the data (Braun and Clarke 2006). It also facilitates a rich description of the data (Braun and Clarke 2006). In this study, the data analysis was first conducted through a data-driven inductive process, and then through a deductive process. The analysis consisted of six phases as per Braun and Clarke's (2006) recommendations. Firstly, the recordings were listened to repeatedly, and then transcribed by the first author. The transcriptions were read and re-read several times to ensure familiarisation, whilst noting down initial thoughts. The data, including interview transcripts, field notes and reflective notes, was then coded, with a data-driven approach based on the participants' descriptions of experiences during participation in the design activities. The codes were discussed by all authors to reach a consensus, and consequently themes were developed. The themes were then reviewed and discussed by the authors. Themes were deductively analysed with a focus on the theoretical categories of competence, autonomy, and relatedness. The participants were not involved on the academic side of the research process (e.g. verification of analysis and findings). An example of a thematic analysis is presented (Table 5).

3.6. Rigour and quality

The trustworthiness and quality of case studies can be assessed through construct validity, internal validity, external validity, and reliability (Yin 2017). Construct validity, which corresponds closely to confirmability in qualitative research (Riege 2003), involves identifying the correct operational measures for the concepts being investigated (Yin 2017). To enhance construct validity, we have used multiple sources of evidence and triangulated data collection methods against one another. To establish a chain of evidence, interviews were recorded, and field notes and observations were documented and stored.

Internal validity, which is the parallel construct to credibility (Riege 2003), seeks to establish a causal relationship (Yin 2017). To enhance internal validity, we present thick descriptions and information drawn from the interviews with the participants. Other measures such as triangulation and the longitudinal manner of participant observations were taken to ensure internal validity. External validity, which is similar to transferability in qualitative research or generalisation in quantitative research (Riege 2003), involves assessing whether and how the findings in the case study are generalisable beyond the immediate study through analytical generalisation (Yin 2017). In the current study, external validity is enhanced through analytic generalisation and the use of Ryan and Deci's Self-determination Theory. The scope, context and results are described in detail to allow readers to assess the potential of transferability to other or similar settings. Reliability, which is similar to the notion of dependability (Riege 2003), involves showing that the study can be repeated with the same results and that the procedures used in the case study are consistent (Yin 2017). In this study, reliability is enhanced by documenting procedures and maintaining a chain of evidence during the research process. As recommended by Yin (2017) the data collected was effectively organised in a case study database. Key recourses such as notes, audio from interviews, field notes are all anonymised and saved in a storage cloud provided by the University and the data management software programme NVivo was used to organise the data during analysis. Moreover, all the authors continually communicated about methodological decisions thorough the research process to safeguard against biases.

3.7. Ethical considerations

The study's ethical approval was provided by the Norwegian Centre for Research Data (648227) and the Faculty's Ethical Committee at the University. All participants received and signed an adapted voluntary informed consent form. In addition, their parents or guardians were informed and asked to consent. The consent form was designed in a manner that allowed the participants to choose whether they wanted to be recorded. They received easy-to-read information about the study and the purpose of the project. They were informed about anonymity and that they could withdraw at any point, even after the interviews. Throughout the study, the researchers and teachers looked for signs that could indicate that the young adults no longer wanted to participate. Parents or guardians were also asked to observe and inform the researchers of indications that the young adults did not wish to participate. The support staff also received and signed a consent form and could withdraw at any point. During the introduction of the project the researchers talked about why the participants were asked to be part of the project. We talked about how a design process, informed by user needs, could enhance the design and that technology development is an iterative process where difficulties with the design can be encountered. Throughout the entire project we had a dialogue with the participants' proxies and other

Table 5. Examples of a thematic analysis.

Data Extract	Coded for	Main theme	Category
'In the beginning I did not know what to do, […] But after a while I learned how to navigate (using the app). I now know how to go back to the overview and backwards to see what I answered'.	Learning new skills, knowledge of technology.	Enhancing skills and knowledge.	Competence
'By participating and being part of this, I can contribute with my ideas help create the app. And it may then help others like me who may need assistance in getting work. […] Instead of just sitting at home'.	Contribute to important technology, help others (Meaningful participation).	Sense of meaningfulness.	Relatedness

stakeholders to ensure that the expectations of the design process and design activities were realistic.

The design activities took place during school hours as the self-reflective tool is planned to be used in school hours as part of the mapping process in the transition from school to work. In addition, the design sessions were described as a positive addition to the ongoing curriculum by the involved teachers. The workshops were not set up after school due to challenges with transport and collision with leisure activities. As it is important that participants are comfortable and relaxed during design activities it is recommended that they take place in locations that are familiar to the participants (e.g. at their homes or schools) (Robb et al. 2021).

4. Results

The inductive data analysis resulted in six themes describing what motivates participation in a technology design process. The themes were deductively analysed, and five of the six themes were categorised within the three basic psychological needs categories in Ryan and Deci's (2002) Self-Determination Theory. *Influencing the designed technology and the design activity* was identified within the category of autonomy. Within the competence category, *enhancing skills and knowledge,* and *a sense of self-efficacy* were identified. Furthermore, *developing social relationships* and a *sense of meaningfulness* were identified within the relatedness category. Lastly, a *sense of enjoyment* was categorised as an additional theme outside of the three categories of psychological needs of the Self-Determination Theory.

4.1. Autonomy

4.1.1. Influencing the designed technology and the design activity

The participants described that it was important for them to influence both the designed technology and the design activities. Moreover, they described that it was important *how* their contribution was incorporated in the technology design. They described situations where they had been actively taking part in decision-making, and later seen that their opinions had been included in the design. The following example illustrated the importance of involvement in decision making:

> Hege: I gave feedback. For example, I gave feedback about a button on the app. They had one button, but I suggested to change that and have two.
>
> Researcher: Great, so were you listened to [by the researchers]?
>
> Hege: Yeah, they listened to what I had to say, and then they tried to include my suggestion in the app. That is what they usually do, they get our suggestions and then include them in the app, and then we try and test the app.
>
> Researcher: So, can you remember if any of your suggestions have been included in the app?
>
> Hege: Actually, I have given a suggestion about smiley faces. And the suggestion was included, and we have even tested it on the app. I really hope that the smileys are included in the app if it gets released.
>
> Researcher: So, it's important for you that your suggestions are included?
>
> […] Hege: Yes.
>
> Researcher: And if they are to be excluded?
>
> Hege: Well, it would be kind of sad because we have participated many times and have given a lot of feedback and suggestions. If we participate, we want to be listened to. That's why we participated. If you don't listen to us, then you can just make the app yourselves.

The importance of influencing the technology was elaborated on by Eric. When asked about important factors during participation, he stated: 'It was important that our ideas were included and that the people making the apps let us decide. It means a lot'. As illustrated here, the participants felt acknowledged because they were listened to.

The theme of influencing the design was also identified by teachers in the reflective notes. Mina wrote,

> The students liked participating, and they were very interested in the process and how far you have gotten in developing [their ideas in] the app. […] I can see that they are very proud when they have an idea and that it [idea] is written down

Tor confirmed the importance of influencing the design. He wrote, 'it is important that the students' experience being seen and taken seriously. That they feel like they can influence the development of something they can use'.

The participants mentioned the importance of being able to influence the design activity, for instance during design activity workshops. When asked about the decision making, Eric stated,

> I think we have been given the opportunity to make decisions. I remember we had to draw or something like that. Or actually, we were supposed to write, but I wanted to draw instead. And everybody was fine with it. Not everyone is usually fine with us drawing instead of writing. It is important that people respect my choice when I want to work differently. As long as I try, it should be fine.

He later elaborated: ‘It is difficult for me to write, and I get to contribute more if I can draw. It is different because at school I have to write. Here, I can draw if I prefer, and that’s why I enjoy participating here’.

4.2. Competence

4.2.1. Enhancing skills and knowledge

While the design activities had predictable and known tasks such as writing and collaborating, the participants mentioned that they also learned new skills and enhanced their knowledge. For example, when asked if they had learned new skills, Hege stated,

> You learn a lot (when participating in design). It’s like school. You learn a lot in both places. You learn a lot of new things, and you get help when you need it in both places. But it’s a little more interesting in design activities. Because at school you have classes and subjects and all that. But here it’s all about what interests you, and you are allowed to do more as you wish.

The students described using their skills in different ways during the design activities. However, they also described learning new skills such as using technology (tablet), how to give feedback, and how to search online. This is illustrated by the following example. When asked about skills, Beate responded, ‘I have learnt how to express myself on the Internet. Also, I have learnt how to navigate in apps and how to use the suggestions (i.e. interests) that come up’. This quote was given after a design activity in which the participants tested adding information and mapping interests in the prototype of the tool.

The participants described enhanced knowledge in two main categories: knowledge about technology and knowledge about technology design processes. Speaking of enhanced knowledge about technology, Andreas said, ‘participating in these workshops and activities have made me realise how difficult it is to design technology. And now I know more about apps and how they work on iPhones and iPads’. The participants described gaining knowledge about the technology design process. When asked about the process, Marit stated, ‘I already use many apps on my phone and play many games at home. But I did not know how they were designed. But now I know more of how apps and such things are made’.

4.2.2. Sense of self-efficacy

During the design activities, participants used many of the same skills as in school. According to them, this led to feelings of predictability and security. When asked about what the design activities consisted of, Andreas stated, ‘Well, we mostly do usual things, like writing down ideas, reading instructions, brainstorming and discussing our ideas. So, it is not that difficult to participate’. Moreover, they described that participating in design activities led to feelings of confidence. As illustrated by Beate, ‘sometimes you do not know if your idea is good or not. But here you learn that often even if you thought your idea was bad, it might actually be really good’. Confidence was mentioned in reflective notes gathered from teachers that participated in the design sessions. During the project, it was observed that some participants seemed bored and not engaged. One example was a student who did not wish to participate in parts of the workshops or activities. However, when activities were in line with his interests, such as the gamification workshop, he was engaged and gave feedback on both the tested games and other games he had tried during leisure activities. For instance, Joakim, a university student, stated: ‘They were all very active in giving feedback and were interested in playing and trying the games we tested’ and the teacher, Martin reflected on the same situation: ‘One of the students was very engaged. It surprised me that he was involved in some of the tasks. He usually expresses himself as little as possible in class’.

However, the participants also described a sense of self-efficacy (ability to cope) as the design activities made them feel competent, and they were viewed as experts throughout the design activities. Eric stated, ‘It was important that when we had ideas, we were listened to. You never said that the idea or suggestion was bad. And that made me feel good about the ideas I had’. Also, the data indicated that it was important that they were helped when they did not master or understand given tasks. As illustrated by the following example from the interview with Eric,

> Researcher: During the activities, did you experience situations you found difficult?
>
> Eric: Yes, sometimes there were things that were difficult.
>
> Researcher: Do you have an example?
>
> Eric: Yes, it was, for example, when we were playing Mario cart and eating, then there was a question I did not understand [on the consent form]. Then a researcher came and just explained to me what it was about. [Because] I have some difficulty understanding what I read. It is a lot easier when people read to me. If I do not understand, they give an example. And then it’s like … ok then I understand what they meant.
>
> Researcher: What do you think about that?
>
> Eric: It is important. And that is why I liked it here because I could always get help when I needed or did not understand.

Participants described that taking part in the design activities was daunting at first, but as they learned about the design activities and got to know the designer and researchers, it became fun. For instance, Eric stated,

> At first it was daunting when we were asked to participate. I did not know much about design. So, I just jumped into it. But after the first time, I realized that everything went well, and it's really just fun to participate

This was confirmed in reflective notes gathered from teachers that participated in the design sessions. For instance, Mina wrote, 'I think that the humour and the informal setting in the workshops contribute to creating an environment where the students are relaxed. They then dare to talk and present their opinions and desires'.

4.3. Relatedness

4.3.1. Developing social relationships

Participation in the design activities led to the development of relationships between the participants, the researchers, and the design team. Throughout the design process, participants built social relationships with researchers and the designer through social interaction. When asked about the social part of design activities Eric said, 'We know you [the researchers] well now because you have been here every time we have had design activities. I think it would be very strange if new people came instead of you. And we also have lunch and talk about other things like games with you'. This corresponds with the observations during the design sessions, where participants and researchers had conversations about topics not related to the design workshops, such as leisure activities. In addition, when a researcher or designer was absent, participants reacted with non-verbal cues such as shaking of the head and shoulder shrugging and asked why.

The participants described that the social interactions in the design activities were different from their interactions in other settings. The social relationships that had been built over time led to confidence and trust, which subsequently led to them expressing themselves more freely. They expressed that they experienced the relationship with the researchers as collaborative. For instance, when asked about collaboration, Beate said, 'if new researchers came, it would be difficult to communicate at first. I think … some of us have some things we struggle with, and when you are here over time, you know a little more about it than others'.

Participants also developed social relationships amongst each other. The social relationship between the participants led to collaboration and the opportunity to elaborate on each other's ideas. Furthermore, they expressed that it was important to participate as a group and not individually with researchers. When asked about the other participants, Tom stated, 'it is important that the others [students] also are here. Because we can work together and build upon each other's ideas. […] I think I like working with them more than I would alone'. It was observed that the students would give each other a 'thumbs up' in encouragement and clap for each other in appreciation during the design activities.

4.3.2. Sense of meaningfulness

The participants described that an essential element of participation was that it was meaningful. This was characterised by contributing to the design of technology that has the potential of helping other people with intellectual disabilities in the community. This is illustrated by Hege, when asked if she felt that participating was important, she stated,

> Yes, because if you struggle with something in your everyday life, maybe the app we are creating can help you. Many people like me struggle with writing [a cv], and if they use the app it may help them. It can make it easier for people

This suggests that participation in design activities led to feelings of contributing to a larger community and society.

The participants viewed the technology as something they could use too; not just others. This is illustrated by Andrine, who stated, 'I think it is important to participate because I think that it [the app] is something that I can use myself. So, I hope that the app gets developed and I can use it when applying for a job'.

4.4. Sense of enjoyment

The participants described their participation in the design activities as enjoyable. During the design activities, there was laughter, engagement, and shared lunch. It was often observed that participants and researchers were engaging in small talk and banter during the design activities and breaks. Non-verbal cues such as smiling laughing were observed. The participants described that elements connected to their interests and preferences were important for their enjoyment. For instance, when Andreas was asked about the length of the design activity, he stated, 'I wouldn't mind if we used more time because this is more fun than school classes'. He then elaborated, 'It is more exciting here. It is more fun to work with technology and creating the app than to have math class'.

Furthermore, the tasks carried out during the design activities were also described as enjoyable. For instance, after the fifth design activity, which centred on gamification, Beate said, ‘well, the most exciting part of the day was getting to try many different games’. She elaborated, ‘I like playing games at home, so it fits me well to try games here as well’. This was confirmed by the reflective notes from the teacher who participated. Mina wrote, ‘the part about games was of course extra motivation for the students. It was clear that the students had a lot to contribute with in that part [of the design activity]’. She also elaborated, ‘[…] I think participation in the design activity was enjoyable and engaging for the students’. Participants also mentioned that activities during breaks and having lunch with the researchers and the designer made the design activities more enjoyable. As illustrated by Hege, ‘it was fun participating today, we got to test the app, and have free lunch as well’.

