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# The digital communities of young individuals living with cognitive disabilities

*Mapping the use and meaning of digital technology with capable youth*

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# THE DIGITAL COMMUNITIES OF YOUNG INDIVIDUALS LIVING WITH COGNITIVE DISABILITIES

## MAPPING THE USE AND MEANING OF DIGITAL TECHNOLOGY WITH CAPABLE YOUTH

**BY**
**DITTE LYSTBÆK WEBER**

DISSERTATION SUBMITTED 2022

AALBORG UNIVERSITY
DENMARK

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Dissertation submitted

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# CV

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I have a bachelor's degree in public health from Aarhus University (2013) and a Master of Science in global health from Copenhagen University (2017). I started my PhD study in 2018. I have been a caretaker for youth living with disabilities with the Danish disability organization, 'Foreningsfællesskabet Ligeværd' from 2016-17 and a caretaker for people with physical disabilities at Aarhus and Silkeborg Municipality from 2008-10. I was a research assistant in Rwanda from 2015-16 with Center for Global Health, Aarhus University, working with primary health care in Rwanda, and from 2012-17 I volunteered in a project with International Medical Cooperation Committee (IMCC), which sought to promote sexual and reproductive health education in Tanzania.

From my educational background, PhD study and working life I have gained scientific competencies in collecting, analysing, and disseminating research and knowledge about and with people living with cognitive disabilities and other vulnerable groups. This includes designing participatory tools and techniques for data collection with people living with cognitive disabilities. I have extensive competencies in qualitative data analysis and interdisciplinary and international project management competences. In addition, I have teaching competencies from teaching and supervising Bachelor students at Techno-Anthropology, primarily within the eHealth Domaine (2018-2021), and teaching medical students in social and community medicine at the Faculty of Medicine & Pharmacology, Rwanda's National University (2015-16).

# ENGLISH SUMMARY

Disability research within the domain of health information technology tend to focus on individuals living with cognitive disabilities as passive users of digital technology in need of protection from the digital sphere and support from assistive technologies due to the adaptive, communication and interaction challenges they experience. Moreover, the concentration is mainly on the digital challenges rather than on managing and coping with these digital challenges.

In contrast to the paternalistic perspective on individuals living with cognitive disabilities adopted by extensive research within health information technology field, research also examine how this study population uses digital technology to maintain and develop social and romantic relationships. This research seeks to advance a perspective of the study population as active, independent, and capable users of digital technology. This PhD study adheres to the aforementioned perspective and approach and seeks to fill the current knowledge gaps in disability and health information technology studies concerning the participation in and development of digital relationships and communities by individuals living with cognitive disabilities for them to attain meaningful lives and distinct social identities. This is in addition to a core focus on the study population's abilities, aims, and learning possibilities in their digital lives. Specifically, this study aims to map and explain how young individuals living with cognitive disabilities use digital technology to maintain and develop relationships and communities. Empirically, the research objective is to identify and understand 1) the characteristics of digital technology use and value for the study population; 2) how digital technology forms and challenges the digital relationships of the study population; 3) how the study population manages their digital communities; and 4) their aims in terms of their digital activities and communities. Methodologically, a fifth objective is to determine how to include the study population in researching their digital lives.

To address the research aims and objectives, traditional qualitative methods of unstructured interviews, diaries, observations, and participatory workshops were utilised. The use of traditional qualitative methods to include the participants was made possible by the application of personally developed visual tangible artefacts. These visual tangible artefacts were: Talking Mats; probing with digital artefacts; digital snapshots and inspiration cards and they were used to map, communicate, and validate the empirical findings with the participants, as well as inspire reflections on future technology use and activities. This way, participants were included in the research on technology usage and meaning in their everyday lives. The main methodological contributions of this PhD study are the developed visual tangible artefacts, which serve as an enhanced model of inclusive research with the study population. The visual tangible artefacts were effective in accommodating the methodological and ethical challenges and allowed the participants inclusion in the

research on their digital technology use and the meaning they accord to this usage. Using the visual tangible artefacts made it possible to assign the participants an expert role and obtain perspectives and findings that would not have been possible to access otherwise. Other important elements to ensure a proper inclusion of participants and presentation of their points of view were to consider the role of the researcher, the practice, the camera when recording the study participants, ethical values, and norms, and to conduct a thorough data analysis.

The empirical findings show that young individuals living with cognitive disabilities participate in diverse communities of practice and use a multitude of technologies to develop and maintain meaningful relationships and communities. They negotiate which technologies are at the core of their lives, and their digital use, relationships and aims are dynamic. Notably, all participants value digital technology and find it meaningful in their lives. Digital technology creates a complex, comprehensive, and interconnected composition of artefact ecology and community of practice. The study participants engage in internal digital relationships and communities to maintain personal connections via and around digital technology. In addition, they participate in external digital relationships and communities to interact with individuals outside of their institutional sphere, via peripheral participation or in the context of international gaming platforms. Participants find these communities of practice meaningful as they foster togetherness, intimacy, fun, peer learning, joint enterprise, and recognition.

The participants often have to personalise and individualise their participation in digital relationships and communities due to challenges. These are digital harassment, digital separation, and digital disturbance. The study participants manage challenges in their digital relationships and communities using problem-focused coping responses: togetherness, collaboration, blocking and confrontation, as well as emotion-focused coping responses: acceptance, avoidance, and caution. The leveraging of these coping strategies demonstrates active and independent behaviour, as well as the capability to manage digital relationships and communities. The study participants further aim to acquire and develop their abilities to participate actively and independently in digital relationships and communities by producing digital content and enhancing their gaming and social skills with peers and other important community members.

In light of the foregoing, this PhD study contributes an advanced framework for mapping and understanding the complex composition and value of the digital relationships and communities of young individuals living with cognitive disabilities. In addition, the study highlights their digital abilities to participate in and manage digital relationships and communities of practice, with original findings regarding their digital coping strategies and aims for digital activities and communities.

# DANSK RESUME

I studier af og med personer med handicap indenfor sundhedsinformatik og teknologidomænet er den gængse opfattelse, at unge med kognitive handicap er passive brugere af digitale teknologier, der har brug for beskyttelse fra den digitale arena, og/eller at benytte assisterende teknologier, på grund af deres kommunikations- og interaktionsvanskeligheder. Forskning fokuserer ofte på de digitale udfordringer som unge med kognitive handicap oplever, fremfor hvordan de kan lære at håndtere de digitale udfordringer.

Modsat denne paternalistiske opfattelse af unge med kognitive handicap i eksisterende forskning indenfor sundhedsinformatik og teknologidomænet har forskning ligeså fokuseret på, og undersøgt, hvordan denne målgruppe kan bruge digitale teknologier til at skabe og vedligeholde sociale og romantiske relationer. Denne forskning forsøger at fremhæve et syn på unge med kognitive handicap som aktive, selvstændige og kompetente brugere af digitale teknologier. Dette ph.d.-projekt læner sig op ad sidstnævnte perspektiv og tilgang og forsøger at adresserer den nuværende videns kløft indenfor handicap og sundhedsinformatik domænet. Dette vedrører især et fokus på deltagelse i, og udvikling af, digitale relationer og fællesskaber, der kan bidrage til at opbygge et meningsfuldt liv og en social identitet, for unge med kognitive handicap. Hovedfokus for ph.d.-projektet er ligeså at fremhæve målgruppens evner, ambitioner og læringsmuligheder i deres digitale liv. Mere specifikt søger dette ph.d.-projekt at kortlægge og forklare hvordan unge med kognitive handicap bruger digitale teknologier til at vedligeholde og udvikle relationer og fællesskaber. Empirisk var målsætningerne at identificere og forstå 1) karakteristika for de digitale teknologier som målgruppen bruger og finder meningsfulde i deres liv, 2) hvordan digitale teknologier former og udfordrer digitale relationer og fællesskaber for de unge med kognitive handicap, 3) hvordan de unge håndterer deres digitale relationer og fællesskaber, og 4) hvilke ambitioner de har vedrørende deres digitale aktiviteter og fællesskaber. Metodisk var en femte målsætning at undersøge hvordan man kan inkluderer de unge med kognitive handicap i forskning omkring deres digitale liv.

Der er benyttet traditionelle kvalitative metoder til at undersøge den overordnede målsætning for forskningsprojektet og delmålsætninger. Disse var semistruktureret interviews, dagbøger, observationer, og participatoriske workshops. Det var muligt at udføre traditionelle kvalitative undersøgelser, der inkluderer målgruppen, ved at bruge visuelle og håndgribelige artefakter, som vi selv udviklede i forskningsteamet. Disse var Talende Måtter, digitale snapshots, undersøgelser med digitale artefakter, og inspirationskort. De visuelle og håndgribelige artefakter blev brugt til at kommunikere og validere de empiriske fund med deltagerne, som på den måde blev inkluderet i forskning omkring deres teknologi brug og den værdi som teknologibruget har for dem i deres dagligdag. Det overordnede metodiske bidrag fra dette ph.d.-studie er de visuelle og håndgribelige artefakter, som har bidraget til at videreudvikle en model

for inkluderende forskning med målgruppen. Brugen af disse gjorde det muligt at imødekomme metodiske og etiske udfordringer med målgruppen, og inkludere dem i forskning omkring deres digitale teknologibrug og den mening teknologibrugen har i deres liv. Brugen af de visuelle og håndgribelige artefakter gjorde det muligt at placere deltagerne i en ekspertrolle og opnå perspektiver og fund, som ikke ville have været mulige at tilgå på anden vis. Yderligere var det vigtigt at tage forskerrollen, praksisrollen, kameraets rolle (som vi brugte til at optage), etiske værdier og normer i betragtning, samt at udføre en dybdegående og grundig dataanalyse, for at sikre en ordentlig inklusion af deltagerne og fremstilling af deres synspunkter.

De empiriske fund viser at unge med kognitive handicap deltager i diverse digitale praksisfællesskaber og bruger adskillige digitale teknologier til at udvikle og vedligeholde relationer og fællesskaber. De forhandler om hvilke teknologier der er primære i deres liv, og deres digitale brug, relationer og ambitioner for teknologibrug er dynamisk. Fælles for alle deltagere er, at deres teknologibrug er med til at gøre deres tilværelse værdifuld og meningsfuld. De digitale teknologier skaber en kompleks, omfattende og interagerende sammensætning af en artefaktøkologi. De unge i dette ph.d.-projekt deltager i interne digitale relationer og fællesskaber, med et formål om at vedligeholde personlige relationer via og omkring digitale teknologier. Ligeså deltager de unge i eksterne digitale relationer og fællesskaber, med et formål om at interagere med andre udenfor deres institutionelle sfære, på internationale gaming platforme eller i den perifere deltagelse. Deltagerne finder disse praksisfællesskaber meningsfulde da de giver samvær, intimitet, underholdning, fælles læring, fælles forehavende og anerkendelse.

På trods af de fordele, som de digitale relationer og fællesskaber bringer, er deltagerne ofte nødt til at personalisere og individualisere deres deltagelse pga. udfordringer, som opstår i disse digitale relationer og fællesskaber. Udfordringerne er digital chikane, digital separation, og digitale forstyrrelser. Deltagerne håndterer udfordringer i deres digitale relationer og fællesskaber ved at bruge problem-fokuseret mestringsstrategier: samvær, samarbejde, blokering og konfrontation, og følelses-reguleret mestringsstrategier: accept, undgåelse, og forsigtighed. At kunne håndtere de udfordringer, som de unge møder i deres digitale relationer og fællesskaber demonstrerer en aktiv, selvstændighed og kompetent adfærd fra de unge. Deltagerne ønsker yderligere at lære og udvikle deres kompetencer til at deltage aktivt og selvstændigt i digitale relationer og fællesskaber, ved at producere digitalt indhold, øge deres gaming og sociale kompetencer, til at interagere med vigtige medlemmer af deres digitale fællesskaber.