While enjoyment was prominent during the design activities, boredom and non-engagement did occur. It was observed that a participant did not wish to participate in some activities. For instance, Tom was observed pulling up his jumper over his face when asked for suggestions on how to map interests. Moreover, there were observations of lack of interest and losing focus (e.g. turning away from the task, talking to others about other subjects, observing others outside) when lacking immediate assistance during certain activities.

5. Discussion

Studies have highlighted the importance of user involvement of people with intellectual disabilities in design activities (e.g. Benton and Johnson 2015; Robb et al. 2021). However, there is a lack of research on motivation (Hansen and Iversen 2013) and participation benefits (Benton and Johnson 2015) in design activities. Furthermore, few studies have specifically focused on people with intellectual disabilities (Raman and French 2021). This study aimed to explore what motivates young adults with intellectual disabilities to participate in technology design activities. In particular, we investigated how the participants’ experiences relate to the fulfilment of autonomy, competence, and relatedness during participation. Our study suggests that *influencing the designed technology and the design activity*, *enhancing skills and knowledge*, *experiencing a sense of self-efficacy*, *developing social relationships*, and *experiencing a sense of meaningfulness* can lead to the fulfilment of the need for autonomy, competence, and relatedness. Our findings show that these elements are important motivational factors in design activity participation for young adults with intellectual disabilities. In addition, *enjoying the activities* seems motivating.

5.1. Importance of autonomy

User involvement in design processes is essential as people with intellectual disabilities are best situated to communicate their needs and suggest how to improve technological solutions. Moreover, meaningfully involving the stakeholders in the design activities reduces the possibility of non-use of technology (Ghanouni et al. 2020). Providing participants with real power during design processes (Robb et al. 2021) is also in line with the wish of individuals with disabilities, who have repeatedly stated that they want self-determination and control over their lives (Stancliffe 2001). The findings in this study emphasise the significance of *influencing the designed technology and the design activities*. This ability to influence is connected to autonomy, which occurs when people feel that they have a choice and can control activities (Niemiec and Ryan 2009). When the need for autonomy is satisfied, people are more likely to engage and persist with activities. While people with intellectual disabilities often lack autonomy (Petner-Arrey and Copeland 2015), this study suggests that when participants have the opportunity to influence a design activity and contribute to creating a solution for a problem, participation in design processes can lead to autonomy. The possibilities of shared decision-making, contribution of experiences, and engagement during design activities (Robb et al. 2021) make autonomy a critical concept to consider in design activities with people with intellectual disability.

The participating members of the study group reported receiving support and guidance throughout the design activities as important. Despite depending on help and facilitation during design activities, they experienced autonomy. A possible explanation is that people with intellectual disabilities experience few opportunities for autonomy and may not feel inclined or empowered to influence the setting or environment (Wehmeyer and Shogren 2017). An opportunity to influence the design process and the technology provides a valuable opportunity for the development of a sense of autonomy even though the participants need support and guidance. As supported by Frielink, Schuengel, and Embregts (2018), this study shows that people can depend and rely on other people for help and still experience autonomy. Still, according to Chinn and Pelletier (2020), it is important that people with intellectual disabilities exercise greater authority and influence in decision making in design processes.

Moreover, in line with our study, participants with intellectual disabilities should not be limited to certain roles having limited influence on the final solution (Chinn and Pelletier 2020). Our findings suggest that people with intellectual disabilities can be more motivated to participate in design activities if they see that their contribution is viewed and considered valuable by the design team and the research team.

While autonomy in technology design activities with people with intellectual disabilities is important, tensions between facilitators or designers and the participants can occur. Action design research stresses the principle of mutually influential roles among the different participants (Sein et al. 2011). Researchers and facilitators may offer and bring theoretical knowledge and technological advances to the process, and participants bring practical knowledge and lived experiences. These contributions may be complementary, or in some cases compete with one another (Sein et al. 2011). In this study, our findings suggest that it is important to reflect and collaborate with the participants in decision making as not being listened to can lead to diminished motivation. While having a voice and a choice can support the need for autonomy (Niemiec and Ryan 2009), it does not guarantee that the participant can influence the design activity or the designed technology. For instance, participants with better communication or writing abilities may have higher chances of influencing the decision making in the design process and the design outcome. Therefore, as suggested by earlier literature (Safari, Wass, and Thygesen 2021), providing an overview of the importance of the participants' involvement and suggestions without overcommitting is important to avoid disappointment. Tensions regarding excluded ideas and expectations to the designed technology can also be managed by focusing on the design process as a whole, rather than solely on the final solution (Safari, Wass, and Thygesen 2021).

The results show that it was experienced as *meaningful* to contribute to a technology that may help the participants themselves and other people in the community. The sense of meaningfulness described by the participants may provide a sense of relatedness as the participants describe contributing to a tool that can help others in the community. This finding is in line with Deci and Ryan (2002), who refer to relatedness as having a sense of belongingness with other individuals and being part of a community. Relatedness can therefore be understood as a sense of belonging both at a micro-level and a macro-level. Participation in design activities may fulfil the need for relatedness at a macro-level as the participants experience contributing to a larger community. Our findings suggest, when possible, informing the participants about why they are invited to participate, and what they are contributing to, can give the participants a sense of relatedness and ownership. In turn, such a sense of ownership to the process and the solution can motivate participants in design activities (van Rijn and Stappers 2008).

5.2. Facilitation and participation over time

The findings in this study suggest that participation in design activities over time was influential in the fulfilment of several psychological needs. For instance, participants stated that collaborating with the same designers and other participants over time was essential in the development of social relationships. Repeated interactions and frequent contact with the same people are considered important in forming social bonds and in fostering a sense of belonging (Baumeister, Leary, and Steinberg 1995). The present study raises the possibility that the participants were motivated to take part in the design activities as the activities facilitated for and offered lasting, frequent, and pleasant social interactions over time. The *development of social relationships* was an influential motivating factor for participation in design activities. Frielink, Schuengel, and Embregts (2018) state that the need for relatedness refers to feeling connected and taking, and being taken, care of by other people. Some interpersonal activities require a greater need for relatedness in order to maintain intrinsic motivation, as opposed to solitary activities (Deci and Ryan 2002). One can argue that design activities with people with intellectual disability is a context that may require the fulfilment of the need for relatedness to maintain intrinsic motivation.

In the current study, participating with co-students, teachers, and facilitators throughout design activities was described as more fun than participating alone. Indeed, people with intellectual disabilities are among the most socially excluded groups (Xu et al. 2014) and participate less in social and leisure activities than people without disabilities (Badia et al. 2013). It is possible that the participants were motivated to participate due to the opportunity to develop new social relationships and social skills. As a socially excluded group (Xu et al. 2014), socialising with new people outside their primary and secondary social groups over time may be a motivating factor. While social benefits such as making new friends have been reported as an outcome in design activities (Raman and French 2021), our study suggests that social relationships led to confidence and trust, which subsequently led to more outgoing behaviour and expressing themselves more freely.

In terms of influencing the design and design activities, the duration of the project may have influenced the participants' fulfilment of the need for autonomy. The participants witnessed their ideas being incorporated into the designed technology as opposed to if they had only participated once or been presented to the solution without providing input. In line with earlier studies, genuine participation and empowering the participants in creativity and decision-making is essential (Raman and French 2021) and can motivate the participants to participate further.

The participants described a *sense of self-efficacy* as the design activities made them feel competent and confident. Ryan and Deci (2002) state that competence is not necessarily an attained skill or capability, but rather a sense of confidence in one's own mastery, which is, in turn, is essential for motivation. Our study suggests that the participants were motivated to participate over a period of time because they felt able to cope with the tasks given and encouraged by the positive feedback throughout the design activities. Consequently, the design activities allowed the participants to use their skills and enhance their capabilities through involvement and engagement. Moreover, in line with our findings, earlier studies on co-designing technologies with people with intellectual disabilities have stressed the importance of incorporating the competencies of the participants (representative practical skills from their participation in life activities) (Bayor et al. 2021). On the other hand, while a competency-based design approach can empower and enhance the skills of people with intellectual disabilities (Bayor et al. 2021), it can also cause tensions between the participants and the designers or facilitators. The process of mapping competencies, abilities and need for additional support when tailoring the design activities can be time-consuming and demanding for designers and facilitators. However, our findings suggest that the sense of self-efficacy that occurs when participants can use their skills and abilities can lead to engagement and motivation. This accords with Niemiec and Ryan (2009), who state that a central notion in participation is that people engage with and value the activities they understand and master. Indeed, the participants expressed that it was necessary to have support when unable to master a given task. This finding suggests that it is vital to find the right match between the tasks and the participants' abilities as experiences of incompetence or failure can lead to lack of confidence and thereafter less motivation.

However, design activities should also challenge, test, and expand the participants' capabilities (Dent-Spargo 2018). While the tasks during the design activities were predictable and known, the design activities were situated in a different setting with different requirements than the participants were used to. Still, we found that in design activities with people with intellectual disabilities, it can be difficult to both challenge the participants and ensure predictability. However, working longitudinally with few participants led to an in-depth understanding, which contributed to necessary knowledge on facilitating mastery while also challenging the participants. For instance, some participants needed more time to process before answering or partaking tasks. Therefore, with this knowledge of the participants' use of time, we were able to facilitate and not rush the participant during decision-making or during creative thinking. Moreover, we were able to differentiate when the participant needed facilitation (e.g. support or explanation) or simplification of a task and when the participant was thinking or visualising. The knowledge on facilitating mastery while challenging the participants is in line with the conditions for flow, which is the sweet spot between not being too easy, as it then becomes boring, and not being too hard, as it might cause frustration or anxiety (Nakamura and Csikszentmihalyi 2009). When in flow, a person is in an intrinsically optimal state and is intensely engaged in an activity while excluding all other thoughts (Nakamura and Csikszentmihalyi 2009). While design activities with people with disabilities are often limited to one-off sessions, our study suggests that participation over time may profoundly enhance skills and knowledge and foster motivation through the fulfilment of the need for competence.

5.3. The importance of enjoyment

Our study indicates that it is crucial to ensure that design activities are enjoyable, as they can, in turn, influence the motivation and level of engagement. While participation was daunting at first, the participants described *enjoying the design activities* after a while. For instance, our participants reported enjoying the activities when experimenting with new tasks, testing technology, and in interactions with others. The participants described that the design activities led to a sense of enjoyment and matched their interests and preferences, which is, according to Benton and Johnson (2015), the minimum positive outcome such activities should have. Having fun is important to people with disabilities, but this tends to be overlooked (Brereton et al. 2015).

One can argue that the sense of enjoyment described by the participants is connected to the fulfilment of the three basic psychological needs (autonomy, competence, and relatedness). Earlier studies have reported a relation between the satisfaction of basic psychological needs and enjoyment (e.g. Ryan, Rigby, and Przybylski 2006; Tamborini et al. 2010). While defining enjoyment as the fulfilment of the three basic psychological needs is incomplete – autonomy, competence and relatedness have been found to serve as a predictor of enjoyment (Tamborini et al. 2010). In line with Schepers, Dreessen, and Zaman (2018), enjoyment in design activities can be a direct user gain and also relate to additional gains, such as stepping out of the comfort zone and developing a sense of self-esteem. Our study suggests that creating an enjoyable experience, and fulfilling the need for autonomy, competence and relatedness, may be essential for motivating participants with intellectual disabilities in design activities. In addition, in terms of ethical considerations, enjoying the design activities is a central factor as ensuring beneficence is important when designing with people with intellectual disabilities.

5.4. Limitations

This study has limitations that need to be considered. The current study has a limited number of participants. However, the number of participants and interviews is deemed sufficient for a small project (Braun and Clarke 2013) and were longitudinal. Moreover, it is essential to acknowledge that people with intellectual disabilities are not a homogenous group and that the design project and activities were tailored to participants with certain abilities and age range. Therefore, the participants' capabilities, age, interests and technology experience may have contributed to their experiences and motivation to participate. The second author participated in the design activities as a facilitator, and the first author as an observer in all the design activities. While the roles of the researchers did provide information that would otherwise be inaccessible, it may also have an impact on the results of this study. The context of this study, including the design activities and the designed technology may also have contributed to the experiences and motivation to participate. The current study explored the participants' motivation of participation in technology design activities, a possible limitation is that we did not compare these motivational aspects to other settings in their daily life. Lastly, a possible limitation to our study is that we did not involve the participants on the academic side of the research process (e.g. verification of analysis and findings).

5.5. Implications for practice

We suggest that given the importance of in-depth knowledge on the participants' abilities and capability to facilitate the fulfilment of the basic psychological needs, it is vital that researchers and designers invest time, are interested in forming a relationship with the participants on their own terms, and understand their needs throughout participation. Consequently, participation in design activities should contribute to fulfilling the Convention on the Rights of Persons with Disabilities (2007), proclaiming people's fundamental right to make their own choices, participate and being included. Lastly, while our study indicates that design activities should be facilitated to match the capabilities of the participants, it also indicates that it is necessary to challenge the participants. As organising and conducting design activities with people with intellectual disabilities can be time-consuming, we suggest contextual preparation and emphasising on in-situation facilitation rather than one size fits all approaches. Moreover, having a competency-based design approach in both design activities and designed technology (Bayor et al. 2021) may be less time-consuming.

6. Conclusions

This case study shows that competence, autonomy, and relatedness are important motivational factors for participation in technology design activities for young adults with intellectual disabilities. Findings in this study show that several of the factors that may lead to the fulfilment of the basic psychological needs were initiated because the participants participated over a period of time. As facilitation throughout participation is linked with in-depth knowledge and understanding of the participants' needs, our study suggests that participation in a longitudinal manner may be particularly important for people with intellectual disabilities. This study suggests that to motivate people with intellectual disabilities in design activities, designers and practitioners should implement strategies that aim to improve and fulfil the persons' basic psychological needs of autonomy, competence, and relatedness. Our findings show that influencing the designed technology and the design activity, enhancing skills and knowledge, experiencing a sense of self-efficacy, developing social relationships, and experiencing a sense of meaningfulness can contribute to motivation. Moreover, enjoying the activities was also identified as an essential motivational factor in design activities. There is a need for further research on motivation in different design contexts, different populations, and both on longitudinal and short-term design activities. Moreover, more research on barriers that prevent the fulfilment of autonomy, competence and relatedness in technology design activities is needed.