Afslutningsvist bidrager dette ph.d.-studie med en avanceret teoretisk ramme for at kortlægge og forstå den komplekse sammensætning og værdi af digitale relationer og fællesskaber for unge med kognitive handicap. Ph.d.-projektet forsøger ligeså at fremhæve deres kompetencer til at deltage i, og håndtere, digitale relationer og

praksisfællesskaber, med originale fund omkring digitale mestringsstrategier og målsætninger for digitale aktiviteter og fællesskaber blandt målgruppen.

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I also want to thank my husband, Peter, for being both my partner in life and my PhD-partner. While it has been a challenge at times to do a PhD simultaneously (especially at the end), it has also been amazing that you are always able to understand what I am going through. I appreciate all our interesting discussions about our respective PhD studies, sharing of frustrations and victories, and mutual support. It has been amazing to share this experience with you.

While all my professional appreciation is inevitable, my parents and parents in law are the ones who are actually responsible for me being able to finish my PhD thesis on time. They have been there day, night, and weekends to take care of my daughter and making me healthy meals, when I needed to write. All the while giving me the impression that I have done them a favour by letting them spend time with their grandchild. You are truly amazing and greatly valued in my working and private life.

Also, a thank you to my amazing friends for always remembering to ask about my "other baby" (the PhD), taking care of everything on New Year's Eve, and tolerating me being even more forgetful and absent-minded than I usually am.

Lastly, I want to thank my daughter, Bjørk, for giving me some perspective on work-life balance and for reminding me almost every day that I can do so much more than I anticipate.

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# CHAPTER 1. BACKGROUND

*'Many people ask me: what is normal? Then I say that's a store' ~ P11*

## 1.1. INTRODUCING THE PHD PROJECT

This thesis presents the findings from a three-year PhD project entitled 'The digital communities of young individuals living with cognitive disabilities: Mapping the use and meaning of digital technology with capable youth'. The overall aim of the PhD project is to understand the digital use, activities, habits, values, needs, abilities and aims of young individuals living with cognitive disabilities, allocating particular attention to their digital relationships and communities. The premise behind this is the increase in digital technology mediating social and meaningful relationships, combined with the limited knowledge about the complexity of these digital relationships and communities. We aim to study this complexity, including how a study population, who experiences numerous challenges in their social encounters, manages their digital relationships (Seale, 2007; Wright, 2017a) and what they aim for in their digital activities and communities.

The PhD study is part of a larger research project examining and exploring how digital technology can be used as a social arena for young individuals living with cognitive disabilities. The DiGi logo in Figure 1 is intended to illustrate a focus on the sense of unity and community in a manifold and diverse study population not only in terms of their disabilities but also of their personalities, activities, and abilities. The research design for the DiGi project is shown in Figure 2. It represents how the research activities are carried out through fieldwork, evaluation, and implementation, in close collaboration with researchers and practitioners at three institutions for youth with special needs in Denmark, the natural environment where the digital communities are studied. In addition, there are activities in the 'laboratory', where the researchers facilitate the development of theories and strategies for digital communities. Results are disseminated through scientific publications and via reports, handbooks, and seminars to make the empirical findings accessible to practitioners and involve them as much as possible in the research process and evaluation.

Understanding how these young individuals use and value digital technology is the crucial initial and preparatory study that would inform the participatory design interventions and strategies that can expand upon the possibilities for forming and

maintaining digital relationships and expressing social identities among young individuals living with cognitive disabilities. Hence, the findings of this thesis constitute the foundation of the participatory design interventions conducted by a fellow PhD student (more on this in Section 1.4: academic positioning). They are also essential for the final research aim of the DiGi project, namely, integrating the digital strategies and insights into practice.

**Figure 1: Logo of the DiGi project**

**Figure 2: Project activities**

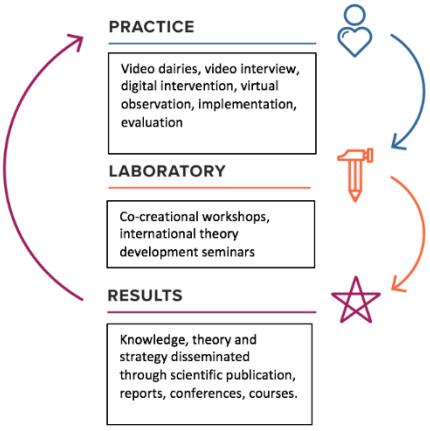



*Figure 1 portraits the logo of the DiGi project. Figure 2 illustrates the project activities (practice, laboratory, results). Anne Marie Kanstrup (Aalborg University, Denmark) has developed the logo and Figure 2.*

The following sections present the underlying understanding and definitions (terminology) of the key concepts relevant to the study: cognitive disability and communities. Following this is the mapping of the related work.

## 1.2. TERMINOLOGY

### 1.2.1. DEFINITIONS OF COGNITIVE DISABILITY

Disability refers to a long-term physical, mental, intellectual or sensory impairment which, in interaction with various obstacles or demands, may hinder an individual's full and effective participation in society on an equal basis with others (Arnadóttier,

2012). The prevalence of individuals living with cognitive disabilities is approximately 1% in high-income countries and 2% in low- and middle-income countries, with a high comorbidity of other psychological disorders (Carulla et al., 2015; Cooper et al., 2007), especially anxiety.

In disability research, there have been conflicting perceptions of how cognitive disability should be named and defined over the past 25 years (Arnadóttier, 2012; Carulla et al., 2015). The terms cognitive, intellectual, developmental, or learning disability are used differently depending on the researcher, context, and research field. The 11th Edition of the International Classification of Disease and Related Health Problems (ICD-11) calls the condition 'intellectual developmental disorder', which is the term used in most countries, along with 'intellectual disability' (Carulla et al., 2015). All of these terms describe conditions characterised by significant impairments of the core cognitive functions necessary for learning, reasoning, adapting and managing behaviours and emotions at the level of peers of the same age and/or the expectations in the cultural and social environments (AAIDD, 2021; Carulla et al., 2015; Schalock and Luckasson, 2004). This emphasises the influence of the societal expectations evident in our study as it recognises disability from a biopsychosocial model. Herein, the disability is considered a product of the individual's cognitive impairment as much as the context and the society that the individual is a part of (AAIDD, 2021; Carulla et al., 2015; Goodley and Runswick-Cole, 2016; Rieber and Carton, 1993; Schalock and Luckasson, 2004). With this viewpoint, the cognitive impairment is part of the disability and the individual but not limited therein (Carulla et al., 2015). As such, the ICD recognises cognitive disability as a health condition, in line with the American Association on Intellectual and Developmental Disabilities (AAIDD), which has a long history of identifying and classifying cognitive disabilities.

Engaging in social encounters can be challenging for individuals living with cognitive disabilities due to these inherent cognitive and adaptive impairments. The patterns of cognitive impairment differ for different intellectual conditions, but most individuals have troubles with memory, processing speed and verbal comprehension; therefore, they prefer visual and simple communication with slow tempo, repetition and familiar structure in interactions (AAIDD, 2021; DeMuro et al., 2012; Schalock and Luckasson, 2004).

This definition and view on disability as a health condition distance itself from the former view on disabilities by the International Classification of Functioning, Disability and Health (ICF), which labelled disabilities as a disorder. The term 'mental retardation' was used until the introduction of ICD-11. Such understanding was based on the medical model (AAIDD, 2021; Schalock and Luckasson, 2004), which labelled mental retardation as low intelligence and its associated limitations in adaptive behaviour (Carulla et al., 2015). This is a narrow-minded view on cognitive disabilities. The discussion in Chapter 8 provides an argument for why it may also be

narrow-minded or even erroneous to use these disability definitions and labels in the digital sphere.

In this study, the term 'cognitive disability' is used to describe the study participants' cognitive impairments from a belief that this is a precise and proper reflection of their impairments (Carulla et al., 2015). In paper 5, we use the term 'learning disability' to adhere to the journals' requirements and from a belief that the term is rich in presenting our study participants precisely and correctly. The term 'intellectual disability' can be misleading, as many of the study participants have high intellect, but all have some form of cognitive impairment that challenges their social and functional adaptation and participation. For example, the concept of cognitive disability can incorporate autism, which is a neurodevelopmental disorder (Carulla et al., 2015) but not an intellectual disorder. As such, the term 'cognitive disability' can encompass a broad study population of individuals living with cognitive impairment, which is important for this research.

### 1.2.2. DEFINING COMMUNITIES

The focus on relationships and communities comes from the following perspectives: it is in our nature to be social (Wenger, 1998a) and interpersonal relationships and belonging to a community are inherent needs and desires for the majority of individuals (Baumeister and Leary, 1995), including individuals living with cognitive disabilities.

There are, and have been for decades, many practical and academic definitions for a 'community' (Nicolini, 2017). The understanding of what a community is differs from culture to culture, country to country and language to language. In Denmark, the term used is 'fællesskab'. In German, Tönnis made a value-laden distinction between the terms 'Gemainshaft' and 'Gesellshaft'. Gemainshaft refers to a traditional community where values of enduring, genuine, and intimate relationships are rooted in family and kinship and where members of the community find strength in their similarities (shared language and tasks) and operate under a collective conscience (face-to-face communication). In contrast to Gemainshaft, Gesellschaft refers to individualisation, which goes hand in hand with industrialisation, where the communities are characterised by superficial, impersonal and individualistic relationships (Nicolini, 2017).

Overall, the common characteristics of a community are as follows: 1) the existence of social interactions among the people; 2) people in the community have some common ties, such as social life and a consciousness of their homogeneity (or norms); and 3) a reference to some defined (and limited) geographic area (Nicolini, 2017). The first two pillars remain the most evident, with a consensus of solidarity, mutual

understanding, stability, commonality, reciprocity, shared interest (and sharing with one another), boundaries and rules of inclusion and exclusion. These are all positive attributes, and a community is perceived as a positive value-laden concept, making conflicts and inequality a morally unacceptable sign of selfishness and betrayal of the common bond (Nicolini, 2017).

With the introduction of virtual communities, the importance of the geographical area has diminished. In some virtual communities, the community members do not know each other personally, which requires a reinterpretation of the community pillars (Nicolini, 2017). In Chapter 2 - Theoretical Framework, the characteristics, and elements of a digital community of practice are described in detail.

To sum up the terminology, 'cognitive disability' has been defined from the biopsychosocial model as a health condition by established organisations, a product of cognitive and adaptive impairments and societal structure and expectations. 'Community' has been defined as a positive concept about solidarity, common ground and understanding, whether in a physical or a virtual community.

## 1.3. RELATED WORK

The following sections present the related work from which the PhD thesis is based and developed. An extensive and systematic literature search was carried out (cf. Appendix A) to map the related work and identify knowledge gaps concerning the study population, digital technology, social relations, digital challenges, and opportunities. The outcome of the literature search is reflected in research about disability rights and inclusion, prospects of digital communities for the study population, voice (or lack of voice) in research, digital abilities (vs disabilities), and digital vulnerabilities, for the study population.

### 1.3.1. DISABILITY RIGHTS AND INCLUSION

Throughout history, community participation and inclusion in society have been challenging endeavours for individuals living with cognitive disabilities. They have a long history of exclusion and discrimination, and they are particularly vulnerable because their human rights are easily violated (Alper, 2014; Goodley and Runswick-Cole, 2016; Louw et al., 2019; United Nations Children's Fund, 2013).

The enactment of disability laws is a relatively new measure worldwide in terms of allocating specific attention to disability. The core international treaties recognise the human rights of individuals living with disabilities to some extent, for example, the

right to self-determination. These treaties are the International Covenant on Economic, Social and Cultural Rights (ICESCR), the International Covenant on Civil and Political Rights (ICCPR) and the Universal Declaration of Human Rights (UDHR) (The international journal of human rights Paris: United Nations, 1997; United Nations Human Rights, 1976, 2014).

Non-discrimination and equality principles underpin human rights, which are the most fundamental rights for individuals living with disabilities, as well as respect for human dignity (Arnadóttier, 2012). However, only the ICESCR explicitly recognises the right to non-discrimination of individuals living with physical and mental disabilities in general comment no. 14 on the right to the highest attainable standard of health (United Nations Human Rights, 2000). This general comment further highlights the principles of availability, accessibility and acceptability (the three As) for all human beings, including digital accessibility (Toebes et al., 2012; United Nations Human Rights, 2000), which are important notions in the rights of individuals living with disabilities. The UDHR and the ICCRP recognise the right to non-discrimination but not specifically for individuals living with disabilities (United Nations Human Rights, 2014).

In 2006, the Convention on the Rights of Persons with Disabilities (CRPD) was established. It was the first and only international disability-specific human rights convention (Arnadóttier, 2012). The purpose of the convention is 'to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedom by all individuals living with disability' (United Nations Human Rights, 2006). The CRPD postulates that all rights should also apply to individuals living with disabilities and that this should be formulated explicitly. This includes the access to the internet (article 9). The convention states that it is essential 'to take appropriate actions to promote access for persons with disabilities to new information and communications technologies and systems, including the Internet' (United Nations Human Rights, 2006). In addition to incorporating principles and human rights pertaining to individuals living with disabilities in core international treaties, it also sets forth the principles of participation in politics and communities, which are crucial in amplifying the voice of individuals living with cognitive disabilities (Toebes et al., 2012; United Nations Human Rights, 2006).

Today, there is a legal and a political focus on the rights and the inclusion of individuals living with cognitive disabilities as active citizens as opposed to passive receivers of help; they have the right to participate equally in society, also the digital society, at the same level as their non-disabled peers (United Nations Children's Fund, 2013; United Nations Human Rights, 2006).

### 1.3.2. DIGITAL COMMUNITIES: PROSPECTS FOR INDIVIDUALS LIVING WITH COGNITIVE DISABILITIES

Although the inclusion of individuals living with cognitive disabilities in both the physical and digital arena has been enhanced, loneliness is still a phenomenon that this study population struggles with (McVilly and et al, 2005; Merrells et al., 2019). Literature also suggest a digital divide among individuals living with cognitive disabilities and their non-disabled peers (Ågren Alfredsson et al., 2020a; Chadwick et al., 2013; Dobransky and Hargittai, 2016; Duplaga, 2017; Lussier-Desrochers et al., 2017). This digital divide suggests that individuals living with cognitive disabilities do not use digital technology to the same extent as their non-disabled peers. For this reason, there is a need for supportive initiatives to help individuals living with cognitive disabilities to stay in touch or form new and meaningful relationships and communities (McVilly and et al, 2005).

Studies have found benefits in developing and maintaining social and romantic relationships using digital technology for individuals living with cognitive disabilities (Alcorn et al., 2011; Alper, 2014; Caton and Chapman, 2016; Darragh et al., 2017; Löfgren-Mårtenson, 2008; Löfgren-Mårtenson et al., 2015; Pinchevski and Peters, 2016; Ringland et al., 2016; Seymour and Lupton, 2004; Shpigelman and Gill, 2014; Söderström, 2009). These include being able to express a social identity in the study population (Alcorn et al., 2011; Löfgren-Mårtenson, 2008; Söderström, 2009), developing confidence (Alper, 2014) and agency (Näslund and Gardelli, 2013), having a stronger voice and being able to communicate opinions, for example, through blogs or other digital content (Alper, 2017; Hjelholdt and Rasmussen, 2017). Studies have also addressed the fact that digital technologies and platforms are used for entertainment and finding interest-based encounters (Bayor, Bircanin, et al., 2019; Caton and Chapman, 2016), as well as a lifeline to reach support persons (Söderström, 2011). As such, inclusion in society should also entail inclusion in digital societies for individuals living with cognitive disabilities.

Studies suggest that digital technology mostly supports the maintenance of existing relationships and seldom works in developing new relationships with individuals without cognitive disabilities or those beyond their institutional sphere (Bayor, Bircanin, et al., 2019; Burke et al., 2010; Hjelholdt and Rasmussen, 2017; Löfgren-Mårtenson, 2008; Seale, 2007). In addition, it is suggested that individuals living with cognitive disabilities engage with only a small number of people online (White and Forrester-Jones, 2020).

### 1.3.3. DIGITAL DISABILITIES VS. ABILITIES

Various research examining the digital activities of youth and adults living with cognitive disabilities are available, but the majority are primarily technologically oriented. In this sense, there is a knowledge gap in addressing the complex and contextual aspects of the everyday use and meaning accorded to digital technology by this study population and the way that digital technology can mediate their social relationships and communities (Alper, 2014; Söderström, 2009). This study seeks to explore all these elements.

Many studies have focused on how technology can compensate for a disability, wherein the goal is to develop and use assistive technology for this study population (Balasuriya et al., 2018; Boyd et al., 2015; Davies et al., 2015; Sonne et al., 2016; Washington, 2016). This focus on assistive technology is not necessarily negative and is a necessity for many individuals living with cognitive disability. However, it reduces them to consumers of technology in need of specialised, assistive tools rather than seeing them as equal users (and developers) of technology. Roughly speaking, it reduces them to their disabilities (Frauenberger, 2015; Söderström, 2013).

A dominant assumption seems to be that individuals living with cognitive disabilities are passive consumers of digital technology (Benton and Johnson, 2015; Brereton et al., 2015; Foss and et al, 2013; Frauenberger et al., 2011). Thus, research contradicting this passive use of the study population is warranted. The present PhD study addresses the active and comprehensive use of a wide range of digital technology by individuals living with cognitive disabilities, which is not developed specifically for them but used by the general population. Studies argue that individuals living with cognitive disabilities want to be online and use the available digital technologies, just like everyone else (Chadwick et al., 2013; Hjelholdt and Rasmussen, 2017; Löfgren-Mårtenson, 2008). Active digital use is apparent in the sharing of digital content and opinions, particularly when young individuals develop their digital abilities (e.g. on gaming platforms) and produce their own digital content (e.g. YouTube videos) (Alper, 2017; Duplaga, 2017; Hjelholdt and Rasmussen, 2017; Näslund and Gardelli, 2013; Ringland et al., 2016; Sallafranque-St-Louis and Normand, 2017).

### 1.3.4. VOICE IN RESEARCH

Along with the perception of the study population as passive consumers of technology, they are often treated as passive users of technology in Health Information Technology (HIT) focused disability research, because of their inherent communication challenges (Andreasen and Kanstrup, 2019a; Benton et al., 2014; DeMuro et al., 2012; Hendriks et al., 2015). This means that they are frequently used to test assisting technology or included by proxy in technological designs (i.e. having

their resource persons present their view instead of themselves) (Benton and Johnson, 2015; Brereton et al., 2015; Druin, 2002; Foss and et al, 2013; Frauenberger et al., 2011; Seale and Chadwick, 2017). Thus, scholars in the field of inclusive research and Participatory Design (PD) argue that individuals living with cognitive disabilities are important and should be included in research on their digital use and behaviours (Baykal et al., 2020; Bayor, Sitbon, et al., 2019; Frauenberger, 2015; Nind and Vinha, 2014; Seale et al., 2015).

Regarding this inclusive and developmental perspective for individuals living with cognitive disabilities, design research has mainly focused on people living with autism (Alcorn et al., 2011; Burke et al., 2010; Pinchevski and Peters, 2016; Ringland et al., 2016). This may be due to the fact that cognitive impairment regarding learning and reasoning is not necessarily as prevalent for individuals with autism or attention deficit hyperactivity disorder (ADHD) depending on where they are on the spectrum. Thus, this study argues that there is a need to focus more broadly on individuals living with cognitive disabilities as a homogenous group and examine the possibilities that digital technology can provide to this study population. In this process, common needs, perspectives, and design possibilities may be unveiled in this study population or these may need to be tailored to the individual, not necessarily based on diagnosis but on personality.

### 1.3.5. DIGITAL VULNERABILITY AND COPING

Individuals living with cognitive disabilities are considered particularly vulnerable because of their difficulties in communicating and understanding social cues and norms, including digital language and codes. Thus, they can be more vulnerable to challenges regarding usability and accessibility (Ågren Alfredsson et al., 2020b; Bayor, Bircanin, et al., 2019; Chadwick et al., 2013; Feng et al., 2010; Louw et al., 2019; McClimens and Gorden, 2008; Newman et al., 2017; Rajapakse et al., 2018; Shpigelman and Gill, 2014), victimisation (Chiner, Gómez-Puerta, et al., 2017; Holmes and O'Loughlin, 2014; Iglesias et al., 2019; Normand and Sallafranque-St-Louis, 2016; Wells and Mitchell, 2014; Wright, 2017a), discrimination (Chiner, Gómez-Puerta, et al., 2017; Iglesias et al., 2019), as well as overstimulation and addiction (Becker and Lienesch, 2018; Gwynette et al., 2018). The challenges they experience online have been extensively explored, but there is a knowledge gap in the literature addressing how these individuals and their resource persons manage these digital challenges. Merely few studies address how the study population manage, or cope with, digital challenges, and they all call for more research in this regard (Ågren Alfredsson et al., 2020b; Borgström, 2021; Seale et al., 2013; Seale, 2007; Wright, 2017a). Borgström (2019) highlights the importance of support from others in managing digital challenges (Borgström, 2021), but literature suggest that individuals living with cognitive disabilities experience a lack of digital support from resource

persons (Hjelholdt and Rasmussen, 2017; Löfgren-Mårtenson, 2008), as social, cultural and digital resources in the home and in school are crucial for the individuals digital abilities, because individuals living with cognitive disabilities are highly dependent on their resource persons. Resource persons are often family members, staff at the institutions or other important relations who help support the study population (Alper, 2017). In this regard, overprotection by resource persons as a response to digital challenges and inadequate digital behaviour is a concern experienced by a study population who wants to be online just like everyone else (Chadwick et al., 2013; Hjelholdt and Rasmussen, 2017; Löfgren-Mårtenson, 2008; Seale, 2014, 2007), and who may benefit more from participating in the digital arena than not participating – a term called positive risk taking, which will be addressed later (Seale et al., 2013). Thus, finding the balance between supporting and protecting the study population can be challenging for resource persons. While many studies suggest that resource persons, including parents, see benefits of digital participation for the study population (Buchholz et al., 2013, 2018, 2020), studies have addressed how parents and teachers have limited insights and understanding of the digital sphere in which the study population participates (Löfgren-Mårtenson et al., 2015; Molin et al., 2015). They seek formal training in managing risks and promoting the safe inclusion of the study population in the digital arena (Chiner, Gómez-puerta, et al., 2017). Resource persons in the DiGi-project have stated that they know that young individuals use an immense number of digital technologies, but they have no insights into what they use these for. They seek this understanding as the first step to support the study participants' digital use and behaviour properly.

### 1.3.6. SUMMARY

This section sums up and maps what is known and what is not known from the presented literature search in the related work section. To our knowledge, fundamental human rights, including the right to digital accessibility, have a long history of being violated for individuals living with cognitive disabilities because of discrimination, inequality, and social exclusion, both in the physical and digital arena. The study population struggle with loneliness, and there is a digital divide between individuals with and without cognitive disabilities. We know that the study population can benefit from participating in meaningful interpersonal digital relationships and that they have an inherent right to experience the benefits that these can bring. This includes treating them as capable and independent human beings who can express their voices and participate actively in digital communities while also considering their vulnerabilities in the digital arena.