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Authors' contributions

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

ORCID

Mugula Chris Safari http://orcid.org/0000-0002-8691-6022
Sofie Wass http://orcid.org/0000-0003-3052-6014
Elin Thygesen http://orcid.org/0000-0003-3242-8864

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Article

Photovoice—Towards Engaging and Empowering People with Intellectual Disabilities in Innovation

Sofie Wass [1,*] and Mugula Chris Safari [2]

1 Centre for eHealth, University of Agder, 4879 Grimstad, Norway
2 Department of Psychosocial Health, University of Agder, 4879 Grimstad, Norway; chris.safari@uia.no
* Correspondence: sofie.wass@uia.no

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Abstract: E-health and welfare technology offer new ways to support health and social care delivery. While initiatives are made to engage disadvantaged user groups in innovation, people with intellectual disabilities tend to be excluded from design activities. This is a concern as this group can benefit from the use of assistive technology. However, it can be time-consuming and challenging to involve end-users in the design of technology. This calls for processes that are creative, empowering and that facilitate user involvement. In this study, we report and reflect on the process of using photovoice to understand user needs and to empower participants with intellectual disability in an innovation process. Nine persons with intellectual disability participated in photovoice to identify user needs connected to the design of assistive technology. The findings in our study suggest that the use of photovoice can contribute to the sharing of contextual and individual needs and an empowerment process that includes coping, self-determination and ownership. Photovoice can be a tool to reduce or remove some of the challenges that are faced when identifying user needs and is a way to strengthen the individual's capacity to cope with the demands of participating in an innovation process.

Keywords: photovoice; intellectual disability; assistive technology; innovation

1. Introduction

It is well recognized that user involvement is important for the design, impact and adoption of technology, both in healthcare and social care [1]. However, it is time-consuming and challenging to involve end-users in design processes [2]. For those living with cognitive disabilities such as intellectual disabilities, this can be especially challenging. Earlier research has highlighted that intellectual disability characteristics may create barriers and limitations when involving this population in design activities [3]. Although these characteristics often vary in different individuals with intellectual disability, there are some difficulties that people with intellectual disabilities are likely to encounter. Characteristics such as communicative difficulties, difficulties with abstract concepts, understanding turn-taking and difficulties expressing themselves adequately may pose challenges during design activities [4,5]. While initiatives have been made to include people with intellectual disabilities in research [6], this group of users tends to be excluded from design activities [7]. Thus, their needs are not included in the design process or merely communicated by people close to them [7]. This is a concern as people with intellectual disabilities can benefit greatly from the use of assistive technology [8]. As highlighted in previous research, this is distressing as it can lead to even more inequalities between advantaged and disadvantaged users of technology if needs are not met or taken for granted [9,10].

The primary rationale for involving users in innovation and design is twofold: to increase system satisfaction and to give a voice and empower future users [1,2]. Photovoice is such a research method where participants are actively involved in the research process [11]. As described by Booth and Booth [12] (p. 431), "photovoice uses photography as a means of accessing other people's worlds and making those worlds accessible to others". The method was developed by Wang and Burris [13,14] and was traditionally used to conduct participatory needs assessments and evaluations in health promotion and education. In photovoice, the participants take photographs that document various aspects of their lives, which are later used as input in qualitative interviews to encourage reflections on feelings and experiences [14,15]. As a technique, photovoice aims to enable participants to find personal strength and project a vision of their lives that may educate others to better understand their reality. Photovoice is a part of a growing trend in the use of participatory research approaches with people with intellectual disabilities as it can offer participants the opportunity to engage in research [11]. Still, photovoice requires researchers to share power and control [11] and facilitate the process for useful involvement of users.

In this study, we contribute to the understanding of user involvement of vulnerable user groups in the design of assistive technology. The aim of our study is to report and reflect on the process of using photovoice to understand user needs and to empower participants with intellectual disability in an innovation process. More specifically, we aim to answer the following research question: how can photovoice empower participants with intellectual disabilities when participating in an innovation process?

1.1. Intellectual Disability

Intellectual developmental disability is defined as "a group of developmental conditions characterized by significant impairment of cognitive functions, which are associated with limitations of learning, adaptive behavior, and skills" [16] (p. 177). The primary descriptors of intellectual disability are a marked impairment of core cognitive functions, which lead to limitations in the development of knowledge, reasoning and symbolic representations. People with intellectual disabilities have difficulties in verbal comprehension and working speed, as well as working memory. Intellectual disability is classified into four main clinical severity subcategories, mild, moderate, severe and profound intellectual disability, in addition to the provisional category of unspecified intellectual disability [16]. Intellectual disability is typically operationalized as scoring more than two standard deviations below the population mean on an intelligence test [17,18] and it is often a lifelong health condition that originates before age 18 [16]. Approximately 1–2% of the world's population has an intellectual disability and it is predicted that this population will grow [19].

Historically, the concept of disability has been defined by the medical and social model of disability. The medical model, also referred to as the deficit or individual model of disability, views the individual as a patient [20]. This model places the problem or impairment with the individual, meaning that the person must be treated or rehabilitated as far as possible [21]. This view makes disability a technical problem rather than a social one. However, the medical model is usually mentioned in a critical light, with little discussion devoted to defending the model [20]. The social model of disability, which calls for social and structural change, places the problem with society [21]. In contrast to the medical model, the social model of disability emphasizes that social and structural change must be made to enable full participation for people with disabilities [20,22].

In recent years, a third perspective on disabilities has emerged: the Nordic relational model, also known as the Scandinavian model and the Gap model. According to this model, disability occurs when there is a mismatch between the individuals' abilities and the demands from the context or the society [22]. Within the gap model, disabilities may be reduced or removed by either changing the environment or strengthening the individual, or both [21]. However, in recent years, the role of critical disability studies has grown and disability research seems to be shifting towards posthuman approaches to disability [23]. There is also an ongoing development of the theorization of learning disability to provide more inclusive approaches [24].

1.2. Empowerment

Empowerment is a concept that incorporates issues of control, awareness and participation [25]. It is, therefore, closely connected to the goals of user involvement and photovoice [11,13,14].

Empowerment can be understood both as a process and as an outcome of such a process. Zimmerman and Warschausky [25] provide a framework for empowerment which includes three dimensions: values, processes and outcomes that all contribute to empowerment. Empowerment values can be described as an approach that guides the collaboration between the person with disabilities and the support network. Empowering processes are those opportunities and actions that support persons to "gain mastery and control over issues that concern them, develop a critical awareness of their environment, and participate in decisions that affect their lives." [25] (p. 5). In addition, these processes are areas for learning and an opportunity to influence the environment. Empowerment outcomes deal with consequences of being involved in an empowering process [25]. There are several ways and degrees of including and empowering research participants. In design and information systems research, common concepts include co-design, co-creation and participatory research [2,26]. Within disability studies, inclusive research is another example, used to classify research where people with disabilities are actors and co-researchers of projects and academic output [27].

2. Materials and Methods

In this section, we describe the photovoice process and ethical considerations.

2.1. Data Collection

The data collection on user insights included nine photovoice interviews with adults with intellectual disability. The participants were recruited in close collaboration with employees at three different sheltered workplaces in Norway. The employees were asked to nominate potential participants based on their ability to (1) give consent, (2) take photos on their own or with the assistance of a researcher and (3) describe and reflect verbally on photos taken. In addition, they either had to walk or go by bus, taxi or use other means of transportation to get to work. To ensure that informed consent was given, the manager first informed the participants about the aim of the study and the photovoice activity. As a second step, the researchers visited the workplace to present the research project, themselves, how to take photos and with what aim. We also talked about ethics in regard to taking photos as data protection restricted whom the participants were allowed to include in photos without written consent. As a reminder, each participant was given printed instructions on what to focus on when taking photos. To identify user needs for transport support, we used the following instruction: On your way to and from work take photos of things, places or animals that are important, difficult or which make you happy/calm/insecure/sad/scared/stressed. We offered to send a text message reminding the participants to take photos, but all declined.

The participants included seven men and two women with mild or moderate intellectual disability. Five participants traveled by public transport to work (three by bus and two by combining subway and bus), one participant by taxi, two participants by maxitaxi and one participant by combining taxi and bus. All but one participant used their smartphones to take photos on their way home and/or to work. Two participants decided to not take any photos but took part in the interview (Table 1).

Table 1. Overview of the participants, with fictive names.

Participants	Gender	Transport	Number of Photos
Emma	Female	Maxitaxi	1
Tobias	Male	Maxitaxi	10
Ellen	Female	Bus	4
Olav	Male	Bus	6
Even	Male	Bus	0
Dag	Male	Taxi	2
Nicolai	Male	Subway + bus	3
Kenneth	Male	Taxi + bus	3
Adam	Male	Subway + bus	0

The day after the photos were taken, we conducted interviews with the participants. The interviews took place at their workplaces and the participants could invite a colleague or manager to accompany them during the interview if they wished (no one did so). The focus of the interviews was twofold: (i) to identify user needs for the design of transport support and (ii) to identify the participants' experiences of using photovoice. During the first part of the interview, the participants were asked to tell us about their current mode of transportation and their experiences connected to traveling. As a second part, the participants were asked to show us the photos they had taken, one by one. In connection to each photo, we asked what the photo showed, why they had taken it, if it represented something important or difficult and how the photo made them feel. They were also asked if they would have liked to have taken other photos. The third part of the interview focused on the possibilities of using other means of transportation. During the final part of the interview, the participants were asked about the use of photovoice as a method. All interviews were recorded and later transcribed by the researchers.

2.2. Data Analysis

The data material presented in this study (i.e., participants' experiences of using photovoice) was analyzed by thematic analysis and followed the steps as recommended by Braun and Clark [28]. The approach was chosen as the method is flexible and helps to identify, analyze and report patterns throughout collected data [28]. To start the analysis of the data, the photos taken were inserted into the interview transcripts. This made it easier to connect the reflections made by the participants to their photos. During the first step, the material was reread several times to gain familiarity with the data. Initial thoughts were also noted in the margin of the interview transcripts. As a second step, the two researchers generated initial codes, focusing on the participants' experiences of using photovoice. This first coding was done individually by the researchers. The codes and the extracted data were then discussed between the two researchers to reach a consensus. Minor changes were made to the codes based on the discussion. As a third step, the codes were grouped into potential themes. Through a discussion between the two authors, a thematic map was generated (Figure 1).

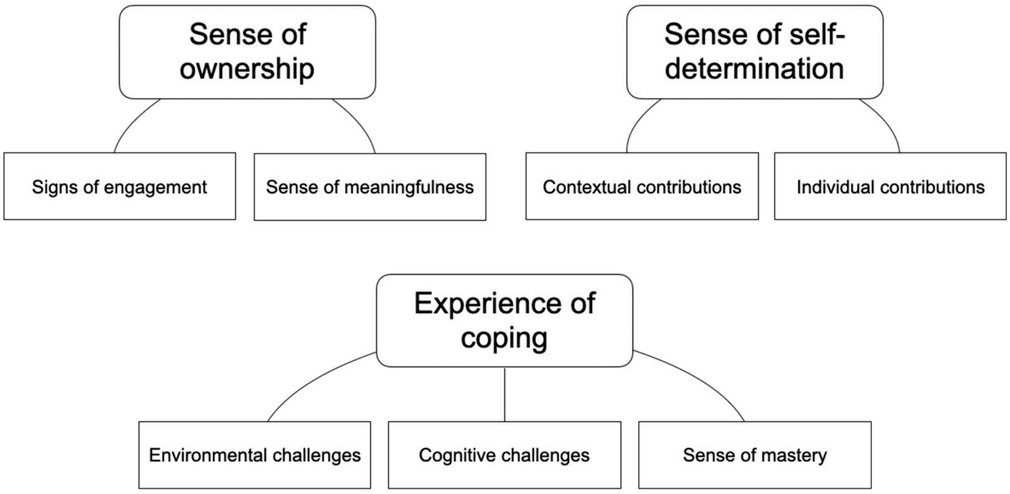

Figure 1. Thematic map showing the main themes and subthemes.

2.3. Ethical Considerations

The participants in the study were informed about the aim of the research project. They were told that participation was voluntary and that they could withdraw from the research project at any time without any consequences. This was stressed when the study was presented, when the photo session started and at the interview. Regulations regarding data protection prevented the participants from taking photos of persons who had not given formal consent to be part of the study. Mitchell [15] discusses ethical issues when doing visual research, including informed consent. In our study, we found it more limiting than valuable to put the responsibility on the participants to interact with unknown people and ask for informed consent. Therefore, we stressed the importance of only taking photos of things, places or animals. The research project was approved by the National Centre for Research Data (648227) and was performed in accordance with the Declaration of Helsinki.

3. Results

The thematic analysis resulted in three main themes: (a) experience of coping, (b) sense of self-determination and (c) sense of ownership (Figure 1).

3.1. Experience of Coping

The experience of coping was characterized by three sub-themes: a sense of mastery, environmental challenges and cognitive challenges. Most participants appeared to master the photovoice activity and described it as "fun" and "natural". During the interviews, the participants were able to describe what the photos represented to them and why they had taken them. Olav described the act of taking photos in the following way: "It was great. It went great to take photos from the bus. It's not that difficult to take photos. One only needs to find that picture of a camera on the phone. And then it's just to snap away". Kenneth described a similar experience:

> **Researcher:** You were asked to take photos, what did you think about that?
>
> **Kenneth:** Yes, that was super.
>
> **Researcher:** Why?
>
> **Kenneth:** No, because I often take photos anyway. It was totally natural for me.

Most participants expressed that they took the photos they wished to take and that the photos represented their travel to and/or from work. Still, they expressed difficulties connected to photovoice. During the interviews, comments were made regarding the quality of the photos. Ellen expressed that she found it difficult and said, "I'm not that very good at taking photos". Kenneth, on the other hand, started talking about a photo he had taken and suddenly said: "No, but it is … Now when I look at it (the photo) in hindsight, I find it quite nice".

Environmental challenges were mentioned by some of the participants. This included for instance that it was too dark to take photos, it was raining or that people were standing in the way of the object to be photographed. When Tobias showed his photos, he commented on the weather affecting the quality of a photo: "But most of them (the photos), most of them are easy to see. Apart from that one. Eh, it's raining and the only thing we can get out of it [the photo] is that the house is probably white". Regulations regarding data protection prevented the participants from taking photos of persons who had not given formal consent to be part of the study. This was reflected in the results. For instance, Dag said: "I tried to not take photos of people. Because a girl sat next to me, and when I tried to aim (the smartphone) at the vending machine, she got in the photo. So, I had to get up and stand in front of the vending machine to be able to take the photo". Another participant also mentioned that he tried to avoid getting other persons in the photos, something that could result in embarrassing situations. Nicolai said "... it looks a bit stupid to stand and take photos of the floor, right. I'm thinking hell, what if someone sees that I take a photo and then they wonder, what the hell is he up to?". In addition, one participant would have preferred to use a camera instead of a smartphone.

Apart from environmental challenges, there were cognitive challenges. For instance, two of the participants forgot to take photos and some were too tired to engage in the activity. Some participants, therefore, had to give it a new try the day after. When Olav explained how it felt to participate in the photovoice he said: "It was great, but I didn't take any photos yesterday because I was so tired that I had to go to bed, because I was a bit more tired than I expected so I didn't manage to take any photos yesterday".

3.2. *Sense of Self-Determination*

Participation through photovoice was experienced to be open and with few boundaries. The participants mentioned a freedom of choice when it came to taking photos and that they could provide contextual as well as individual contributions. As Dag said: "I think that it was fun that I could take photos of whatever I wanted in a sense. Because you didn't put any boundaries on what I could do." The freedom to decide was also mentioned by Olav. He said: "Well because then I can talk a bit about which photos I like and which type of photos I don't like. I could have taken photos I don't like but then I had simply deleted them just as fast, at once." The photovoice activity made it possible to contribute with contextual insights. Several of the participants took photos of their journey to and from work and contributed with insights to the innovation process. This included photos of places that were important to them, the scenery and settings that were stressful. Figure 2 shows examples of photos that described the context of the participants.

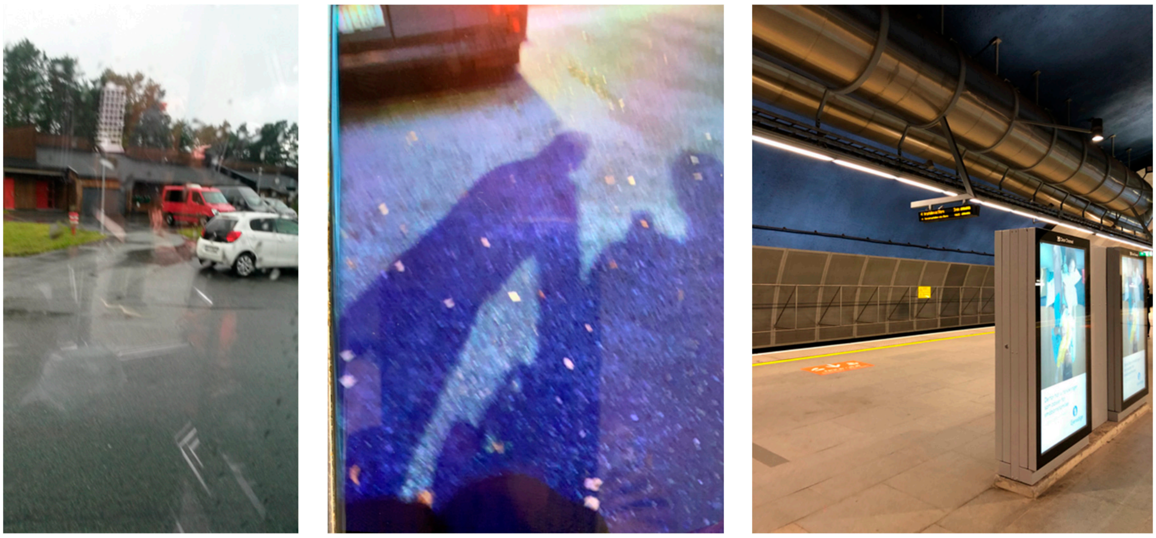

Figure 2. Example of participants' photos describing the scenery and context of transport.

Through the photos and the interview, the participants also shared individual stories about themselves. For instance, Emma took a photo of the door to her apartment and explained why.

Emma: That's the photo of my door. In the apartment.

Researcher: Uhm.

Emma: Eh, there's a bathroom and a sleeping room and a living room and a kitchen.

Researcher: Yes, would you like to tell me why you took the photo?

Emma: Uhm, why I took the photo. I've moved in.

Researcher: Was that something that made you feel happy or . . .

Emma: Eh, I'm so happy.

3.3. *Sense of Ownership*

The analysis of the data showed that the participants experienced that photovoice led to a sense of ownership. The sense of ownership was characterized by two sub-themes: signs of engagement and a sense of meaningfulness. The findings show that the participants were engaged, showed interest and were motivated during the photovoice activity. For instance, towards the end of the interview, Tobias asked: "Do you (the second author) wants me to take more photos? Just in case you need more photos". The participants also expressed interest in further participation. For example, when asked if they would participate again, all participants expressed an interest in further research activities. While taking photos was a vital part of the experience, Nicolai stated, "participating through photovoice was fun and exciting . . . and talking (the interview) was possibly my favorite part of participating". Nicolai elaborated and noted that he valued the opportunity to be part of something new: "it was exciting to be part of something new, and fun as well".

In addition, the analysis showed that the participants experienced a sense of meaningfulness when participating through photovoice. They explained that participation was an opportunity to contribute to something important and meaningful. Several of the participants noted that they hoped that the results of their participation could contribute to helping other individuals with intellectual disabilities. Nicolai stated, "I hope (my participation) can lead to solutions that can help and make things easier for others as well". In addition, photovoice made it possible for the participants to give descriptions of their lives and lived experiences. When asked about taking photos, Kenneth stated, "Taking photos was fine . . . it is an opportunity to show the wide spectrum (of the lives of people with intellectual disabilities)". Moreover, participation was an opportunity to socialize and meet new people. The participants expressed that, when participating through photovoice, they could express themselves as they wished and without interruptions. Dag explained, "It is important to get the opportunity to talk to someone without being constantly interrupted. It is not easy to have a conversation when someone constantly interrupts".

4. Discussion

In this section, we reflect on the process of using photovoice to empower participants with intellectual disability and understand user needs in an innovation process.

4.1. Reflections on Empowerment

One important element of user involvement, and photovoice in particular, is to contribute to empowerment of the participants [1,2,13,14]. Participants should be given the opportunity to select the photos they wish and to use these to guide the discussion on user needs. In addition, participants should be given the opportunity to contextualize the photos and tell a story connected to the photos [14]. In our study, the participants with intellectual disabilities did express a sense of self-determination and autonomy in connection to selecting which photos to take. For instance, they felt free to remove photos but also to discuss photos that were missing for different reasons. This is in line with Povee et al. [11], who found that photovoice can promote and facilitate empowerment by offering people with intellectual disabilities opportunities to make decisions and exert control over the process. In addition, our participants were encouraged to describe and express their opinions during the photovoice interview. They expressed a sense of control of how they wished to portray their experiences and elaborated on issues not directly connected to transportation.

Empowerment is characterized by and reflected in the ability to master issues that are of importance [25]. In our study, the participants expressed that they coped with and mastered the photovoice activity. They were engaged and motivated to take photos, talk about the photos and described photovoice as natural and fun. While people with intellectual disabilities tend to have difficulties maintaining motivation and engagement [16], photovoice can offer a more exciting way to engage in research [11]. This is in line with our findings, as the participants described the process as an enjoyable experience and expressed a desire to take more photos. The participants were also interested in the quality of the photos and some expressed a desire to take "better" photos. Another element of empowerment is the opportunity to engage in issues that concern and affect oneself [25]. A previous study found that photovoice may foster a sense of ownership as participants are involved in collecting data and are given the opportunity to shape and make policies relevant [25]. This was partly shown in our study as the participants expressed a sense of meaningfulness and ownership. The participants viewed photovoice as an opportunity to contribute to something that could lead to a solution that could help themselves and others to travel independently. Thus, the process of empowerment and the possibility of influencing the environment [25] was articulated in the user needs that influenced the design of the prototype.

4.2. Reflections on Understanding User Needs

The gathering of insights in our study was somewhat different from previous studies involving participants with intellectual disability in photovoice [11,12]. In their process, participants collectively identified a theme to be explored and studied through the use of photovoice, and as a final step, the insights were communicated to policymakers [11,12]. Our focus of research, assistive technology to support independent transport, had been identified prior to the involvement of the photovoice participants. The theme was identified through participant observations of other persons with intellectual disabilities and through focus group interviews with representatives of support networks (parents, employers, nurses etc.). In addition, the target of our insights was not policymakers [11,12] but was used to design a prototype for assistive technology. The insights gathered through our photovoice process highlighted important elements of independent transport. Based on these insights, we designed a prototype of an assistive technology that supports reminders, time management and communication.

This shows that photovoice can contribute to user insights that can be a source for an innovation process and design of a prototype. When people with intellectual disabilities are allowed to express their interests, researchers are given the opportunity to understand the views and needs from their perspective rather than the perspective of caregivers, parents or other professionals [11,29]. According to Jurkowski [29], the engagement of people with intellectual disabilities in photovoice can improve validity as it fosters an authentic perspective of their experiences and knowledge. As a result, findings can be used to develop more effective programs [29], or as in our case, design and development of assistive technology.

4.3. Reflections on the Use of Photovoice

Photovoice offers an alternative approach for understanding user needs [13]. While it has been described as an opportunity to include participants who lack verbal fluency by sharing and presenting experiences visually [12], elements of photovoice have also been questioned, for instance, if a subsequent interview provides useful information and reflections of photos when involving participants with intellectual disabilities [30]. It has been suggested that it might be more beneficial to conduct interviews in the "field" as the photos are taken [30]. Nevertheless, in our study, the participants did reflect on the photos and did return to the photos without force to give examples or elaborate on their reasoning during the interviews. Our findings suggest that photovoice facilitated the understanding of their contextual and individual experiences and that the participants could make decisions based on their preferences. A similar finding was reported by Povee et al. [11], who state that photovoice captures the viewpoints and social realities of people with intellectual disabilities. As photovoice offers tangible representations of concepts and issues, it corresponds well with the concrete way of learning that fits people with intellectual disabilities [12]. Nevertheless, the ability to independently take photos varied among our participants. For one participant, a more guided approach as suggested by Overmars-Marx et al. [30] where the participant takes photos together with a researcher would probably have been more suitable.

We also found that the situation under study, in our case transport to work, took place in a context that made photovoice challenging for some participants. For instance, early mornings can be cognitively challenging in general. Timing of the study, both regarding day and time of the day, therefore, needs to be adjusted to the individual participant. Most participants described taking photos as "natural" and that it was something that they were used to in daily life. This reflects the use of social media in general and shows that people with intellectual disabilities should not be underestimated when contributing to an innovation process and technology design. In addition, photovoice might be more engaging and accessible as it does not require the ability to read and write [13]. Both these issues show the importance of preparation in regard to providing information to the participants and understanding the individual needs and abilities of the participants.

4.4. Limitations

There are potential limitations of our study that need to be considered. Although the number of interviews and participants is deemed sufficient by Braun and Clarke [31], this study had a limited number of participants and only two females. The number of participants and gender disparity may have contributed to the outcomes presented in this study. However, the participants represented the intended end user group of the assistive technology and used varied means of transportation, including maxitaxi, bus, subway and taxi. Still, it is important to acknowledge that people with intellectual disabilities are not a homogenous group. Our study was tailored to participants with certain abilities and they were able to articulate their experience of participating in photovoice. With this in mind, it is likely that the participants in this study were more skilled and capable of using technology than other people with intellectual disabilities. However, other studies such as the one by Cluley [32] include participants with mild, moderate and profound and multiple learning disabilities. Their results show that for participants with profound and multiple learning disabilities, a more flexible approach is recommended which includes both people with learning disabilities and representatives of the support network.

5. Conclusions

There is a need to engage disadvantaged user groups in innovation as it can result in improved digital solutions and inclusion of user groups and needs that have previously been overlooked. However, this calls for processes that are creative and empowering and which facilitate user involvement of groups such as people with intellectual disabilities. The findings in our study suggest that photovoice is a method that can contribute to sharing of contextual and individual needs and an empowerment process characterized by coping, self-determination and ownership. As photovoice emphasizes the visual capacity of people with intellectual disabilities, it promotes a relational perspective of intellectual disability. Photovoice can be a tool to reduce or remove some of the challenges that researchers might face when identifying user needs in design processes and a way to strengthen the individual's capacity to cope with the demands of participating in an innovation and design process.

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Appendix 1

Approval from the Research Ethics Committee of the University of Agder

UNIVERSITETET I AGDER

Mugula Chris Safari

Besøksadresse:
Universitetsveien 25
Kristiansand

Ref: 19/09435

Tidspunkt for godkjenning: : 17/12/2019

Søknad om etisk godkjenning av forskningsprosjekt - Involvering av personer med utviklingshemming i innovasjonsprosesser – en studie av innovasjonsprosesser med fokus på transportløsninger.

Vi informerer om at din søknad er ferdig behandlet og godkjent.

Kommentar fra godkjenner:
Godkjent under forutsetning av at prosjektet gjennomføres som beskrevet i søknaden.
FEK kommenterer også at informasjonsskrivet må tilpasses informantgruppen.

Hilsen
Forskningsetisk komite
Fakultet for helse - og idrettsvitenskap
Universitetet i Agder

UNIVERSITETET I AGDER
POSTBOKS 422 4604 KRISTIANSAND
TELEFON 38 14 10 00
ORG. NR 970 546 200 MVA - post@uia.no - www.uia.no

FAKTURAADRESSE:
UNIVERSITETET I AGDER,
FAKTURAMOTTAK
POSTBOKS 383 ALNABRU 0614 OSLO

Appendix 2

Registration form to the Norwegian Centre for Research Data (NSD)

NSD NORSK SENTER FOR FORSKNINGSDATA

Meldeskjema 648227

Sist oppdatert

01.10.2019

Hvilke personopplysninger skal du behandle?

- Navn (også ved signatur/samtykke)
- Adresse eller telefonnummer
- E-postadresse, IP-adresse eller annen nettidentifikator
- Bilder eller videoopptak av personer
- Lydopptak av personer
- Bakgrunnsopplysninger som vil kunne identifisere en person

Type opplysninger

Du har svart ja til at du skal behandle bakgrunnsopplysninger, beskriv hvilke

alder, kjønn, yrke, arbeidsplass/skole, kommune, utviklingshemming/ikke utviklingshemming, bild

Skal du behandle særlige kategorier personopplysninger eller personopplysninger om straffedommer eller lovovertredelser?

- Helseopplysninger

Prosjektinformasjon

Prosjekttittel

InnArbeid - Behovsdrevet innovasjon for inkludering av personer med utviklingshemming i arbeidslivet ved bruk av teknologi

Dersom opplysningene skal behandles til andre formål enn behandlingen for dette prosjektet, beskriv hvilke

Opplysningene ska brukes genom hele prosjektet (arbeidspakke 3-5).

Begrunn behovet for å behandle personopplysningene

I forbindelse med datainnsamling er det behov for kontaktinformasjon til informantene. Det kan være aktuelt å gjøre datainnsamling i flere iterasjoner og kontaktinformasjon til informantene er da nødvendig. Vi har markert at vi vil samle inn helseopplysninger, da informantene vil være personer med utviklingshemming og dermed har en diagnose. Det vil ikke samles andre helserelaterte opplysninger.

Ekstern finansiering

- Norges forskningsråd (NFR)

Type prosjekt

Forskerprosjekt

Behandlingsansvar

Behandlingsansvarlig institusjon

Universitetet i Agder / Fakultet for helse- og idrettsvitenskap / Institutt for helse- og sykepleievitenskap

Prosjektansvarlig (vitenskapelig ansatt/veileder eller stipendiat)

Elin Thygesen, elin.thygesen@uia.no, tlf: 91571515

Skal behandlingsansvaret deles med andre institusjoner (felles behandlingsansvarlige)?