While there is solid research regarding digital rights, challenges, and possibilities for participating in the digital arena, knowledge is limited about the complexity of the social arena of digital technology and how the study population finds meaning in these

social and interpersonal digital relationships and communities. Most pronounced how the study population handles the complexity and manages their participation in digital communities, including the following challenges. This means studying the digital coping strategies used by youth living with cognitive disabilities to manage their digital participation. Additionally, the study population's ambitions and aims for participating in the digital arena have not been explored. The focus on digital coping strategies and digital aims includes conceptualising individuals living with cognitive disabilities as a group of people who are not studied according to their disabilities but to their individual attributes and abilities.

In this background, the PhD study uses current knowledge about the social arena of digital technology used by individuals living with cognitive disabilities from different academic disciplines and contributes to these research fields. This means that the PhD thesis is interdisciplinary and positioned at an intersection between three research fields; disability studies, HIT and PD. This academic positioning will be elaborated on in the following chapter.

# CHAPTER 2. POSITIONING AND RESEARCH QUESTIONS

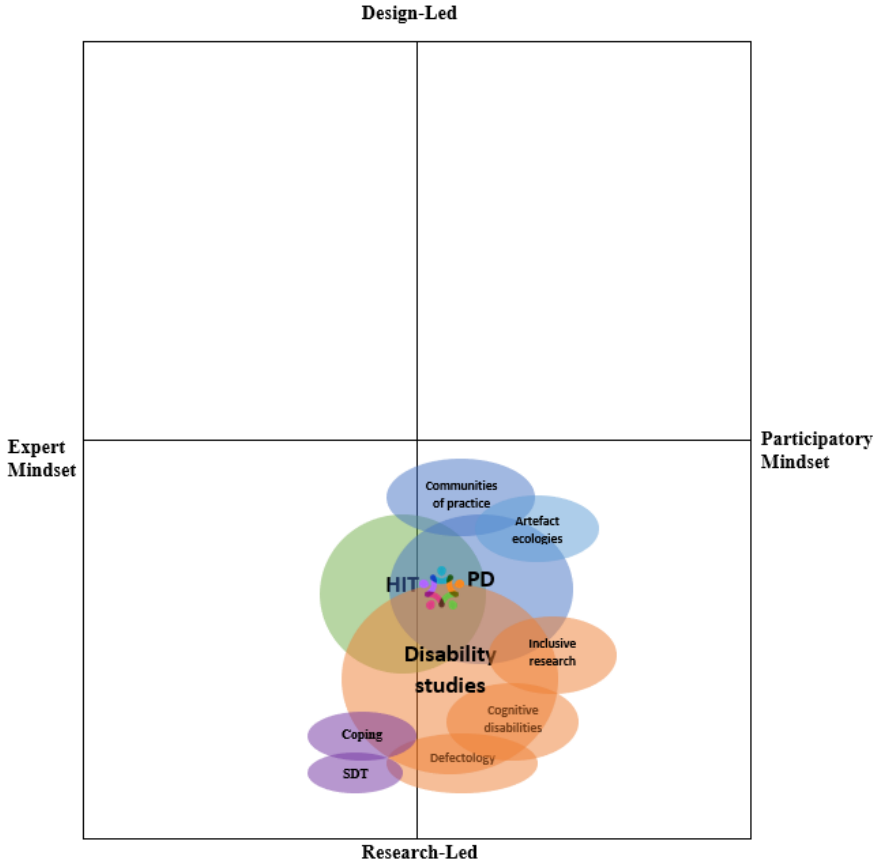
## 2.1. ACADEMIC POSITIONING BETWEEN RESEARCH FIELDS

As addressed above, the PhD thesis is positioned at an intersection of three academic disciplines: disability studies, PD and HIT. These academic research fields and disciplines bring important background knowledge and understandings to the PhD thesis.

The Venn diagram in Figure 3 illustrates the positioning of the PhD study and its contributions to the three academic disciplines. The Venn diagram represents the linkage and relationship between the academic disciplines, related theories and concepts, and the study population. The circles of various sizes represent the importance of the academic disciplines in the positioning between the research fields - the bigger the circle, the more critical the role in the PhD thesis. In the centre of the Venn diagram is the focus point: Digital communities among youth living with cognitive disabilities (the PhD thesis). The PhD thesis is represented using the DiGi-logo (cf. Figure 1, Section 1.1).

The illustration of research fields which overlap for the PhD thesis and its contributions are inspired by Sanders' (2008) design landscape (Sanders, 2008), which is evident in Figure 3. Sanders (2008) created a model to understand and reflect on the many disciplines adding up what she terms design research. It is a tool for mapping research fields, which can, and is encouraged to be used in many different fields and contexts; hence, the model is flexible and evolving (Sanders, 2008). For example, I use the model to position the PhD thesis and its' contributions across academic research fields, not particularly design research. The model is beneficial as it forces researchers to reflect on their role in the research (do they see themselves as experts or partners) and reflect on the overall objective of their research (is it action and product-oriented or descriptive and research-led). In the model, these perspectives of research approach and mindset are illustrated as intersecting dimensions. The approach is either research-led as a pole to a design-led, and the mindset is either expert-minded, where users are seen as subjects, as a pole to a participatory mindset, where users are seen as partners or co-creators and the real experts in the domain of experience (Sanders, 2008). The model presents and supplements the Venn diagram in Figure 3.

**Figure 3: Venn diagram**




*The Venn diagram in Figure 3 is positioned in Sanders' (2008) model (design landscape) illustrating the positioning of PhD thesis in academic disciplines.*

The PhD thesis has a research-led approach, as the research is descriptive and explanatory rather than product or design oriented. The actual design phase is limited, and the PhD study is conducted inductively to generate findings of and map the digital landscape of the young individuals as a preparation for the design phase, cf. Section 1.1. Regarding the mindset of researchers, the thesis is placed between a participatory mindset and an expert mindset. The participatory mindset provides insights for future design possibilities and methodological choice, which was based on PD principles and activities (Bødker et al., 2022a). The principles and activities will be elaborated on in Section 4.1. The positioning towards a participatory mindset is critical as much

research in the intersection between disability studies and HIT uses an expert mindset and includes participants by proxy or minimally in the research and design process, cf. Section 1.3.4. Nevertheless, the mindset in the PhD thesis is not a core participatory one. For example, we treat our study participants as collaborators not co-researchers, cf. Paper 5. Their voice is represented in the data collection process, the research findings and the evaluation of findings, but their voice is presented by the resource persons (by proxy) in the research design, and they were not included in the data analysis or dissemination (Nind and Vinha, 2014).

Turning attention to the academic research fields in the Venn diagram, disability studies (the orange circle in Figure 3) contribute with a core focus on the study population and their social life, quality of life, rights, learning and developmental possibilities, and less on the technological aspects. PD (the blue circle in Figure 3) provides a solid contribution to user studies and user participation in the design and research of digital technology (Bødker et al., 2022a), also within the field of disability studies, with a solid contribution to studies which include people living with disabilities in the research process and design (authors are mentioned further down). HIT research (the green circle in Figure 3) provides a contribution to the design and use of digital technology as integrated into the delivery of health care services to the population (Kanstrup et al., 2017). This includes citizens who live with sicknesses or disabilities and the professionals working with them. This means that we focus on the area of HIT research field focused on vulnerable groups, particularly individuals living with disabilities. To our knowledge, disability research focusing specifically on cognitive disabilities is limited within HIT research (Hendriks et al., 2015), and therefore, the PhD thesis contributes to understanding this particular study population's digital activities and communities. The PhD study and contributions are inherently inspired and influenced by HIT as my academic background is within the health domain and because my interest lies within this discipline. This has inherently influenced my focus, angle, and audience. In this sense, the PhD study combines knowledge from PD and disability studies with a shared focus on HIT for the study population, and the research fields overlap and inspire each other.

When asked (by my supervisor) to place my thesis on a bookshelf at the library, my answer was that I would place it under disability studies, with a tag highlighting that this is about disability and technology. Therefore, the circle representing the disability studies research field is more significant than the HIT and PD circle in Figure 3. While the disability studies and field have most of my attention, the PhD thesis cannot stand alone within disability studies, as the focus on how technology mediates social relations and communities are crucial.

First and foremost, the position between the three research fields is justified by the implications and contributions of the PhD study, primarily pointing toward researchers working within disability studies, PD or HIT and practitioners working with people living with disabilities. Additionally, the thesis is based heavily on

literature from disability studies. Primarily literature combining disability and technology, cf. Table 1. I write Health Information in brackets in Table 1 as many of the studies are not positioned explicitly or directly in the HIT tradition, but I map them as disability specific HIT studies to illustrate the research fields I aim to contribute with in my PhD thesis. This means that the categorisation of the literature in Table 1 is my own categorisation, which illustrates the mapping of the related work (including the related work in the methodological chapter 4). Table 1 also illustrates that the PhD thesis is based on the literature on inclusive research with the study population and literature combining PD and disability studies. Few studies focusing on assistive technologies for people with disabilities are included in the related work, as this was not our focus and therefore not prioritised. The literature is a cross-field between the three academic disciplines, but all studies have a shared disability focus. This overlap in literature makes the distinctions in Table 1 complex, and the Table is meant to illustrate the literary universe I have worked in.

**Table 1: Mapping of the related work**

| **Academic research field** | **Authors** |
|---|---|
| Disability studies | (Cooper et al., 2007; Goodley and Runswick-Cole, 2016; McVilly and et al, 2005; Merrells et al., 2019) |
| Disability and (Health Information) Technology studies | (Ågren Alfredsson et al., 2020c, 2020b, 2020a; Alcorn et al., 2011; Alper, 2014, 2017; Alper and Goggin, 2017; Baric et al., 2018; Becker and Lienesch, 2018; Borg et al., 2015; Borgström, 2021; Boyd et al., 2015; Buchholz et al., 2013, 2018, 2020; Bundsgaard, 2014, 2017; Burke et al., 2010; Caton and Chapman, 2016; Chadwick et al., 2013; Chiner, Gómez-puerta, et al., 2017; Chiner, Gómez-Puerta, et al., 2017; Darragh et al., 2017; Davidsen et al., 2021; Davies et al., 2015; Dobransky and Hargittai, 2016; Duplaga, 2017; Feng et al., 2008; Gwynette et al., 2018; Hjelholdt and Rasmussen, 2017; Holmes and O'Loughlin, 2014; Iglesias et al., 2019; Karadechev et al., 2021; Löfgren-Mårtenson, 2008; Löfgren-Mårtenson et al., 2015; Louw et al., 2019; Lussier-Desrochers et al., 2017; McClimens and Gorden, 2008; Molin et al., 2015; Näslund and Gardelli, 2013; Newman et al., 2017; Normand and Sallafranque-St-Louis, 2016; Pinchevski and Peters, 2016; Reilly et al., 2016; Ringland et al., 2016; Sallafranque-St-Louis and Normand, 2017; Seale, 2014, 2007; Seale et al., 2013; Seale and Chadwick, 2017; Seymour and Lupton, 2004; Shpigelman and Gill, 2014; Söderström, 2009, 2011, |

| | |
|---|---|
| | 2013; Sorbring et al., 2017; Sousa, 2011; Wells and Mitchell, 2014; White and Forrester-Jones, 2020; Wright, 2017a, 2017b) |
| Inclusive research and disability studies | (Booth, 1998; Brewster, 2004; Burke et al., 2003; Cameron and Murphy, 2006; Chappell, 2000; DeMuro et al., 2012; Flood et al., 2013; Goodwin et al., 2015; Harrington et al., 2014; Keyes and Brandon, 2011; Mcclimens, 2008; Mikulak et al., 2021; Murphy and Cameron, 2008; Nind and Vinha, 2014; Riches and O'Brien, 2020; Rojas and Castros, 2011; Schwartz and Durkin, 2020; Seale et al., 2015; Stans et al., 2019; Strnadová and Walmsley, 2018; Tuffrey-Wijne et al., 2020; Walmsley, 2004) |
| Design and disability studies (including primarily Participatory Design but also Human Computer Interaction research) | (Balasuriya et al., 2018; Baykal et al., 2020; Bayor, 2019; Bayor, Bircanin, et al., 2019; Bayor, Ploderer, et al., 2019; Bayor, Sitbon, et al., 2019; Benton et al., 2012, 2014; Benton and Johnson, 2015; Bircanin and Brereton, 2016; Brereton et al., 2015; Foss and et al, 2013; Frauenberger, 2015; Frauenberger et al., 2011; Hendriks et al., 2015; Kanstrup and Bertensen, 2016; Macias et al., 2018; Makhaeva et al., 2016; Rajapakse et al., 2018, 2019; Seale et al., 2018; Sitbon et al., 2018; Sonne et al., 2016; Spiel et al., 2017; Washington, 2016; Williams and Hennig, 2015; Wilson et al., 2016a, 2017, 2019) |

*Table 1 maps the related work (empirical and methodological) across the different academic research fields.*

The disability focus is not evident in the theoretical frameworks about artefact ecology by Jung (2008) and Bødker (2017) and community of practice by Wenger (1998; 2009). These theories are used to analyse and structure the research findings in the PhD thesis, influencing the research findings. These theories are placed between a PD and HIT tradition, as seen in Figure 3, with a core technological focus. Two small purple circles are placed in the Venn diagram, illustrating the theories of coping, stress and appraisal by Lazarus and Folkman (1998) (Lazarus and Folkman, 1998d), and Self-determination Theory (SDT) by Ryan and Deci (2011) (Ryan and Deci, 2011). These theories were used to analyse and explain empirical findings concerning digital coping strategies and digital aims in paper 3 and paper 4. The theories are placed within a psychological tradition; therefore, they are given a purple circle, but the empirical contributions from the theoretical analysis positions within the three academic disciplines (disability studies, PD, HIT).