Nei

Utvalg 1

Beskriv utvalget

Ansatte i privat bedrift med erfaring med ansettelse av person med psykisk utviklingshemming

Rekruttering eller trekking av utvalget

Metoden for utvelgelse vil være strategisk utvalg og snowball sampling. De ulike informantene vil rekrutteres strategiskt via partnere i prosjektet, deltakere i brukerpanelet og ekspertpanelet. Andre informanter vill også ge forslag på vidare personer enligt metoden snowball sampling. Kontaktinformasjon om aktuelle informanter videreformidles til forskergruppen från partnere og tidligare informanter som deretter oppretter en førstegangskontakt via mail eller telefon.

Alder

18 - 70

Inngår det voksne (18 år +) i utvalget som ikke kan samtykke selv?

Nei

Personopplysninger for utvalg 1

- Navn (også ved signatur/samtykke)
- Adresse eller telefonnummer
- E-postadresse, IP-adresse eller annen nettidentifikator
- Bilder eller videoopptak av personer
- Lydopptak av personer
- Bakgrunnsopplysninger som vil kunne identifisere en person

Hvordan samler du inn data fra utvalg 1?

Deltakende observasjon

Grunnlag for å behandle alminnelige kategorier av personopplysninger

Samtykke (art. 6 nr. 1 bokstav a)

Personlig intervju

Grunnlag for å behandle alminnelige kategorier av personopplysninger

Samtykke (art. 6 nr. 1 bokstav a)

Gruppeintervju

Grunnlag for å behandle alminnelige kategorier av personopplysninger

Samtykke (art. 6 nr. 1 bokstav a)

Papirbasert spørreskjema

Grunnlag for å behandle alminnelige kategorier av personopplysninger

Samtykke (art. 6 nr. 1 bokstav a)

Informasjon for utvalg 1

Informerer du utvalget om behandlingen av opplysningene?

Ja

Hvordan?

Skriftlig informasjon (papir eller elektronisk)

Utvalg 2

Beskriv utvalget

Ansatte i offentlig virksomhet involvert i overgangen fra skole til arbeid for personer med psykisk utviklingshemming (f.eks. NAV, bolig, habiliteringstjenesten, videregående skole).

Rekruttering eller trekking av utvalget

Metoden for utvelgelse vil være strategisk utvalg og snowball sampling. De ulike informantene vil rekrutteres strategiskt via partnere i prosjektet, deltakere i brukerpanelet og ekspertpanelet. Andre informanter vill også ge forslag på vidare personer enligt metoden snowball sampling. Kontaktinformasjon om aktuelle informanter videreformidles til forskergruppen från partnere og tidligare informanter som deretter oppretter en førstegangskontakt via mail eller telefon.

Alder

18 - 70

Inngår det voksne (18 år +) i utvalget som ikke kan samtykke selv?

Nei

Personopplysninger for utvalg 2

- Navn (også ved signatur/samtykke)
- Adresse eller telefonnummer
- E-postadresse, IP-adresse eller annen nettidentifikator
- Bilder eller videoopptak av personer
- Lydopptak av personer
- Bakgrunnsopplysninger som vil kunne identifisere en person

Hvordan samler du inn data fra utvalg 2?

Deltakende observasjon

Grunnlag for å behandle alminnelige kategorier av personopplysninger

Samtykke (art. 6 nr. 1 bokstav a)

Personlig intervju

Grunnlag for å behandle alminnelige kategorier av personopplysninger

Samtykke (art. 6 nr. 1 bokstav a)

Gruppeintervju

Grunnlag for å behandle alminnelige kategorier av personopplysninger

Samtykke (art. 6 nr. 1 bokstav a)

Papirbasert spørreskjema

Grunnlag for å behandle alminnelige kategorier av personopplysninger

Samtykke (art. 6 nr. 1 bokstav a)

Informasjon for utvalg 2

Informerer du utvalget om behandlingen av opplysningene?

Ja

Hvordan?

Skriftlig informasjon (papir eller elektronisk)

Utvalg 3

Beskriv utvalget

Pårørande til person med psykisk utviklingshemming

Rekruttering eller trekking av utvalget

Metoden for utvelgelse vil være strategisk utvalg og snowball sampling. De ulike informantene vil rekrutteres strategiskt via partnere i prosjektet, deltakere i brukerpanelet og ekspertpanelet. Andre informanter vill også ge forslag på vidare personer enligt metoden snowball sampling. Kontaktinformasjon om aktuelle informanter videreformidles til forskergruppen från partnere og tidligare informanter som deretter oppretter en førstegangskontakt via mail eller telefon.

Alder

30 - 80

Inngår det voksne (18 år +) i utvalget som ikke kan samtykke selv?

Nei

Personopplysninger for utvalg 3

- Navn (også ved signatur/samtykke)
- Adresse eller telefonnummer
- E-postadresse, IP-adresse eller annen nettidentifikator
- Bilder eller videoopptak av personer
- Lydopptak av personer
- Bakgrunnsopplysninger som vil kunne identifisere en person

Hvordan samler du inn data fra utvalg 3?

Deltakende observasjon

Grunnlag for å behandle alminnelige kategorier av personopplysninger

Samtykke (art. 6 nr. 1 bokstav a)

Personlig intervju

Grunnlag for å behandle alminnelige kategorier av personopplysninger

Samtykke (art. 6 nr. 1 bokstav a)

Gruppeintervju

Grunnlag for å behandle alminnelige kategorier av personopplysninger

Samtykke (art. 6 nr. 1 bokstav a)

Papirbasert spørreskjema

Grunnlag for å behandle alminnelige kategorier av personopplysninger

Samtykke (art. 6 nr. 1 bokstav a)

Informasjon for utvalg 3

Informerer du utvalget om behandlingen av opplysningene?

Ja

Hvordan?

Skriftlig informasjon (papir eller elektronisk)

Utvalg 4

Beskriv utvalget

Personer med psykisk utviklingshemming

Rekruttering eller trekking av utvalget

Metoden for utvelgelse vil være strategisk utvalg og snowball sampling. De ulike informantene vil rekrutteres strategiskt via partnere i prosjektet, deltakere i brukerpanelet og ekspertpanelet. Andre informanter vill også ge forslag på vidare personer enligt metoden snowball sampling.

Kontaktinformasjon om aktuelle informanter videreformidles til forskergruppen från partnere og tidligare informanter. Ansatte som kjenner bruker godt oppretter en førstegangskontakt. Forskergruppen kontakter deretter informanten via personligt møte, eventuellt hvis mulig på mail eller telefon.

Alder

15 - 30

Inngår det voksne (18 år +) i utvalget som ikke kan samtykke selv?

Ja

Begrunn hvorfor det er nødvendig å inkludere voksne som ikke kan samtykke.

Vi ønsker primært å rekruttere brukere med samtykkekompetanse. Men en del av utfordringsbildet er mangel på samfunnsdeltakelse for personer med utviklingshemming. Det har tradisjonelt vært en utfordring å få frem brukerens stemme. Det er bakgrunnen for at vi ønsker å rekruttere brukere med redusert samtykkekompetanse dersom foreldre/ansatte tilråder at brukeren deltar, og brukeren selv formidler at det er ønskelig. Denne vurderingen gjøres i samarbeid med ansatte/foreldre som kjenner bruker godt. I disse tilfellene vil foreldre samtykke på vegne av sine barn. Hvordan informasjonen formidles til brukerne vil vurderes i dialog med nærstående person til brukerne for å sikre at informasjonen blir mottatt og forstått.

Personopplysninger for utvalg 4

- Navn (også ved signatur/samtykke)
- Adresse eller telefonnummer
- E-postadresse, IP-adresse eller annen nettidentifikator
- Bilder eller videoopptak av personer
- Lydopptak av personer
- Bakgrunnsopplysninger som vil kunne identifisere en person
- Helseopplysninger

Hvordan samler du inn data fra utvalg 4?

Deltakende observasjon

Grunnlag for å behandle alminnelige kategorier av personopplysninger

Samtykke (art. 6 nr. 1 bokstav a)

Hvem samtykker for barn under 16 år?

Foreldre/foresatte

Hvem samtykker for ungdom 16 og 17 år?

Foreldre/foresatte

Samtykker pårørende eller verge på vegne av voksne personer som ikke kan samtykke selv?

Ja

Grunnlag for å behandle særlige kategorier av personopplysninger

Uttrykkelig samtykke (art. 9 nr. 2 bokstav a)

Redegjør for valget av behandlingsgrunnlag

Personlig intervju

Grunnlag for å behandle alminnelige kategorier av personopplysninger

Samtykke (art. 6 nr. 1 bokstav a)

Hvem samtykker for barn under 16 år?

Foreldre/foresatte

Hvem samtykker for ungdom 16 og 17 år?

Foreldre/foresatte

Samtykker pårørende eller verge på vegne av voksne personer som ikke kan samtykke selv?

Ja

Grunnlag for å behandle særlige kategorier av personopplysninger

Uttrykkelig samtykke (art. 9 nr. 2 bokstav a)

Redegjør for valget av behandlingsgrunnlag

Gruppeintervju

Grunnlag for å behandle alminnelige kategorier av personopplysninger

Samtykke (art. 6 nr. 1 bokstav a)

Hvem samtykker for barn under 16 år?

Foreldre/foresatte

Hvem samtykker for ungdom 16 og 17 år?

Foreldre/foresatte

Samtykker pårørende eller verge på vegne av voksne personer som ikke kan samtykke selv?

Ja

Grunnlag for å behandle særlige kategorier av personopplysninger

Uttrykkelig samtykke (art. 9 nr. 2 bokstav a)

Redegjør for valget av behandlingsgrunnlag

Annet

Beskriv

Vi planerar att genomföra en photovoicestudie tillsammans med ungdomar med utviklingshemming.

Ungdomarna ombeds att ta bilder av ting som är enkelt och/eller vanskeligt kopplat till transport till och från jobb, skola, fritidsaktivitet och hemmet. Ungdomarna kommer att bruka sin personliga smarttelefon till att ta bilderna under en till tre gånger som de förflyttar sig från jobb, skola, fritidsaktivitet och hemmet.

För att försäkra att ungdomarna inte tar bilder av tredjepersoner kommer vi att förklara att de endast får ta bilder av ting eller djur och inte av några personer. Detta kommer att förklaras i samarbete med en person som känner ungdomen väl, f.eks. en lärare, arbetsgivare, assistent eller pårörande. Om det mot förmodan skulle tas några bilder av tredjepersoner, anonymiserar vi dessa genom att ta bort personen från bilden (om möjligt) eller fjerna hela bilden.

Bilderna kommer att analyseras av forskarna och sedan användas i en uppföljande workshop eller intervju där bilderna diskuteras tillsammans med andra ungdomar och personer som är involverade i deras vardag (f.eks. lärare, arbetsgivare). Workshopen beskrivs i tidigare ansökan som deltagande observation där vi diskuterar idéer som kan förenklar transporten till eller från jobb, skola, fritidsaktivitet och hemmet.

Grunnlag for å behandle alminnelige kategorier av personopplysninger

Samtykke (art. 6 nr. 1 bokstav a)

Hvem samtykker for barn under 16 år?

Foreldre/foresatte

Hvem samtykker for ungdom 16 og 17 år?

Foreldre/foresatte

Samtykker pårørende eller verge på vegne av voksne personer som ikke kan samtykke selv?

Ja

Grunnlag for å behandle særlige kategorier av personopplysninger

Uttrykkelig samtykke (art. 9 nr. 2 bokstav a)

Redegjør for valget av behandlingsgrunnlag

Informasjon for utvalg 4

Informerer du utvalget om behandlingen av opplysningene?

Ja

Hvordan?

Skriftlig informasjon (papir eller elektronisk)

Mottar personer som ikke kan samtykke tilpasset informasjon om prosjektet?

Ja

Utvalg 5

Beskriv utvalget

Proxy, i.e. person som assisterar ungdom med utviklingshemming i samskapingsmøter

Rekruttering eller trekking av utvalget

etoden for utvelgelse vil være strategisk utvalg og snowball sampling. De ulike informantene vil rekrutteres strategiskt via partnere i prosjektet, deltakere i brukerpanelet og ekspertpanelet. Andre informanter vill også ge forslag på vidare personer enligt metoden snowball sampling. Kontaktinformasjon om aktuelle informanter videreformidles til forskergruppen från partnere og tidligare informanter som deretter oppretter en førstegangskontakt via mail eller telefon.

Alder

18 - 80

Inngår det voksne (18 år +) i utvalget som ikke kan samtykke selv?

Nei

Personopplysninger for utvalg 5

- Navn (også ved signatur/samtykke)
- Adresse eller telefonnummer
- E-postadresse, IP-adresse eller annen nettidentifikator
- Bilder eller videoopptak av personer
- Lydopptak av personer
- Bakgrunnsopplysninger som vil kunne identifisere en person

Hvordan samler du inn data fra utvalg 5?

Deltakende observasjon

Grunnlag for å behandle alminnelige kategorier av personopplysninger

Samtykke (art. 6 nr. 1 bokstav a)

Personlig intervju

Grunnlag for å behandle alminnelige kategorier av personopplysninger

Samtykke (art. 6 nr. 1 bokstav a)

Informasjon for utvalg 5

Informerer du utvalget om behandlingen av opplysningene?

Ja

Hvordan?

Skriftlig informasjon (papir eller elektronisk)

Utvalg 6

Beskriv utvalget

Personer med psykisk utviklingshemming

Rekruttering eller trekking av utvalget

Metoden for utvelgelse vil være strategisk utvalg og snowball sampling. De ulike informantene vil rekrutteres strategiskt via partnere i prosjektet, deltakere i brukerpanelet og ekspertpanelet. Andre informanter vill også ge forslag på vidare personer enligt metoden snowball sampling. Kontaktinformasjon om aktuelle informanter videreformidles til forskergruppen från partnere og tidligare informanter. Ansatte som kjenner bruker godt oppretter en førstegangskontakt. Forskergruppen kontakter deretter informanten via personligt møte, eventuellt hvis mulig på mail eller telefon.

Alder

15 - 30

Inngår det voksne (18 år +) i utvalget som ikke kan samtykke selv?

Ja

Begrunn hvorfor det er nødvendig å inkludere voksne som ikke kan samtykke.

Vi ønsker primært å rekruttere brukere med samtykkekompetanse. Men en del av utfordringsbildet er mangel på samfunnsdeltakelse for personer med utviklingshemming. Det har tradisjonelt vært en utfordring å få frem brukerens stemme. Det er bakgrunnen for at vi ønsker å rekruttere brukere med redusert samtykkekompetanse dersom foreldre/ansatte tilråder at brukeren deltar, og brukeren selv formidler at det er ønskelig. Denne vurderingen gjøres i samarbeid med ansatte/foreldre som kjenner bruker godt. I disse tilfellene vil foreldre samtykke på vegne av sine barn. Hvordan informasjonen formidles til brukerne vil vurderes i dialog med nærstående person til brukerne for å sikre at informasjonen blir mottatt og forstått.