In the disability studies circle, a circle with 'cognitive disabilities' is visible to narrow down the studies of this particular study population. The theory, 'defectology' is visible in a circle to illustrate the view on the study population by the research team, but also by the Danish institutions and resource persons we collaborate with, who take a stand and view on the study population from a Vygotskian tradition (more on this in Section 4.1.1). Vygotsky's work originates from the psychological field, while the theory of defectology intersects between the psychological, pedagogical and disability field, particularly learning disabilities (Rieber and Carton, 1993). The defectology circle is placed most to the left side of the diagram, as this theory, in its nature, has an expert-mindset rather than a participatory mindset. A circle representing 'Inclusive research' is placed between PD and disability studies, as inclusive research concerns the study population and overlaps with methods and principles in PD research.

The Venn diagram in Sanders' (2008) model positions the PhD thesis (literature, aim, and contribution to research disciplines) between academic research fields in Figure 3. The positioning of the PhD study's specific contributions (methodological and empirical) is explained and illustrated using a reflection model for qualitative research (Bøttcher et al., 2018), cf. Figure 4. The reflection model uses opposing dimensions of Tradition vs Originality, Improvisation vs Stringency and Solidarity vs Critic to illustrate the empirical and methodological contributions. The circles with contributions match the colours from the research fields they contribute in, in the Venn diagram. As the research fields overlap, the study contributions do too. Therefore, the circles have multiple colours and circles, representing the intersection of the three research fields in Figure 4.

**Figure 4: Reflection model**

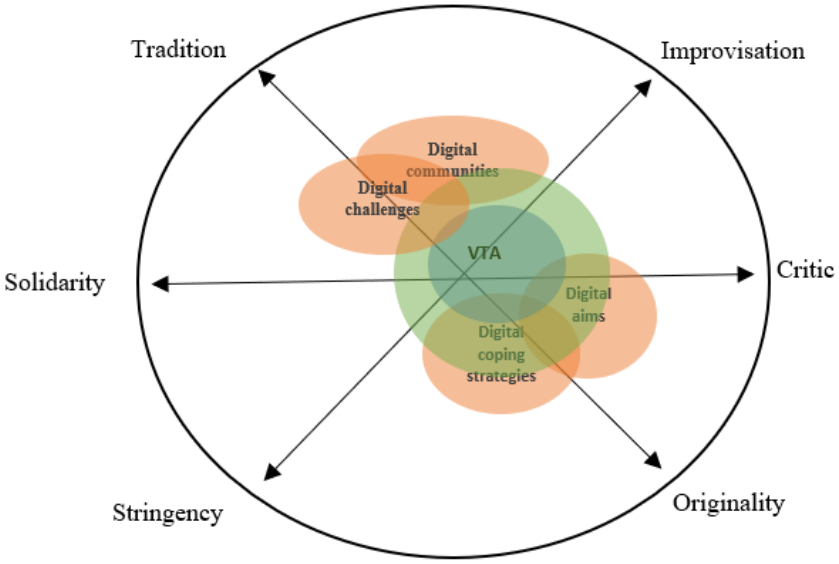



*Figure 4 is a reflection model, which places the research contribution of the PhD study in six dimensions (tradition vs. originality, improvisation vs. stringency, solidarity vs. critic). The model is translated and revised from Bøttcher et al. (2018)*

Concerning the dimension of Tradition vs Originality, the PhD thesis is in dialogue with existing research and knowledge within the three academic disciplines. It contributes to existing knowledge regarding digital communities and digital challenges for the study population (mainly displayed in papers 1, 2 and 6). Therefore, these circles are placed towards the Tradition-dimension in the reflection model.

The original contributions of the PhD thesis are the empirical findings regarding the mapping of, and insights into, coping strategies of the study population (mainly displayed in paper 3), which will be explained in the empirical chapter 7, and the mapping of, and insights into, explicit digital aims of the study population (mainly displayed in paper 4), which will be explained in the empirical chapter 8. Therefore, these circles are placed towards the Originality-dimension in the reflection model.

Methodologically, we contribute with a refined model of inclusive research and PD methods, the Visual and Tangible Artefacts (VTAs), which we use to enter these insights on digital activities, communities, challenges, coping strategies and aims (displayed in paper 5). We follow and are inspired by traditional PD and inclusive

research approaches but contribute with an original foundation of using VTAs within the cross field between PD, HIT, and disability studies. Therefore, this circle is placed between the Tradition - and Originality-dimension while leaning most towards the Original-dimension. The reasoning behind the VTAs will be explained in chapter 4.

Theoretically, we contribute with an understanding of the digital activities and communities through the lens of artefact ecology and communities of practice and as a result of this bring these theoretical frameworks into disability studies. The theoretical analysis contributes new perspectives for understanding and mapping the complexity in digital communities of young individuals living with cognitive disabilities. We do not develop a new theoretical framework but use the two theories and refine the frameworks in a new context and research field. The refined theoretical framework is illustrated in Figure 35, Section 9.1. For this reason, the theoretical framework is not presented explicitly in Figure 4 as this analysis is part of the main empirical contributions but is not the main contribution. The theoretical analysis facilitates an examination and presentation of the empirical findings. This is also the case for the theories used to examine and present the empirical findings in paper 3: coping strategies by Lazarus and Folkman (1998) and paper 5: SDT by Ryan and Deci (2011).

The contributions of the PhD thesis intersect between the three academic disciplines (disability studies, PD and HIT) but has a clear contribution to the research field of disability studies and next the PD and HIT field. Our primary audience for this thesis is researchers and designers across the three academic disciplines, who can benefit from using both the methodological and empirical findings as a solid and proper preparatory work for communicating with and understanding the study population and their digital activities and communities. Nevertheless, the empirical and methodological findings are imperative for practitioners working with the study population, and we have deliberately communicated the findings directly to practitioners in two of the papers (paper 2 and paper 6). These are technical reports written in layman's terms, where we outline specific and tangible recommendations for practitioners to use in their everyday work with the study population. We put forth these recommendations in the discussion in chapter 9 (Section 9.4).

For the dimension of Solidarity vs Critic, the PhD thesis' contributions have high solidarity with the study population, as we present their views and perspectives from an iterative, systematic, and thorough data analysis of the audio and video material (more on this in the analytical strategy in Section 4.7). In addition, we demonstrate solidarity with the research field of PD in trying to present the study population from outlined PD principles (Bødker et al., 2022b). While we show great solidarity with the research fields and population, particularly disability studies and PD, we make a critical view on assumptions that people living with disabilities are passive consumers of technology and enabled citizens in need of protection rather than support. This critical viewpoint is merely evident for the empirical contributions (digital coping

strategies and aims) and not the VTAs. The argument is evident in all the research papers in the PhD thesis, but especially paper 4 emphasises this point. Paper 4 is published in the journal Social Kritik, a journal for social analysis and debate, with a critical view of society and social work in Denmark.

Regarding Stringency vs Improvisation, the contributions of the PhD thesis are placed more towards improvisation than stringency. While the analysis is stringent in the thoroughness and systematic approach in using and describing the width and variation in our empirical material, we improvise by letting the empirical material surprise and challenge us in the process and use it to develop solutions to, for example, communicate with our participants, cf. the VTAs. In the improvisation, the creativity happened, and this was possible with an open and inductive approach to the analysis of research material (Bøttcher et al., 2018).

The following sections explain how the study aims and objectives will be examined and addressed.

## 2.2. RESEARCH AIMS AND OBJECTIVES

This study seeks to map and explain how young individuals living with cognitive disabilities use digital technology to maintain and develop relationships and communities. Empirically, the objectives under investigation are as follows: 1) What characterises the digital technology use, activities and value of young individuals living with cognitive disabilities? 2) How does digital technology form and challenge the digital relationships of this study population? 3) How do the study population manage their digital communities? and 4) What are the aims of the young individuals regarding their digital activities and communities? Methodologically, a fifth objective is to examine how to include the study population in researching their rich digital activities and communities.

The aims and objectives refer to the study population and not the study participants, with the goal of being able to generalise the empirical and methodological findings to individuals living with cognitive disabilities beyond the study participants.

## 2.3. STRUCTURE OF THE PHD

### 2.3.1. CHAPTERS

The chapters contain elaborations of the theoretical explication of the papers and additional empirical and methodological findings that were not included in the papers.

In Chapter 1, the PhD project, terminology, and the related work are introduced. Chapter 2 introduces the academic positioning of the PhD thesis across academic research fields, the research aims and objectives, and the structure of the PhD and the papers. Chapter 3 introduces the theoretical framework used to map and examine the digital relationships and communities: artefact ecology and community of practice that frames the empirical findings in Chapters 5, 6, 7 and 8 in a theoretical scope to explain and expand upon these. Chapter 4 is a methodology chapter that presents the research approach, data foundation, data analysis, and ethical perspectives. The Chapter, particularly the data collection methods, is based on methodological findings from paper 5. Chapter 5 is the first chapter to introduce the empirical findings that examine and present the characteristics of the participants' digital technological use and the meaning that they give to digital technology in their everyday lives. This chapter is based on empirical findings from Paper 1, Paper 2, and Paper 6. In Chapter 6, the purpose of the participants' digital technology use is presented, focusing on how internal and external digital relationships and communities are shaped and maintained. This chapter is based on the empirical findings also presented in Paper 1, 2, 3 and 6. Chapter 7 explores the digital challenges experienced by the study participants and how the participants manage these digital challenges using individualisation and personalisation. This chapter is based on empirical findings presented in Paper 3 and paper 6. Chapter 8 presents the learning possibilities for extending digital relationships and communities with participants, which are based on empirical findings that are also presented in Paper 4 and Paper 6. Chapter 9 is a practical discussion of the empirical and methodological findings and implications. The last Chapter 10 concludes the PhD thesis.

### 2.3.2. PAPERS

The PhD thesis is paper-based, and contributions of the PhD thesis are manifested and disseminated in four scientific papers and two technical reports. The five research objectives are answered via these papers and reports. The first three scientific papers and the technical reports illustrate the processing and analysis of the primary empirical findings. The last one is a methodology paper. These research papers and reports are written to an audience within the three academic disciplines, elaborated on in the following.

#### 2.3.2.1 Paper 1: Digital relationships

Paper 1 entitled 'Digital relations among youth with cognitive disabilities: A field study of technology use for developing and maintaining social relations' maps the digital use and relationships formed by the study participants and utilises the empirical

findings to answer objectives one and two. The paper has been published in the *Proceedings of Communities and Technologies (C&T 2019)*, with Anne Marie Kanstrup (main supervisor) as a co-author.

The audience of paper 1 are researchers working within a more technological venue focusing on disability, for example, researchers within the field of PD and HIT, who can benefit from understanding the study population's digital social activities for design or health information initiatives.

#### 2.3.2.2 Paper 2: Technical report on digital communities 1

Paper 2 is a technical report entitled 'Digitale fællesskaber for unge med kognitive handicap: Arbejdsrapport 1 (Digital communities for youth with cognitive disabilities: Technical report 1)'. It has been published in the Danish Centre for Health Informatics (*DaCHI) Technical Report Series (2019)*, co-authored by main supervisor Anne Marie Kanstrup. The technical report explores all three objectives, as it contains information regarding all preliminary empirical findings from the PhD project.

#### 2.3.2.3 Paper 3: Digital coping strategies

Paper 3 entitled 'Digital coping strategies of young individuals living with cognitive disabilities: Using emotion-focused and problem-focused coping in digital relationships' explores the digital challenges experienced by the study participants in their interactions with others online and the coping strategies they use to manage these digital challenges. The paper explores objectives two and three and includes an extensive literature review of the digital challenges experienced by individuals living with cognitive disabilities. The paper has been submitted to the journal *Disability and Society (December 2021)*, with Ann Kathrin Meilandt Bygholm (co-supervisor) and Anne Marie Kanstrup (main supervisor) as co-authors.

Paper 3 is primarily meant for an audience working within disability studies. We use coping strategies Larazus and Folkman (1998) developed to analyse our data material and explain how participants manage their digital relationships and communities. The theoretical coping framework originates from psychology, and there is a minor overlap with this research field in the PhD thesis, as we use the framework as a tool to examine and explain the participants' behaviour and responses to challenges in the digital sphere.

#### 2.3.2.4 Paper 4: Digital aims, abilities, and independence

Paper 4 entitled 'Selvstændig i stedet for at spørge om hjælp: Digitale ambitioner og kompetencer blandt unge med kognitive handicap (Independent instead of asking for help: Digital aims and abilities among youth living with cognitive disabilities)' is a Danish paper that seeks to create awareness about the digital ambitions of the study participants and their competencies in achieving these digital ambitions autonomously. Paper 4 primarily explores objective four. The paper has been published in the Danish journal *Social Kritik (August 2021)*, co-authored by Anne Marie Kanstrup (main supervisor). The paper is only available in physical format.

Paper 4 is written for a broader community of people working within either a practical or scientific field of social work.

#### 2.3.2.5 Paper 5: Inclusive visual tangible artefacts

Paper 5 entitled 'Developing visual tangible artefacts as an inclusive method to research digital participation with youth living with learning disabilities' addresses objective five, namely, how to include the study participants in researching their digital lives via visual tangible tools used during fieldwork and data collection. The paper is written with collaborating professor Margot Brereton and main supervisor Anne Marie Kanstrup. It has been accepted with major revisions and has been re-submitted to the *British Journal of Learning Disabilities (May 2022)*.

While the paper will be published in a journal focusing on the study population and therefore is positioned in disabilities studies, the paper is a methodological paper, contributing to the PD and HIT researchers and designers.

#### 2.3.2.6 Paper 6: Technical report on Digital Communities 2

Paper 6 entitled 'Digitale unge med kognitive handicap: Om brugen og betydningen af digitale teknologier i sociale fællesskaber' (Digital youth with cognitive disabilities: About the use and meaning of digital technologies in social communities). It has been published in the Danish Centre for Health Informatics (*DaCHI) Technical Report Series (March 2022)*, co-authored by the main supervisor Anne Marie Kanstrup. The technical report explores all objectives, as it contains information regarding all empirical findings from the PhD project, including the methodological contributions including hands-on recommendations on how to use these empirical and methodological findings in practice.

While paper 2 and paper 6 are technical reports written in a language which facilitates accessibility for practitioners working with individuals living with cognitive disabilities (resource persons), it is published by DaCHI and therefore also addresses an audience of practitioners and researchers working within the field of HIT.

# CHAPTER 3. THEORETICAL FRAMEWORK

*'Technology has changed how we think about communities and communities have changed our use of technology' ~ Etienne Wenger (2009)*

## 3.1. ARTEFACT ECOLOGY

As a framework for understanding and mapping the digital communities of young individuals living with cognitive disabilities, artefact ecology, as presented by Jung et al. (2008), and community of practice, as presented by Wenger et al. (1998, 2009), are employed. The framework aids in conducting an examination and presentation of how a multitude of digital artefacts interact and influence the study participants' personal and social lives both in terms of function and meaning and both implicitly and explicitly (Jung et al., 2008; Wenger, 1998a; Wenger et al., 2009b). As such, the complex interactions among artefacts, humans, and the social environment are examined. Following this theoretical framework, technology is understood and treated as a mediator, which shape participants' practices and experiences (Verbeek, 2015) in this PhD study: the digital technologies play a mediating role for social relationships and communities and are tools to enable people living with cognitive disabilities to develop and maintain social relationships and communities.

The following presents how the artefact ecology framework contributes a perspective for mapping the part of our empirical findings that have not been presented (or not presented in detail) in the papers. The communities of practice framework, combined with the functional aspect of artefact ecology, contributes to explaining the empirical data specifically related to digital relationships and communities to raise the abstraction level of the empirical findings.

Jung et al. (2008) introduce the notion of **personal ecology of interactive artefacts** in their artefact ecology framework, which refers to 'a set of physical artefacts with some level of interactivity enabled by digital technology that a person owns, has access to, and uses' (Jung et al., 2008) p 201 (cf. Figure 5). In this sense, 'ecology' is a complex network or constellation of interactive artefacts (Jung et al., 2008).

**Figure 5: Personal ecology of interactive artefacts**

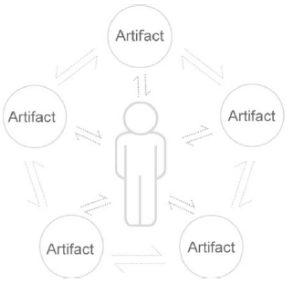



*Figure 5 illustrates the personal ecology of interactive artefacts. From Jung et al. (2008)*

Ecologies are evident as there has been a shift from focusing on the interaction with a single digital artefact to a constellation of digital artefacts (Bødker et al., 2017). Wenger et al. (2009) cite 'community ecologies' and Bødker et al. emphasise how 'artefact ecologies take shape through interactions with people […] interactions with others affects the way people manage the complexities of multiple artefacts' (Bødker et al., 2017, pp 7). She labels this emphasis on the social aspect when examining artefact ecologies as 'community artefact ecology' and adds an additional layer of 'people and collaboration' to Jung's taxonomical layers (Bødker et al., 2017). The term '**layers** of artefact ecologies' in Jung et al.'s (2008) framework refers to the different types of interactive relations between the different artefacts, which shape the artefact ecology (cf. Figure 6). The layers are: purpose of use, context of use and subjective meaning (Jung et al., 2008). The additional layer 'people and collaboration' is essential in the study of digital relationships and communities and the communities of practice framework is applied to complement to this layer in the current PhD study as an analytical framework for studying the digital relationships and communities.

First, the properties, values and layers in the artefact ecology framework are presented, followed by the concept of community of practice, concluding with a final artefact ecology and community of practice framework to investigate the digital relationships and communities.

### 3.1.1. PROPERTIES AND VALUES OF DIGITAL ARTEFACTS

Individuals construct relations among artefacts from properties and values (Jung et al., 2008). The **properties** of artefacts are divided into the following categories:

*Physical aspect*: Physical devices, such as computers (Jung et al., 2008).

*Informational aspect*: Data or content (Jung et al., 2008). In this case, this aspect is used to describe applications that provide information about the individuals' digital interactions and digital lives.

*Interactive aspect*: The way an individual can interact with a physical artefact (usability) (Jung et al., 2008). There were interesting aspects regarding interactivity that the participants elaborated on but in this case, usability is not the main focus but the social interactions via and around digital technology. The first three properties are addressed in Chapter 4.

*Functional aspect*: What the artefact is used for (purpose), such as entertainment, socialisation and individualisation (Jung et al., 2008). In this case, the focus is mainly on the purpose of developing, maintaining, or managing digital relationships and digital communities. This is addressed in Chapters 5 and 6.

Wenger et al. (2009) use *tools* instead of physical aspects to describe physical devices that support activities in a community, *platforms* instead of informational aspects, *features* instead of interactive aspects and *configurations* to describe the overall set of technologies in communities instead of artefact ecology (Wenger et al., 2009c). In this study, the terms are used indiscriminately.

The **values** given to artefacts and their properties are divided into the following categories:

*Emotional value*: Feelings stimulated by an artefact (Jung et al., 2008).

*Experimental value*: Memories or reflective responses stimulated by an artefact (Jung et al., 2008).

*Social value*: Symbolic meaning of an artefact in a social context, such as a social group (Jung et al., 2008). In this case, the social value is, in fact, the *social* value in relation to others (socialisation).

Individuals value artefacts differently; to some, an artefact is primary, to others it is complementary or secondary. In Jung et al.'s (2008) study, computers are valued as the core artefacts in individuals' artefact ecologies, wherein applications connect digital devices and have the potential to support social activities (Jung et al., 2008).

Figure 6 illustrates the composition of artefact ecology (layers, properties, values and complex interactions and connections between artefacts and properties of the artefacts).

**Figure 6: Compositions of artefact ecology**

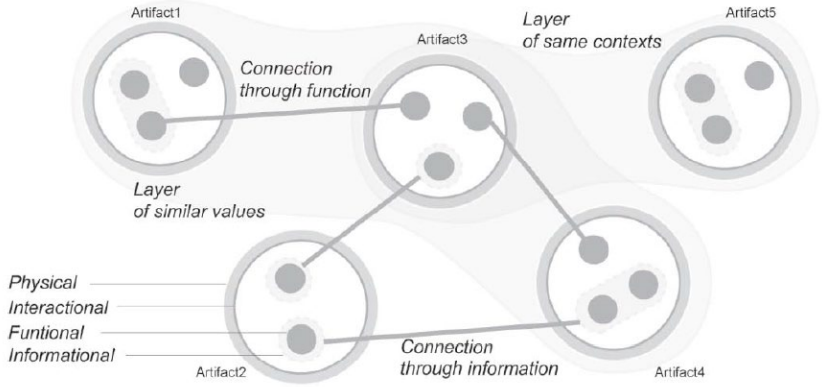



*Figure 6 illustrate the compositions of artefact ecology. From Jung et al. (2008)*

## 3.2. COMMUNITIES OF PRACTICE

The term 'communities of practice' refers to an integrated, informal part of our everyday life (Wenger, 1998a), defined as:

> …the complex process that combines doing, talking, thinking, feeling, and belonging. It involves our whole person, including our bodies, minds, emotions, and social relations (Wenger, 1998a, pp 56).

Wenger's notion of 'communities of practice', as its name indicates, has roots in the field of practice and learning theory. In this sense, and as illustrated in the quote above, **learning** is a key element of this theory. Learning is framed in a social context regarding participation in communities (Nicolini, 2017; Wenger, 1998a). Four elements characterise participation in communities as a process of learning: meaning, practice, community and identity (cf. Figure 7) (Wenger, 1998a).

**Figure 7: Components of communities of Practice**


*Figure 7 illustrates the components of communities of Practice. From Wenger (1998)*

**Meaning** refers to experiencing our life and the world as meaningful, which can change over time ('learning as an experience', cf. Figure 7) (Wenger, 1998a). In Wenger's (2009) later work, the focus is more specifically on 'domains'. It refers to the act of people gathering around something fundamental which they have in common, something they care about and not just a passing interest (Wenger et al., 2009d).