Personopplysninger for utvalg 6

- Navn (også ved signatur/samtykke)
- Adresse eller telefonnummer
- E-postadresse, IP-adresse eller annen nettidentifikator
- Bilder eller videoopptak av personer
- Lydopptak av personer
- Bakgrunnsopplysninger som vil kunne identifisere en person
- Helseopplysninger

Hvordan samler du inn data fra utvalg 6?

Deltakende observasjon

Grunnlag for å behandle alminnelige kategorier av personopplysninger

Samtykke (art. 6 nr. 1 bokstav a)

Hvem samtykker for barn under 16 år?

Foreldre/foresatte

Hvem samtykker for ungdom 16 og 17 år?

Foreldre/foresatte

Samtykker pårørende eller verge på vegne av voksne personer som ikke kan samtykke selv?

Ja

Grunnlag for å behandle særlige kategorier av personopplysninger

Uttrykkelig samtykke (art. 9 nr. 2 bokstav a)

Redegjør for valget av behandlingsgrunnlag

Personlig intervju

Grunnlag for å behandle alminnelige kategorier av personopplysninger

Samtykke (art. 6 nr. 1 bokstav a)

Hvem samtykker for barn under 16 år?

Foreldre/foresatte

Hvem samtykker for ungdom 16 og 17 år?

Foreldre/foresatte

Samtykker pårørende eller verge på vegne av voksne personer som ikke kan samtykke selv?

Ja

Grunnlag for å behandle særlige kategorier av personopplysninger

Uttrykkelig samtykke (art. 9 nr. 2 bokstav a)

Redegjør for valget av behandlingsgrunnlag

Annet

Beskriv

Vi planlegger å gjennomføre en photovoicestudie sammen med ungdommer med psykisk utviklingshemming. Konteksten for photovoicestudien er de samskapningsmøter som skjer i prosjektet. Ungdommene deltar på samskapningsmøter der det diskuteres ideer som kan bidra til økt arbeidsdeltakelse for mennesker med utviklingshemming. Hensikten med denne studien er å undersøke hvordan ungdommene opplever å delta i en slik prosess.

Photovoice er en kreativ metode for å få frem brukerstemmen. I dette prosjektet vil ungdommene bli bedt om å ta bilder av alt som har betydning i samskapningsmøtene i InnArbeid prosjektet. Ungdommene vil bli oppfordret til å ta bilder av det som oppleves som enkelt eller vanskelig når de deltar på møtene. Dette kan også være faktorer/ting som gjør det enklere eller vanskeligere å delta. Vi vil stille med enten et digitalt kamera eller polaroidkamera som er tilgjengelig for deltakerne på alle møter.

Alle som deltar i møtene med InnArbeid vil bli bedt om å underskrive et skriftlig samtykkeskjema knyttet til fotografering i forkant av møtene. Videre vil forskerne avlegge muntlig samtykke knyttet til fotografering. Dersom det er noen som ikke ønsker å bli tatt bilder av vil vi be ungdommene om å ikke ta bilder av vedkommende. Om det skulle mot all formodning skje, så vil vi anonymisere personen ved å ta vekk personen fra bildet, hvis ikke det lar seg gjøre vil vi fjerne hele bildet.

Bildene som tas av ungdommene vil analyseres av forskerne og brukes som grunnlag for samtale/intervju i etterkant av workshopene. Bildene vil diskuteres sammen med ungdommene og der det er behov andre som er involvert i ungdommenes hverdag (for eksempel lærere og foreldre).

Grunnlag for å behandle alminnelige kategorier av personopplysninger

Samtykke (art. 6 nr. 1 bokstav a)

Hvem samtykker for barn under 16 år?

Foreldre/foresatte

Hvem samtykker for ungdom 16 og 17 år?

Foreldre/foresatte

Samtykker pårørende eller verge på vegne av voksne personer som ikke kan samtykke selv?

Ja

Grunnlag for å behandle særlige kategorier av personopplysninger

Uttrykkelig samtykke (art. 9 nr. 2 bokstav a)

Redegjør for valget av behandlingsgrunnlag

Informasjon for utvalg 6

Informerer du utvalget om behandlingen av opplysningene?

Ja

Hvordan?

Skriftlig informasjon (papir eller elektronisk)

Mottar personer som ikke kan samtykke tilpasset informasjon om prosjektet?

Ja

Tredjepersoner

Skal du behandle personopplysninger om tredjepersoner?

Ja

Beskriv tredjepersoner

Personer med psykisk utviklingshemming. Foreldre til personer med utviklingshemming og proxy vil delta i studien. Når de snakker om ulike ideer og løsninger på problemer, kan det hende at noen opplysninger er knyttet til barna sine. Vi vil innhente samtykke fra personen med utviklingshemming at deres foreldre kan dele informasjon relatert til dem.

Typer opplysninger om tredjepersoner

- Bakgrunnsopplysninger som vil kunne identifisere en person

Hvilke utvalg avgir opplysninger om tredjepersoner?

- Utvalg 3: Pårørande til person med psykisk utviklingshemming
- Utvalg 5: Proxy, i.e. person som assisterar ungdom med utviklingshemming i samskapingsmøter

Samtykker tredjepersoner til behandlingen av opplysningene?

Ja

Mottar tredjepersoner informasjon om behandlingen av opplysningene?

Ja

Dokumentasjon

Hvordan dokumenteres samtykkene?

- Manuelt (papir)

Hvordan kan samtykket trekkes tilbake?

Informanten kan sende e-post, SMS eller ring prosjektlederen. Kontaktinformasjon er gitt på papir til informanten i forbindelse med datainnsamlingen. Informanter med psykisk utviklingshemming kan også snakke med en ansatt kontaktperson på bolig eller med pårørande som deretter kontakter prosjektlederen.

Hvordan kan de registrerte få innsyn, rettet eller slettet opplysninger om seg selv?

Informanten kan sende e-post, SMS eller ring prosjektlederen. Kontaktopplysninger er gitt på samtykkeskjema for deltaker i forbindelse med datainnsamlingen. På forespørsel sender prosjektlederen det anonymiserte materialet til informanten via e-post eller brev som deretter kan sende inn det som skal korrigeres eller slettes via e-post, brev eller telefon.

Totalt antall registrerte i prosjektet

1-99

Tillatelser

Skal du innhente følgende godkjenninger eller tillatelser for prosjektet?

Behandling

Hvor behandles opplysningene?

- Maskinvare tilhørende behandlingsansvarlig institusjon
- Mobile enheter tilhørende behandlingsansvarlig institusjon

Hvem behandler/har tilgang til opplysningene?

- Prosjektansvarlig
- Interne medarbeidere
- Eksterne medarbeidere/samarbeidspartnere innenfor EU/EØS
- Databehandler

Hvilken databehandler har tilgang til opplysningene?

Emendo

Tilgjengeliggjøres opplysningene utenfor EU/EØS til en tredjestat eller internasjonal organisasjon?

Nei

Sikkerhet

Oppbevares personopplysningene atskilt fra øvrige data (kodenøkkel)?

Ja

Hvilke tekniske og fysiske tiltak sikrer personopplysningene?

- Opplysningene anonymiseres
- Adgangsbegrensning
- Andre sikkerhetstiltak

Hvilke

Lydopptak og videoopptak vil bli gjort på en opptaker som ikke er koblet til Internett. Når lyd- og videoopptaket er lagret på serveren ved Universitetet i Agder, slettes materialet fra opptakeren. I forbindelse med transkripsjonen blir materialet anonymisert og koblingsnøkkelen lagres i et låst skap. Emendo (transkribering) har taushetsplikt og vil signere en taushetserklæring. Materialet vil sendes kryptert til Emendo.

Varighet

Prosjektperiode

14.05.2018 - 31.12.2021

Skal data med personopplysninger oppbevares utover prosjektperioden?

Nei, data vil bli oppbevart uten personopplysninger (anonymisering)

Hvilke anonymiseringstiltak vil bli foretatt?

- Koblingsnøkkelen slettes
- Personidentifiserbare opplysninger fjernes, omskrives eller grovkategoriseres
- Lyd- eller bildeopptak slettes

Vil de registrerte kunne identifiseres (direkte eller indirekte) i oppgave/avhandling/øvrige publikasjoner fra prosjektet?

Nei

Tilleggsopplysninger

Vi har uppdaterat information om datainsamling som fokuserar på oppleverser av deltagande i samskapingsmøter. Vi har därför lagt till utvalg 5 och utvalg 6 med informationsskriv, intervjumal samt en observationsmal som har lastats upp som 'andre vedlegg'.

Appendix 2B

Approval from the Norwegian Centre for Research Data (NSD)

NSD NORSK SENTER FOR FORSKNINGSDATA

NSD sin vurdering

Prosjekttittel

InnArbeid - Behovsdrevet innovasjon for inkludering av personer med utviklingshemming i arbeidslivet ved bruk av teknologi

Referansenummer

648227

Registrert

08.02.2019 av Sofie Wass - sofie.wass@uia.no

Behandlingsansvarlig institusjon

Universitetet i Agder / Fakultet for helse- og idrettsvitenskap / Institutt for helse- og sykepleievitenskap

Prosjektansvarlig (vitenskapelig ansatt/veileder eller stipendiat)

Elin Thygesen, elin.thygesen@uia.no, tlf: 91571515

Type prosjekt

Forskerprosjekt

Prosjektperiode

14.05.2018 - 31.12.2021

Status

12.10.2019 - Vurdert

Vurdering (3)

12.10.2019 - Vurdert

NSD har vurdert endringen registrert 01.10.2019.

Det er vår vurdering at behandlingen av personopplysninger i prosjektet vil være i samsvar med personvernlovgivningen så fremt den gjennomføres i tråd med det som er dokumentert i meldeskjemaet med vedlegg den 12.10.2019. Behandlingen kan fortsette.

OPPFØLGING AV PROSJEKTET
NSD vil følge opp ved planlagt avslutning for å avklare om behandlingen av personopplysningene er avsluttet.

Lykke til videre med prosjektet!

Kontaktperson hos NSD: Karin Lillevold
Tlf. Personverntjenester: 55 58 21 17 (tast 1)

28.08.2019 - Vurdert

NSD har vurdert endringen registrert 27.08.2019.

Det er vår vurdering at behandlingen av personopplysninger i prosjektet vil være i samsvar med personvernlovgivningen så fremt den gjennomføres i tråd med det som er dokumentert i meldeskjemaet med vedlegg den 28.08.2019. Behandlingen kan fortsette.

OPPFØLGING AV PROSJEKTET
NSD vil følge opp underveis (hvert annet år) og ved planlagt avslutning for å avklare om behandlingen av personopplysningene er avsluttet/pågår i tråd med den behandlingen som er dokumentert.

Lykke til videre med prosjektet!

Kontaktperson hos NSD: Karin Lillevold
Tlf. Personverntjenester: 55 58 21 17 (tast 1)

15.03.2019 - Vurdert

Det er vår vurdering at behandlingen vil være i samsvar med personvernlovgivningen, så fremt den gjennomføres i tråd med det som er dokumentert i meldeskjemaet 15.03.2019 med vedlegg, samt i meldingsdialogen mellom innmelder og NSD.

MELD VESENTLIGE ENDRINGER
Dersom det skjer vesentlige endringer i behandlingen av personopplysninger, kan det være nødvendig å melde dette til NSD ved å oppdatere meldeskjemaet. Før du melder inn en endring, oppfordrer vi deg til å lese om hvilke type endringer det er nødvendig å melde:
https://nsd.no/personvernombud/meld_prosjekt/meld_endringer.html

Du må vente på svar fra NSD før endringen gjennomføres.

TYPE OPPLYSNINGER OG VARIGHET
Prosjektet vil behandle særlige kategorier av personopplysninger om helse og alminnelige personopplysninger frem til 31.12.2021.

LOVLIG GRUNNLAG
Prosjektet vil innhente samtykke fra de registrerte til behandlingen av personopplysninger. Vår vurdering er at prosjektet legger opp til et samtykke i samsvar med kravene i art. 4 nr. 11 og art. 7, ved at det er en frivillig, spesifikk, informert og utvetydig bekreftelse, som kan dokumenteres, og som den registrerte kan trekke tilbake.

Lovlig grunnlag for behandlingen vil dermed være den registrertes uttrykkelige samtykke, jf.

personvernforordningen art. 6 nr. 1 a), jf. art. 9 nr. 2 bokstav a, jf. personopplysningsloven § 10, jf. § 9 (2).

PERSONVERNPRINSIPPER
NSD vurderer at den planlagte behandlingen av personopplysninger vil følge prinsippene i personvernforordningen om:

- lovlighet, rettferdighet og åpenhet (art. 5.1 a), ved at de registrerte får tilfredsstillende informasjon om og samtykker til behandlingen
- formålsbegrensning (art. 5.1 b), ved at personopplysninger samles inn for spesifikke, uttrykkelig angitte og berettigede formål, og ikke viderebehandles til nye uforenlige formål
- dataminimering (art. 5.1 c), ved at det kun behandles opplysninger som er adekvate, relevante og nødvendige for formålet med prosjektet
- lagringsbegrensning (art. 5.1 e), ved at personopplysningene ikke lagres lengre enn nødvendig for å oppfylle formålet

DE REGISTRERTES RETTIGHETER
Så lenge de registrerte kan identifiseres i datamaterialet vil de ha følgende rettigheter: åpenhet (art. 12), informasjon (art. 13), innsyn (art. 15), retting (art. 16), sletting (art. 17), begrensning (art. 18), underretning (art. 19), dataportabilitet (art. 20).

NSD vurderer at informasjonen som de registrerte vil motta oppfyller lovens krav til form og innhold, jf. art. 12.1 og art. 13.

Vi minner om at hvis en registrert tar kontakt om sine rettigheter, har behandlingsansvarlig institusjon plikt til å svare innen en måned.

FØLG DIN INSTITUSJONS RETNINGSLINJER
NSD legger til grunn at behandlingen oppfyller kravene i personvernforordningen om riktighet (art. 5.1 d), integritet og konfidensialitet (art. 5.1. f) og sikkerhet (art. 32).

Prosjektet fremstår som et samarbeidsprosjekt mellom flere institusjoner. Dersom det skal deles personopplysninger mellom institusjoner forutsetter vi at dette er regulert i avtaler om felles behandlingsansvar, jf. personvernforordningen art. 26.

Emendo er databehandler i prosjektet. NSD legger til grunn at behandlingen oppfyller kravene til bruk av databehandler, jf. art 28 og 29.

For å forsikre dere om at kravene oppfylles, må dere følge interne retningslinjer og eventuelt rådføre dere med behandlingsansvarlig institusjon.

OPPFØLGING AV PROSJEKTET
NSD vil følge opp ved planlagt avslutning for å avklare om behandlingen av personopplysningene er avsluttet.

Lykke til med prosjektet!

Kontaktperson hos NSD: Øivind Armando Reinertsen
Tlf. Personverntjenester: 55 58 21 17 (tast 1)

Appendix 3

Information letter about Papers I-II & the participants' informed consent forms

Vil du delta i forskningsprosjektet

”InnArbeid”?

Du er invitert til å være med i et forskningsprosjekt som heter InnArbeid. Vi ønsker å finne ut av hvordan det oppleves å være med i et slikt forskningsprosjekt og vi lurer derfor på om du kunne tenke deg å hjelpe oss med dette?

Hva vil vi finne ut av?

Vi skal finne ut hvordan ungdommer opplever å være med i et forskningsprosjekt og hva som er viktig for ungdommene underveis. Vi ønsker også å finne ut om hvordan det er lurt å legge til rette for at det skal være meningsfullt å delta i slike forskningsprosjekter i framtiden.

Hvem er vi?

Universitetet i Agder er ansvarlig for prosjektet. Vi samarbeider med: Songdalen kommune, Arkitektur- og designhøgskolen i Oslo, Grimstad kommune, Egde Consulting, Stiftelsen Mjåvann arbeidstreningssenter (Blå Kors Arbeid og Inkludering), NHO Agder, JodaCare, Norsk forbund for utviklingshemmede (Vest Agder) og Vest Agder fylkeskommune.

Hvorfor får du spørsmål om å delta?

Vi spør deg fordi du har takket ja til å være med i forskningsprosjektet InnArbeid og vi vil undersøke hvordan du synes det er å delta. Vi vil også vite noe om hva som bidro til opplevelsen du hadde.

Hva innebærer det for deg å delta?

Hvis du samtykker til deltagelse, vil du bli invitert til å delta i intervjuer om din opplevelse av møtene i InnArbeid prosjektet. Intervjuene vil vare i ca. 30 minutter. I intervjuene vil vi spørre om hva som har vært viktig i innovasjonsprosessen, hva som var positivt og hva som opplevdes om utfordrende. Vi ønsker vil også spørre om hva du synes om å samarbeide med de andre deltakerne i møtene. Det kan være om du synes alle kom til ordet eller synes det var hyggelig. Ved disse intervjuene ønsker vi å ta lydopptak og notater. Det kan også være at noen av møtene blir observert. Når vi observerer vil vi se etter situasjoner og episoder som kan si noe om hvordan det er å være med på møtene.

Videre vil det bli tatt bilder i forbindelse med møtene. Disse bildene vil bli brukt til å få mer innsikt i hvordan det var å være med på møtene. Bildene som er tatt på møtene kan også presenteres ved anledninger der InnArbeid skal vise frem prosessen i forskningsprosjektet.

Det er frivillig å delta

Det er frivillig å delta i prosjektet. Hvis du velger å delta, kan du når som helst trekke samtykke tilbake uten å oppgi noen grunn. Alle opplysninger om deg vil da bli anonymisert. Det vil ikke ha noen negative konsekvenser for deg hvis du ikke vil delta eller senere velger å trekke deg.

Ditt personvern – hvordan vi oppbevarer og bruker dine opplysninger

Vi vil bare bruke opplysningene om deg til formålene vi har fortalt om i dette skrivet. Vi behandler opplysningene konfidensielt og i samsvar med personvernregelverket. Kun forskere knyttet til prosjektet vil få adgang til opplysningene. Det vil ikke være mulig å identifisere deg i resultatene av studien når disse publiseres. Navnet og kontaktopplysningene dine vil vi erstatte med en kode som lagres på egen navneliste adskilt fra øvrige data og datamaterialet vil vi lagre på forskningsserver.

Lydopptak fra møtene vil transkriberes (skrives som tekst) av bedriften Emendo. I forbindelse med dette skriver de under en taushetserklæring, som sikrer at din informasjon ikke deles med andre.

Hva skjer med opplysningene dine når vi avslutter forskningsprosjektet?

Prosjektet skal etter planen avsluttes 31. desember 2021. Alle personopplysningene vil da slettes.

Dine rettigheter

Så lenge du kan identifiseres i datamaterialet, har du rett til:

- innsyn i hvilke personopplysninger som er registrert om deg,

- å få rettet personopplysninger om deg,

- få slettet personopplysninger om deg,

- få utlevert en kopi av dine personopplysninger (dataportabilitet), og

- å sende klage til personvernombudet eller Datatilsynet om behandlingen av dine personopplysninger.

Hva gir oss rett til å behandle personopplysninger om deg?

Vi behandler opplysninger om deg basert på ditt samtykke.

På oppdrag fra Universitetet i Agder har NSD – Norsk senter for forskningsdata AS vurdert at behandlingen av personopplysninger i dette prosjektet er i samsvar med personvernregelverket.

Hvor kan jeg finne ut mer?

Hvis du har spørsmål til studien, eller ønsker å benytte deg av dine rettigheter, ta kontakt med:

- Elin Thygesen, tlf. 91 57 15 15, e-post: elin.thygesen@uia.no ved Universitetet i Agder.
- Mugula Chris Safari, tlf. 96 67 39 30, e-post: chris.safari@uia.no ved Universitetet i Agder.
- Vårt personvernombud: Ina Danielsen, tlf: 452 54 401, e-post: ina.danielsen@uia.no
- NSD – Norsk senter for forskningsdata AS, på epost (personverntjenester@nsd.no) eller telefon: 55 58 21 17.

Med vennlig hilsen

Mugula Chris Safari

PhD stipendiat

Samtykkeerklæring

Jeg har mottatt og forstått informasjon om prosjektet InnArbeid, og har fått anledning til å stille spørsmål. Jeg samtykker til:

☐ å delta i individuelle intervju

☐ å delta i gruppeintervju

☐ bilde, observasjon og lydopptak

Jeg samtykker til at mine opplysninger behandles frem til prosjektet er avsluttet, ca. desember 2021.

(Underskrift, dato)

Appendix 4

Information letter about Paper IV & the participants’ informed consent form

Vil du delta i forskningsprosjektet ”InnArbeid”?

Vi er en gruppe forskere ved Universitetet i Agder som har et prosjekt som heter InnArbeid. Vi ønsker å hjelpe ungdommer med utviklingshemming som går på skolen og som jobber. Vi lurer på om du kunne tenke deg å hjelpe oss med dette.

Hva vil vi finne ut av?
Vi skal finne ut hvordan ungdommer kan finne seg en jobb. Vi vil finne ut hva som er lett eller vanskelig når du skal slutte på skolen og begynne å jobbe. Vi vil finne ut hva som kan hjelpe deg, de som jobber på skolen, og de på jobben.

Hvem er vi?
Universitetet i Agder er ansvarlig for prosjektet. Prosjektet skjer i samarbeid mellom Universitetet i Agder, Songdalen kommune, Arkitektur- og designhøgskolen i Oslo, Grimstad kommune, Egde Consulting, Stiftelsen Mjåvann arbeidstreningssenter, NHO Agder, JodaCare, Norsk forbund for utviklingshemmede (Vest Agder) og Vest Agder fylkeskommune.

Hvorfor spør vi deg?
Vi spør deg fordi vi vil vite hvordan du synes det er å jobbe. Vi vil også vite hvordan du har det i jobben din. Vi har fått tips fra noen du kjenner om at du kanskje kan hjelpe oss. Vi vil spørre det om hva du synes er viktig på jobben. Vi vil spørre deg om hvordan du synes jobben din skal være.

Hva betyr det for deg å delta?
Hvis du ønsker å delta, vil vi spørre deg om du kan bruke telefonen din til å ta noen bilder på veien til/fra jobb eller skole. Vi ønsker ikke at du tar bilder av personer, men av ting eller steder som du opplever som viktige (kan også være dyr). Etterpå ønsker vi at du viser oss bildene og forteller oss om din vei til jobb eller skole.

Det er frivillig
Dette er bare et spørsmål om å delta. Du trenger ikke å si ja. Hvis du sier ja, men senere ikke vil være med likevel, er det bare si fra til oss. Det er helt ok. Da sier du det for eksempel til noen på bolig eller dine foreldre. Eller du kan ringe til Elin som leder prosjektet på telefonnummer 91 57 15 15.

Hvordan bruker vi det du har sagt og hvordan sparer vi på lydopptakene og bildene
Det vi får vite kommer vi kun til å bruke i forskningen. Hvis du snakker litt om hvordan du har det, eller forteller noe du har opplevd eller lært på jobb, kommer vi kanskje til å skrive om det. Men ingen får vite at det er du som har sagt det.

Hvis du for eksempel sier: «Jeg liker ikke å begynne på jobben så tidlig» når vi snakker sammen, vil vi fortelle det videre sånn her: «En av de vi snakket med likte ikke å begynne så tidlig på jobben». Vi vil aldri si navnet ditt.

Navnet ditt og kontaktopplysningene dine byttes ut med en kode som skrives på en navneliste som ligger et annet sted enn de andre notatene, bildene og lydopptakene våre.

Lydopptak fra møtene vil skrives ut av et firma som er gode til å skrive fort. De kommer ikke til å snakke med noen om det de hører.

Hva skjer til slutt
Når prosjektet er ferdig i 2021 vil navnet ditt og lydbåndopptakene bli slettet.

Dine rettigheter
Hvis du kan kjennes igjen i noe av det som vi har samlet inn så har du rett på dette:

- Se hva vi skrevet ned om deg,
- Rette opp hvis vi har skrevet noe feil om deg.
- At vi sletter noe vi har skrevet om deg som du er uenig i eller ikke liker
- Du kan få et papir der det vi har skrevet om deg står
- Du kan sende klage hvis du er uenig i noe av det vi har gjort. Denne sender du til personvernombudet som heter Ina Danielsen eller til Datatilsynet.

Hva får vi lov til
Hvis du er enig kan vi få lov til å skrive ned og ta lydopptak og bilder når du er til stede. Vi vil også spørre foreldrene dine om det er i orden.

Hvor kan jeg finne ut mer?
Hvis du har spørsmål eller vil benytte deg av dine rettigheter kan du kontakte:

- Elin Thygesen, tlf. 91 57 15 15, e-post: elin.thygesen@uia.no ved Universitetet i Agder.
- Mugula Chris Safari, tlf. 96 67 39 30, e-post: chris.safari@uia.no ved Universitetet i Agder.
- Vårt personvernombud: Ina Danielsen, tlf: 452 54 401, e-post: ina.danielsen@uia.no
- NSD – Norsk senter for forskningsdata AS, på epost (personverntjenester@nsd.no) eller telefon: 55 58 21 17.

Med vennlig hilsen

Mugula Chris Safari
PhD stipendiat

Samtykkeerklæring

Jeg har mottatt og forstått informasjon om prosjektet InnArbeid, og har fått anledning til å stille spørsmål.

- ☐ En person fra prosjektet har forklart meg hva de skal gjøre i prosjektet InnArbeid
- ☐ Jeg samtykker til å ta bilder på veien til/fra jobb eller skole
- ☐ Jeg samtykker til å gå på intervju med en forsker
- ☐ Jeg samtykker til at det blir tatt bilder og lydopptak av det jeg sier

Jeg samtykker til at mine opplysninger behandles frem til prosjektet er avsluttet, ca. desember 2021.

(Navn, dato)

Appendix 4B

Information letter to proxies/parents about Paper IV

Vil du delta i forskningsprosjektet ”InnArbeid”?

Dette er en invitasjon til å delta i forskningsprosjektet InnArbeid, hvor formålet er å hjelpe personer med utviklingshemming i overgangen mellom skole og arbeid gjennom teknologiske løsninger. I dette skrivet gir vi deg informasjon om målene for prosjektet og hva deltakelse vil innebære for ditt barn/deltakeren.

Formål

Forskningsprosjektet InnArbeid vil utvikle innovative tjenester og teknologi for at personer med utviklingshemming kan finne, skaffe og holde på et arbeid. Det innebærer en ny tjenestemodell med ulike former for teknologi, som vil støtte overgangen fra skole til arbeid og videre deltakelse i arbeidslivet. InnArbeid vil identifisere barrierer og behov for overgang fra skole til arbeidsliv og utvikle innovative teknologistøttede tjenester som møter behovene.

Hvem er ansvarlig for forskningsprosjektet?

Universitetet i Agder er ansvarlig for prosjektet.

Prosjektet skjer i samarbeid mellom Universitetet i Agder, Songdalen kommune, Arkitektur- og designhøgskolen i Oslo, Grimstad kommune, Egde Consulting, Stiftelsen Mjåvann arbeidstreningssenter, NHO Agder, JodaCare, Norsk forbund for utviklingshemmede (Vest Agder) og Vest Agder fylkeskommune.

Hvorfor får ditt barn/deltakeren spørsmål om å delta?

Vi henvender oss til deg fordi vi ønsker å forbedre overgangen fra skole til arbeidsliv for personer med utviklingshemming. Vi har fått din kontaktinformasjon fra en samarbeidspartner i prosjektet eller en annen informant som tror att ditt barn/deltakeren har verdifulle erfaringer å dele med oss.

Hva innebærer det for ditt barn/deltakeren å delta?

Vi ønsker å spørre ditt barn/deltakeren om han eller hun kan bruke telefonen sin til å ta noen bilder enten på veien til/fra jobb eller skole. Vi ønsker ikke at det tas bilder av personer, men av ting eller steder som opplever som har betydning for jobben, skolen eller veien dit (kan også være dyr). Etterpå ønsker at bildene blir vist og være utgangspunkt for samtale/intervju.

Ved disse møtene ønsker vi å ta lydopptak, bilder og notater.

Det er frivillig å delta

Det er frivillig å delta i prosjektet. Hvis du velger å la ditt barn/deltakeren delta, kan du, han eller hun når som helst trekke samtykke tilbake uten å oppgi noen grunn. Alle opplysninger om ditt barn vil da bli anonymisert. Det vil ikke ha noen negative konsekvenser for ditt barn/deltakeren hvis han eller hun ikke vil delta eller senere velger å trekke seg.

Ditt barns personvern – hvordan vi oppbevarer og bruker opplysningene

Vi vil bare bruke opplysningene om ditt barn til formålene vi har fortalt om i dette skrivet. Vi behandler opplysningene konfidensielt og i samsvar med personvernregelverket. Kun forskere knyttet til prosjektet vil få adgang til opplysningene. Det vil ikke være mulig å identifisere ditt barn i resultatene av studien når disse publiseres. Navnet og kontaktopplysningene til ditt barn vil vi erstatte med en kode som lagres på egen navneliste adskilt fra øvrige data og datamaterialet vil vi lagre på forskningsserver.

Lydopptak fra møtene vil transkriberes (skrives som tekst) av bedriften Emendo. I forbindelse med dette skriver de under en taushetserklæring, som sikrer at informasjonen ikke deles med andre.

Hva skjer med opplysningene dine når vi avslutter forskningsprosjektet?

Prosjektet skal etter planen avsluttes 31. desember 2021. Alle personopplysningene vil da slettes.