**Practice** means that communities have a shared repertoire of historical and social resources, frameworks, aims, engagements and perspectives (Wenger, 1998a), where they learn from and with each other via formal or informal activities ('learning as doing', cf. Figure 7). History does not necessarily mean that the members have known one another for a long time but that they share some mutual history which makes them mutually engaged in the community of practice (Wenger et al., 2009d).

**Identity** is created via participation in a community and, as such, is a social identity. Identity is created both when entering and exiting a community of practice ('learning as becoming', cf. Figure 7) (Wenger, 1998a).

**Community** refers to the way our participation in a community is perceived as legitimate by the community members, including ourselves ('learning as belonging', cf. Figure 7). As such, to reduce feelings of isolation and to advance togetherness, trust and mutual engagement are essential prerequisites for learning together in a community (Wenger, 1998a; Wenger et al., 2009d).

The concept of communities of practice emphasises multi-membership, that is, we can (and do) belong to several communities of practice at a given time (Wenger, 1998a). **Legitimate Peripheral Participation (LPP)** is a central concept in communities of practice formulated by Wenger and Lave in 1991. LPP emphasises the richness and legitimacy of peripheral participation in digital communities both in terms of passive and active participation (Lave and Wenger, 1991; Wenger, 1998a; Wenger et al., 2009d). Passive participation may include 'lurking' (reading online), whereas active participation may comprise posting online (Wenger et al., 2009d). Legitimacy means that the members of a community learn by becoming part of an activity in the community, taking responsibility, and becoming a stakeholder in their respective communities. In this sense, learning is both a condition for membership in a community and for evolving in the membership, which takes place because of interactions with others. As such, communities of practice is a social theory of learning, where learning is not necessarily a cognitive or individual process that happens in a formalised educational sphere. Learning is much more about belonging, engagement, inclusiveness and developing identifies (Nicolini, 2017; Wenger, 1998a), which is central in this study's exploration of digital communities and relationships. As such, the example of 'lurking' is still considered a legitimate peripheral participation as it is a 'crucial process where communities offer learning possibilities to those in the periphery' (Wenger et al., 2009d)9). However, whether participation is active or passive (or silent) is not as important as the ability to learn in the periphery (Wenger et al., 2009d).

According to Wenger et al. (2009), a digital community is not defined by the place or personal characteristics as per the traditional understanding of community (as defined in Chapter 1) but by the people's potential to learn together, which he terms **digital habitat** (community in the ecological sense). As such, there is no strict unity, and people find learning partners on a larger scale using technology as a tool to engage with them meaningfully (Wenger et al., 2009d). As such, technology expands the community infrastructure, as suggested by Wenger et al. (2009):

> Technology has changed how we think about communities, and communities have changed our use of technology (Wenger et al., 2009e, pp 22).

Communities of practice and the understanding of LPP retain the moral and normative aspects in the traditional understanding of community, with characteristics of **mutual engagement**, **common enterprise** negotiated by the community, **shared repertoire and shared history of learning** (Nicolini, 2017).

Communities have different **orientations**, which are patterns of activities and ways to connect towards learning together and experience being part of a community. These are meetings, open-ended conversations, projects, content, access to expertise, relationships, individual participation, community cultivation and serving a context.

These orientations have implications of which technologies the communities use (Wenger et al., 2009f).

When individuals interact around a common enterprise or something they care about and recognise each other as learning partners, new communities may be formed, that is, communities can unfold over time without a predefined ending (Nicolini, 2017; Wenger et al., 2009d). This perspective is important for understanding the study participants and users and the digital communities they are part of, as well as the way these communities of practice allow and facilitate personal and social growth (identity). With that in mind, having diverse groups using a multitude of technologies and tools to interact in multiple ways and moving in and out of community spheres make digital behaviours dynamic, messy and complex (Bødker et al., 2017; Wenger et al., 2009a).

In communities of practice, members can **negotiate** enterprise, norms, perspectives, and meanings. Negotiation can create collaborations but also disagreements if the former does not happen under the process of fitting into a community as a member. Identification with members and community enterprise can help overcome inequalities and other emerging problems (Wenger et al., 2009c).

The last concept mentioned in this theoretical passage is **technology stewardship**, which is used to describe individuals or groups that take care of a community. They use technology to learn together, that is, they take responsibility for the communities' technical resources and, as such, are often combined with a role of leadership but should not be confused with IT support. Technology stewards are defined as:

> …people with enough experience of the workings of a community to understand its technology needs, and enough experience with or interest in technology to leadership in addressing those needs. Stewarding typically includes selecting and configuring technology, as well as supporting its use in the practice of the community (Wenger et al., 2009g, pp 25).

## 3.3. DIGITAL COPING STRATEGIES: INDIVIDUALISATION AND PERSONALISATION

As stated in Section 1.2.2, communities are a positive concept (Nicolini, 2017). Moreover, as described above, individuals can obtain togetherness and belonging in their digital communities, referred to as public activities of socialisation (Jung et al., 2008). Thus, individuals may also want to detach themselves from others and conduct private or personal activities using digital artefacts, referred to as individualisation or personalisation (Jung et al., 2008; Wenger et al., 2009f). Formulated by Jung et al.

(2009) as 'adjusting the boundary of personal or social space using interactive artefacts' (Jung et al., 2008, pp 207), and by Wenger et al. (2009) as:

> Members can individualise their experience of the community to serve personal needs and circumstances and control access to their information (Wenger et al., 2009f, pp 91).

This individual orientation is not viewed as a negative response but a coping response to manage digital interactions with others. Bødker et al. (2017) and Verbeek et al. (2015) point to different responses to how individuals manage the complexity of multiple artefacts and their community artefact ecologies. For some, it can be stressful to be constantly 'on' or 'available' online, and some are also exposed to 'peer and community pressure' online (Bødker et al., 2017; Kiran et al., 2015). In this regard, the strategy of 'non-use' is used to manage and shape the individuals' interactions with technology (Bødker et al., 2017; Kiran et al., 2015). Wenger et al. (2009) point to the fact that there are three challenges that drive communities to adopt technology, and each challenge has two inherent and mutually dependent poles that need to be balanced. These challenges are *Rhythms* with togetherness and separation as poles; *Interaction* with participation and reification (physical and conceptual artefacts which the participation is organised around) as poles; and *Identities* with individual and group as poles (Wenger et al., 2009h).

To explain and expand upon how individuals cope with the complexity in their community artefact ecologies, Lazarus and Folkman's conceptual coping framework (primarily problem-focused and emotion-focused coping) (Lazarus and Folkman, 1998d) and the concept of 'personal infrastructuring' (Rajapakse et al., 2018) were used in Paper 3. The concept of personal infrastructuring combines a relational orientation with an individual orientation, as it refers to the ways by which individuals living with disabilities exercise self-control by using a personal approach to manage the existing digital infrastructure and to express values, needs and challenges, with social support from family, friends or institutional staff (Rajapakse et al., 2018). Personal infrastructuring is seen as an act of adjusting boundaries of personal or social space using interactive artefacts; as such, it is an act of personalisation (Jung et al., 2008).

Lazarus and Folkman postulate two coping responses that are intertwined: emotion-focused coping and problem-focused coping (cf. Paper 3). Emotion-focused coping is a passive response wherein emotions towards a challenge are regulated by re-appraising a challenging situation for it to become manageable for the individual without actually changing the objective situation. Problem-focused coping is an active response towards the environment, directed at changing the objective challenging situation. The problem-focused response can also be inwards, such as a cognitive change or reappraisal, which is where the two responses are intertwined, as inwards problem-focused coping is also an emotion-focused response (Lazarus and Folkman, 1998a, 1998b, 1998c).

## 3.4. SUMMARY

In summary, the notions of artefact ecology and community of practice constitute properties, values and community understandings that can be used to map and explain the way our users (individuals with cognitive disabilities) interact with one another in different ways to form and manage digital communities and relationships using a multitude of interactive technologies. The key concepts for the analysis are personal artefact ecology, community artefact ecology, digital habitats, layers, properties, values/meanings, practice, learning, identity, community, LPP, shared enterprise and repertoire, mutual engagement, negotiation, tech stewards, coping responses and orientations (particularly personalisation and individualisation).

# CHAPTER 4. METHODOLOGY

*'There are many ways of doing research inclusive' ~ Nind & Vinha (2013)*

This chapter is a methodological chapter addressing the research approach, the study population, the data foundation, the important roles in data collection, the challenges in mapping digital communities, the analytical strategy to analyse data, and the ethical assessment. This chapter aims to understand and examine the fifth objective: how to include the study population in researching their rich digital activities and communities.

## 4.1. RESEARCH APPROACH

In the following, the ontology (defectology) epistemology (participatory research) and understanding of the technology is addressed.

### 4.1.1. DEFECTOLOGY

Section 1.2.1 described how the biopsychosocial model views a cognitive disability as the product of the individual impairment and the societal response to this impairment - the counterpoint to the view that a disability is simply a functional disorder (AAIDD, 2021; Carulla et al., 2015; Goodley and Runswick-Cole, 2016; Rieber and Carton, 1993; Schalock and Luckasson, 2004). In this study, we adhere to this model and leverage a Vygotskyan (Rieber and Carton, 1993) view of studying the nature of individuals living with cognitive disabilities (the ontology). The notion of 'defectology' defines and understands disability from the societal and cultural structures and responses to individuals living with disabilities rather than as a sickness or a defect (Rieber and Carton, 1993). In this sense, a disability is an inconsistency between the individual's cognitive and psychological structure and the structure in the surrounding culture and environment, including the digital sphere. Individuals are recognised as unique and are not reduced to their diagnoses or decrease in functionalities. Disability is recognised as a dimension of human differences, and it is precisely this diversity that the individual represents which Vygotsky (1993) find interesting and seeks to understand (Rieber and Carton, 1993). Herein, individuals are not reduced to their disabilities. The focus is on the whole person, wherein the

disability or impairment is part of the person but not limited to the person; it is the society that needs to be structured with regards to the needs of individuals who experience different challenges. The Vygotskyan model is also the reason for adding the element of 'living' with cognitive disabilities in the labelling of the participants in this study to avoid reducing them to their disabilities.

Vygotsky combines the pedagogic and disability field in his work on defectology, particularly concerning learning disabilities and abnormal psychology. He was a psychologist himself, and therefore, the theory originates from psychology. The special institutions in Denmark, including the institutions we work with in this PhD study, uses the Vygotskyan perspective and tradition in their work with individuals living with cognitive disabilities. As such, it was essential for us researchers to have the same conviction as practitioners in the special pedagogical field.

There are many variations of the biopsychosocial perspective on the study population, for example, 'ablism' as a pole to 'disablism' (social, cultural, material and economic conditions which exclude people living with disabilities and promote treating them unequally) (Goodley and Runswick-Cole, 2016), and 'crip theory' which 'seek to analyse and challenge connections between the social construction of heteronormativity and able-bodiedness' (Goodley and Runswick-Cole, 2016, pp 3). These perspectives on individuals living with disabilities have in common the search for and recognition of 'sameness' and equality for individuals living with disabilities (Goodley and Runswick-Cole, 2016). The notion of defectology agrees with these theories of ablism and crip theory.

In practice, the implications of using a theory that intersects between the pedagogical field and disability studies are that we were able to facilitate a common understanding between researchers and practitioners on how we view and study our study participants. This shared understanding means we view the study participants as abled rather than disabled. Furthermore, the implications of using the notion of defectology in our case were that the participants were not labelled into categories with their diagnoses when the empirical findings were analysed, as this differentiating was not deemed relevant.