Dine rettigheter

Så lenge ditt barn kan identifiseres i datamaterialet, har du og ditt barn rett til:

- innsyn i hvilke personopplysninger som er registrert om ditt barn/deltakeren,
- å få rettet personopplysninger om ditt barn/deltakeren,
- få slettet personopplysninger om ditt barn/deltakeren,
- få utlevert en kopi av ditt barns/deltakerens personopplysninger (dataportabilitet), og
- å sende klage til personvernombudet eller Datatilsynet om behandlingen av ditt barns/deltakerens personopplysninger.

Hva gir oss rett til å behandle personopplysninger om deg?

Vi behandler opplysninger om ditt barn basert på ditt samtykke. Vi vil også innhente samtykke fra ditt barn.

På oppdrag fra Universitetet i Agder har NSD – Norsk senter for forskningsdata AS vurdert at behandlingen av personopplysninger i dette prosjektet er i samsvar med personvernregelverket.

Hvor kan jeg finne ut mer?

Hvis dere har spørsmål til studien, eller ønsker å benytte dere av deres rettigheter, ta kontakt med:

- Elin Thygesen, tlf. 91 57 15 15, e-post: elin.thygesen@uia.no ved Universitetet i Agder.
- Mugula Chris Safari, tlf. 96 67 39 30, e-post: chris.safari@uia.no ved Universitetet i Agder.
- Vårt personvernombud: Ina Danielsen, tlf: 452 54 401, e-post: ina.danielsen@uia.no
- NSD – Norsk senter for forskningsdata AS, på epost (personverntjenester@nsd.no) eller telefon: 55 58 21 17.

Med vennlig hilsen

Mugula Chris Safari
PhD stipendiat

Samtykkeerklæring

Jeg har mottatt og forstått informasjon om prosjektet InnArbeid, og har fått anledning til å stille spørsmål. Jeg samtykker til:

☐ at mitt barn/deltakeren kan delta i individuelt intervju
☐ at mitt barn/deltakeren tar bilder av veien til/fra jobb eller skole
☐ bilde og lydopptak av mitt barn/deltakeren

Jeg samtykker til at mitt barns opplysninger behandles frem til prosjektet er avsluttet, ca. desember 2021.

(Signatur, dato)

Appendix 4C

Information letter about Paper III & the participants' consent form

Vil du delta i forskningsprosjektet ”InnArbeid”?

Dette er en invitasjon til å delta i forskningsprosjektet InnArbeid, hvor formålet er å hjelpe personer med utviklingshemming i overgangen mellom skole og arbeid gjennom teknologiske løsninger. I dette skrivet gir vi deg informasjon om målene for prosjektet og hva deltakelse vil innebære.

Formål

Forskningsprosjektet InnArbeid vil utvikle innovative tjenester og teknologi for at personer med utviklingshemming kan finne, skaffe og holde på et arbeid. Det innebærer en ny tjenestemodell med ulike former for teknologi, som vil støtte overgangen fra skole til arbeid og videre deltakelse i arbeidslivet. InnArbeid vil identifisere barrierer og behov for overgang fra skole til arbeidsliv og utvikle innovative teknologistøttede tjenester som møter behovene.

Hvem er ansvarlig for forskningsprosjektet?

Universitetet i Agder er ansvarlig for prosjektet.

Prosjektet skjer i samarbeid mellom Universitetet i Agder, Songdalen kommune, Arkitektur- og designhøgskolen i Oslo, Grimstad kommune, Egde Consulting, Stiftelsen Mjåvann arbeidstreningssenter, NHO Agder, JodaCare, Norsk forbund for utviklingshemmede (Vest Agder) og Vest Agder fylkeskommune.

Hvorfor får du spørsmål om å delta?

Vi henvender oss til deg fordi vi ønsker å forske på design og innovasjonsprosesser der personer med utviklingshemming deltar. Vi har fått din kontaktinformasjon fra en samarbeidspartner i prosjektet eller en annen informant som tror at du har verdifulle erfaringer å dele med oss.

Hva innebærer det for deg å delta?

Vi ønsker å spørre/intervjue deg om erfaringene med å delta i ulike samskapings- og design aktiviteter der personer med utviklingshemming har også deltatt. Hensikten med intervjuene er få mer kunnskap om hvordan vi kan tilrettelegge og engasjere personer med utviklingshemming i design av teknologi.

I intervjuet vil vi spørre om hva som har vært viktig i aktivitetene, hva som var positivt og hva som oppleves om utfordrende. Videre vil vi spørre noe om engasjement, motivasjon og sosiale elementer underveis i aktivitetene.

Ved disse intervjuene ønsker vi å ta lydopptak og notater. Intervjuene vil vare i omtrent 30 minutter.

Det er frivillig å delta

Det er frivillig å delta i prosjektet. Hvis du velger å delta, kan du når som helst trekke samtykke tilbake uten å oppgi noen grunn. Alle opplysninger om deg vil bli anonymisert. Det vil ikke ha noen negative konsekvenser for deg hvis du ikke vil delta eller senere velger å trekke deg.

Ditt personvern – hvordan vi oppbevarer og bruker opplysningene

Vi vil bare bruke opplysningene om deg til formålene vi har fortalt om i dette skrivet. Vi behandler opplysningene konfidensielt og i samsvar med personvernregelverket. Kun forskere knyttet til prosjektet vil få adgang til opplysningene. Det vil ikke være mulig å identifisere deg i resultatene av studien når disse publiseres. Navnet og kontaktopplysninger vil vi erstatte med en kode som lagres på egen navneliste adskilt fra øvrige data og datamaterialet vil vi lagre på forskningsserver.

Lydopptak fra møtene vil transkriberes (skrives som tekst) av Mugula Chris Safari.

Hva skjer med opplysningene dine når vi avslutter forskningsprosjektet?
Prosjektet skal etter planen avsluttes 31.08.2022. Alle personopplysningene vil da slettes.

Dine rettigheter
Så lenge du kan identifiseres i datamaterialet, har du rett til:

- innsyn i hvilke personopplysninger som er registrert om deg,
- å få rettet personopplysninger om deg,
- få slettet personopplysninger om deg,
- få utlevert en kopi av dine personopplysninger (dataportabilitet), og
- å sende klage til personvernombudet eller Datatilsynet om behandlingen av dine personopplysninger.

Hva gir oss rett til å behandle personopplysninger om deg?
Vi behandler opplysninger om deg basert på din samtykke.

På oppdrag fra Universitetet i Agder har NSD – Norsk senter for forskningsdata AS vurdert at behandlingen av personopplysninger i dette prosjektet er i samsvar med personvernregelverket.

Hvor kan jeg finne ut mer?
Hvis dere har spørsmål til studien, eller ønsker å benytte dere av deres rettigheter, ta kontakt med:

- Elin Thygesen, tlf. 91 57 15 15, e-post: elin.thygesen@uia.no ved Universitetet i Agder.
- Mugula Chris Safari, tlf. 96 67 39 30, e-post: chris.safari@uia.no ved Universitetet i Agder.
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- NSD – Norsk senter for forskningsdata AS, på epost (personverntjenester@nsd.no) eller telefon: 55 58 21 17.

Med vennlig hilsen

Mugula Chris Safari
PhD stipendiat

Samtykkeerklæring

Jeg har mottatt og forstått informasjon om prosjektet InnArbeid, og har fått anledning til å stille spørsmål. Jeg samtykker til:

- ☐ å delta i individuelt intervju
- ☐ lydopptak

Jeg samtykker til at mine opplysninger behandles frem til prosjektet er avsluttet, ca. desember 2022.

(Signatur, dato)

Appendix 5

Interview guide for Paper I, II, IV

Intervju mal med ungdommen angående opplevelse av deltakelse.

Hva synes du om å være med? Har du vært med mange ganger?

Kan du fortelle om hvordan du ble tatt imot da du kom?

Kan du fortelle om hva du gjorde på møtene?

Hvis det er behov for å utdype:

- Hva synes du om det som skjedde på møtene?
- Synes du at du ble hørt på? Fikk du sagt det du ønsket?
- Fikk du støtte og hjelp av de andre?

Synes du at det var viktig å være med? Og hvorfor?

Hvordan synes du det var jobbe med de andre på møtene? Hvorfor synes du det?

Hva synes du om oppgavene dere fikk? Har du noen kommentarer om hvordan oppgavene skulle gjøres?

Har du lært noe mens du har vært med? Fortell om mer om det.

Er du fornøyd med det du gjorde? (Ditt bidrag) Hvorfor?

Er det noe mer du vil fortelle?

Hva synes du om lengden på møtene?

Hvis du blir invitert, ville du vært med igjen?

Appendix 5B

Introduction to interviews (Papers I, II, IV)

INTRO TIL INTERVJU:

Du er i ferd med å være med i et intervju. I intervjuer diskuterer folk ideer og tanker med hverandre. Jeg har en liste med spørsmål med meg, og jeg vil lese dem en om gangen. Etter hvert spørsmål jeg stiller, vil du få sjansen til å svaret på spørsmålet og si det du mener. Når du har fortalt meg det du mener, så går vi videre til neste spørsmål. Når vi nærmer oss slutten, vil jeg fortelle deg om det. Det er ingen gale svar. Jeg vil bare vite hva du synes eller mener.

Appendix 6

Interview guide for Paper III

Interview guide facilitators

1) Kan du fortelle om din bakgrunn og hva du jobber nå?

- Hva er din erfaring med å jobbe med personer med utviklingshemming?

- Har du deltatt i design aktiviteter tidligere? Hvilken rolle?

2) Kan du fortelle om din rolle i design aktivitetene?

- Hvor mange aktiviteter var du med på?

- Kan du si noe om ditt bidrag før selve aktiviteten?

- Kan du si noe om din rolle underveis i aktiviteten?

- Hvordan opplevde du å ha en slik rolle? (Vanskelig, lett, gøy osv) + Hvorfor?

3) Kan du fortelle om hvordan du tilrettela aktivitetene for deltakerne? Gi konkrete eksempler (beskriv en situasjon)

- Kan du fortelle litt om deltakerne trengte hjelp eller støtte i aktivitetene? (Evt.om hva slags hjelp de trengte?)

- Kan du gi konkrete eksempler/eller referere til konkrete situasjoner der du hjalp en deltaker?

- Kan du fortelle hva du gjorde for å hjelpe deltakeren?

- Kan du si kort som resultatet av hjelpen du ga? (Gikk det bra eller ikke? Evt. refleksjon på hvorfor det gikk slik)

- I ettertid, hvis du havnet i samme situasjon, har du noen tanker om hva du ville gjort?

-Hvordan ble du gjort oppmerksom på om noen trengte hjelp? (Kroppsspråk osv.)

- Kan du gi noen konkrete eksempler på hvordan du ble oppmerksom på at noen trengte hjelp?

-Hadde deltakerne noen spesifikke utfordringer? - Hvilke utfordringer så du at deltakerne hadde underveis i aktivitetene?

3) Hvordan var det å delta i design aktiviteter med personer med utviklingshemming?

- Hva var positivt (for deg som tilrettelegger) med å delta i design aktivitetene? Hvorfor? - Hvilke positive kvaliteter mener du at denne målgruppa kan bidra med i design aktiviteter?

- Hva var utfordringene (for deg som tilrettelegger) med å delta i design aktivitetene? Hvorfor?

Hvilke utfordringer kan denne målgruppa ha i design aktiviteter?

- Hvordan synes du at designaktivitetene var lagt opp?

Hvordan var aktivitetene lagt opp slik at du kunne tilrettelegge for deltakerne underveis?

4) Er det noe du tenker bør være annerledes i designaktiviteter med personer med utviklingshemming? (Gi konkrete eksempler)

5) Hvis du skulle lagt til rette for deltagelse i designaktiviteter igjen, hvordan hadde du gjort det? (Har aktivitetene du har vært med på påvirket hvordan du hadde lagt til rette i lignende aktiviteter?)

7) Har du noen råd til andre som skal tilrettelegge (i lik rolle som du har hatt) for personer med utviklingshemming i design aktiviteter?

8) Har du andre opplevelser eller tanker du om din deltakelse som du ønsker å dele med oss?

Appendix 7

Field notes template for Papers I-III

Observasjonsmal

Observasjonsmalen som vil bli brukt som utgangspunkt for observasjon av deltakerne. Observasjonene vil fokusere på situasjoner der ungdommen engasjeres. Observasjonene vil være av spesielle interaksjoner i workshopen (Blir spurt, spør, velger, gjør noe utover å prate, informeres om noe, osv.)

Situasjon: Beskrivelse av det som skjer:	**Involverte:** Eks. Ungdommen-forsker Ungdommen-lærer/proxy	**Tematikk:** (I interaksjonen)

Se etter faktorer på individ nivå som kan hindre deltakelse:

Alder

Kjønn

Språk

Forståelse

Appendix 8

Smileyometer scale (Paper I)

Hvor mye likte du aktiviteten der du hjalp til med å lage/designe app?

Velg et av ansiktene for å se hvor mye du likte eller ikke likte det.





Fryktelig	Dårlig	Bra	Veldig bra	Strålende

Appendix 9

Introduction to Photovoice (Paper I)

Introduksjon til Photovoice.

Nå skal de som ønsker ta noen bilder. Vi tar bilder for å huske og vise noe om det vi tenker og mener. Jeg har en liste av forskjellige ting jeg vil dere skal tenke på når dere tar bilder. Jeg vil lese dem en om gangen før vi tar bildene. Etter at jeg har lest, vil du få muligheten til å ta et bilde av det du vil. Det er ingen bilder som er feil, bare ta bilder at det du selv mener passer. Jeg ønsker bare å få et bilde av det du mener.

Appendix 9B

Photovoice prompts (Paper I)

Kartlegging av oppmøte:

Ta to bilder; som viser det du er med på.

For eks. Hvis du skulle fortelle noen som hva du er med på i dag, hva hadde du vist bilder av?

Du kan også ta bilder som sier noe som hvorfor du er med, eller ønsker å være med.

Ta bilder av hva som helst (*steder, ting, deg selv osv*)

Kartlegging av involvering:

Ta to bilder; av det beste med å være her.

For eks. Hvis du skulle fortelle noen om det du synes var gøyest med å være med, hva hadde du vist bilder av?

Ta bilder av hva som helst *(steder, ting, deg selv osv)*

Kartlegging av engasjement:

Ta to bilder av noe som har vært viktig for deg idag.

Du kan også ta bilder som sier noe om hva du har gjort. Hva som var lett/vanskelig eller noe som gjorde deg glad, stresset, trist, redd eller rolig.

Appendix 10

Reflection questions (Log) - Facilitators (Paper II)

- Hva synes du om workshopen i dag?

- Hvordan bidro ungdommene? Har du noen eksempler?

- Hvordan opplevde du ungdommenes engasjement i workshopen? Har du noen eksempler på lite/mye engasjement?

- Har du lært noe nytt om workshops med ungdommer i denne målgruppa etter aktiviteten i dag?

-Er det noe mer du ønsker å fortelle oss?