Other disability studies differentiate diagnostic subgroups of cognitive disabilities in their research (cf. Section 1.3), for example, research and design with individuals with autism (Alcorn et al., 2011; Burke et al., 2010; Gwynette et al., 2018; Harrington et al., 2014; Iglesias et al., 2019; Pinchevski and Peters, 2016; Ringland et al., 2016; Spiel et al., 2017) or ADHD (Becker and Lienesch, 2018; Reilly et al., 2016; Sonne et al., 2016), or down syndrome (Feng et al., 2008). We take inspiration from these studies in the data collection and the interpretation of our empirical findings. However, in our case, we were occupied with examining and differentiating the participants according to their digital and social behaviours and habits, for example, being an introvert or extrovert or implicit and explicit – not their diagnosis. The

participants' diagnoses were also not well known before and during the fieldwork; merely their triggers were known to be able to consider, which was crucial. We did not want to prejudice toward their digital behaviour and abilities.

Treating our study participants as a homogenous diagnostic group does not mean that we do not recognise the benefits of providing individuals with a diagnosis, as this allows them to receive the healthcare and pedagogical care they need (Carulla et al., 2015). In addition, it opens up the possibility of examining and understanding the challenges this study population experiences and their abilities.

### 4.1.2. PARTICIPATORY RESEARCH WITH PEOPLE LIVING WITH DISABILITIES

Underpinning our research principle of treating the study participants as people and not as their disability is a research aim for democracy in data collection and representation, where the goal is to give a fair and honest representation of the participants' tacit knowledge and to emphasise their points of view (Blomberg and Burrell, 2003; Brandt et al., 2012). In this sense, it is vital to use a participatory research approach (the epistemology), which is highly inductive and fieldwork-based (Wadel, 1991), to examine the study participants' digital reality. A participatory research approach enables a study of digital participation in practice and the performance of collaborative research *with* the participants and their resource persons (the staff at the institutions) throughout the research process. This advances giving a voice to or amplifying the voice of the participants, which is especially important when collaborating with people living with disabilities (Benton and Johnson, 2015; Foss and et al, 2013; Frauenberger et al., 2011; Kanstrup and Bertensen, 2016; Nicolini, 2009; Nind and Vinha, 2014; Ringland et al., 2016; Strnadová and Walmsley, 2018). 'Amplifying a voice' or 'listening to a voice' are more correct statements as 'giving a voice' indicates that the study population did not have a voice to begin with.

In a systematic search conducted regarding inclusive/participatory research and individuals living with cognitive disabilities (see Appendix A for the detailed search protocol), the characteristics of inclusive and participatory research were identified (cf. Paper 5). The literature indicates that inclusive research needs to benefit the individuals in the study, for example, by empowering them or amplifying their voices. In addition, inclusive research has to be collaborative between the individuals living with disabilities and the researchers without disabilities, for example, by using techniques of co-researching, mutual learning, negotiation and supportive roles (Burke et al., 2003; Chappell, 2000; Flood et al., 2013; Goodwin et al., 2015; Keyes and Brandon, 2011; Nind and Vinha, 2014; Riches and O'Brien, 2020; Schwartz and Durkin, 2020; Seale et al., 2018). The literature also emphasises that training the

individuals living with disabilities who are involved in the study to become co-researchers has proven to be beneficial in many research settings (Mikulak et al., 2021; Tuffrey-Wijne et al., 2020). However, this was beyond the scope of this particular study.

#### 4.1.2.1 Participatory Design

We used PD principles and activities in our study to collect (or shape) our empirical data as the study constituted the initial investigation for a larger PD research project (cf. Section 1.1 and 2.1). PD principles used in the PhD study follow principles for inclusive research. PD principles emphasise the following: 1) Participants as design partners, rather than informants. 2) Mutual learning to support emancipation. 3) Empowerment of participants (through the process of design), 4) Democracy in data collection and presentation, and 5) Skilfulness of all people involved in the research and design process (Bødker et al., 2022a). The principles comply with treating participants according to a bio-psychosocial and competency-based model (Bayor, Sitbon, et al., 2019); as unique and capable human beings, not as their diagnosis. This also means that we see participants as the experts and the researchers are trainees (Wadel, 1991) and that we plan and approach participants according to their individual needs (Harrington et al., 2014; Hendriks et al., 2015). In addition, we have a 'give-and-take principle' (Kanstrup and Bertelsen, 2016), which is elaborated in paper 5. These principles were outlined before conducting the data collection.

PD traces its roots to Scandinavia in the 1970s to empower individuals who worked with technology to have a say in the development and use of the technology under the lens. PD activities are typically 1) fieldwork to understand the practice and initiate mutual learning. 2) Workshops facilitate collaboration and mutual learning between diverse actors, share experiences and discuss the items used for design purposes. 3) Collaborative prototyping; exploring and developing design alternatives with participants, iterative modification of design solutions to decide what to do or not. 4) Infrastructure; securing that social, organizational, and technical infrastructure can support the sustainability of findings. 5) Evaluation; assessing the design outcome (Bødker et al., 2022b). The activities used in this PhD study are mainly fieldwork (informal interviews and diaries), workshops, and evaluation (of research findings). The activities are elaborated in Section 4.3 (data foundation). Simple materials, photographs, stories, acting, game-playing, and mock-ups are often used to give users without design skills the chance to contribute to the design process by enabling them to express their needs and provide feedback and suggestions for improvements. In addition, to elicit design feedback and suggestions, a central challenge in PD is to keep the collaboration grounded in the user's context (Bødker et al., 2022b; Simonsen and Robertson, 2013; Ylirisku and Buur, 2007a). The PD techniques and methods (activities) used in this PhD study were mainly inspired by PD research with

individuals living with cognitive disabilities. This research is manifold and beneficial for different purposes, and not all PD methods for individuals living with cognitive disabilities have been examined. Some examples that were studied and inspired this research are 'Techshops' (Bayor, Ploderer, et al., 2019), respectful design (Rajapakse et al., 2019), reflective agile iterative design and person-centred planning (Wilson et al., 2016b) and co-design beyond words using joint attention, turn-taking and imitation (Wilson et al., 2019) (cf. Paper 5). In addition, interface design experience for the autistic spectrum (Benton et al., 2012), interest-based learning (Wilson et al., 2017), 'Handlungspielraum' (Makhaeva et al., 2016), inclusive design for individuals with Down syndrome (Macias et al., 2018), design-after-design (Brereton et al., 2015) and participatory evaluation with autistic children (Spiel et al., 2017) were also explored. Initiatives were also made to optimise the website design for people with cognitive disabilities (Williams and Hennig, 2015), wherein the importance of including them in the design interface of websites or games is underscored (Chadwick et al., 2013).

## 4.2. STUDY POPULATION

In the following subsections, the study population, and the Danish institutions that they are part of, as well as the premise behind the sampling and sampling size, are discussed.

### 4.2.1. THE INSTITUTIONAL SPHERE

The study participants are from three institutions for youth living with cognitive disabilities in the municipality of Aalborg in Denmark: a primary school, an educational centre with a programme for youth with special needs and a sheltered residence. These were chosen to represent and include youth living with cognitive disabilities from different life stages. The three institutions present the stages that a significant part of the study population goes through in their young life: from school to youth education to their own residence. All the institutions use digital technologies in their daily practice, and the young participants all use digital technology in their free time. All of the institutions want to obtain a better understanding of the digital lives and communities of their students and residents.

Participants from **the primary school** are between 14–17 years old. At the primary school, the students require extensive one-on-one contact with the possibility of shielding oneself from others during classes and breaks by having walls that isolate the participants at their desk or a room where they can go if they feel overstimulated. They also have an aim: for everyone to have a friend in school. The students receive

social training during the school's weekly classes. The primary school has made several initiatives to integrate digital activities into the school's pedagogical work with social competencies using 'digital fabrication'. 'Digital fabrication' is an overall concept for initiatives meant to promote creativity, independence (problem solving) and reflection on societal matters through digital technologies (Davidsen et al., 2021). This has been deemed challenging for the study population due to their communication and interaction difficulties. Thus, the primary school has found a way to make digital fabrication possible with this particular study population using individual rather than team-based activities, personal interests rather than societal problems and teacher support rather than self-driven activities (Davidsen et al., 2021). These initiatives have primarily been made possible by a teacher with a master's degree in IT and pedagogic and enthusiastic personality to bring digital fabrication initiatives into the teaching process. The first digital fabrication initiative was a 'Makerspace' session, which took place once a week. Here, students were taught different technological skills, for example, creating different objects in a programme called Tinker cad, which they 3D printed at the local library. The Makerspace initiative was further developed into a computer room, where the students sit together using their own computers to game, make games or for other activities. This initiative started during the project period. The second digital fabrication initiative was an individually planned course for one of the students for which the Makerspace sessions were not a good fit (Davidsen et al., 2021).

Participants from the **youth education** are between 18–22 years old. The youth programme focuses on the practical development of social competencies in the students' everyday lives rather than 'professional' competencies. At the youth education centre, the students are divided into five groups depending on their needs and abilities. There is an A group for students with severe disabilities, an X group for those who are well functioning, for example, students who are able to attend lessons on personal development, Danish and mathematics, a U group for those who have severe communication challenges (with an IQ of around 40) and a K group for those who have extensive communication and adaptation challenges, such as lack of speech and anxiety. The youth education has initiative teaching sessions about online behaviour. The goal is to help the students gain beneficial social experiences online. They are provided with assistance in handling communication challenges and inappropriate and destructive behaviour online, from themselves and others whom they interact with, to help them understand the consequences of their digital actions. The youth programme has an 'IT-robot project' as a weekly selection course where students build Lego robots for a national competition with other youth clubs in Denmark. They build the robots from scratch and programme them for different functions. Their creations are very detailed, with engines, gears, etc. They use a programme called Lego Creation to find out what the robot's function should be and what parts they need to build for the robot. This requires collaboration among the students, who sit together and make the robots, except for one who sits alone. They learn technological skills and mathematics more easily via a project like this.

Participants at **the sheltered residence** are between 23–27 years old. They have diverse social relationships and activities, and they are at a stage in their adult lives where they and their resource persons need to balance support and independence, including in their digital lives. There have been different initiatives supporting independence in digital activities at the sheltered residence, such as QR codes, where the participants can view the different conversations and tutorials, they have made themselves, for example, those regarding cyberbullying and other activities.

The resource persons (supportive staff at the three institutions) were essential in planning, conducting data collection and evaluating the research data. They contributed passionately in this regard in a valuable collaboration with the researchers. There were 3–4 resource persons from each of the institutions in the DiGi project, and each institution had one or more resource persons who were familiar with the technological sphere in different aspects.

### 4.2.2. STUDY PARTICIPANTS

The study participants are diagnosed with either autism, ADHD, developmental impairment, or Down syndrome. Most of the study participants live with other mental and physical disorders. As their diagnosis was not the focal point but their behaviours, habits and values, the participant characteristics and their triggers are presented in Table 2. These were carefully considered during the data collection, and although the triggers are often related to the participants' individual diagnoses (for example, Down syndrome), they are not limited to their diagnosis.

**Table 2: Participant characteristics**

| P | Age | Gender | Institution | Triggers and considerations |
|---|---|---|---|---|
| **P1** | 27 | Male | Sheltered residence | Social anxiety, trust issues, one-to-one contact, high abstraction level but slow tempo in speech, memory issues, smoker, disorder (Williams syndrome) and reflux. Sleeps late and wakes up late. No social network incl. family. Lonely. Great interest in the project and expressing his story. |
| **P2** | 19 | Male | Youth education | Social anxiety |

| | | | | |
|---|---|---|---|---|
| **P3** | 19 | Male | Youth education | Low comprehension level, temper. |
| **P4** | 19 | Female | Youth education | Shy. |
| **P5** | 20 | Female | Youth education | Jabbers, temper. |
| **P6** | 27 | Male | Sheltered residence | Accountability issues. |
| **P7** | 25 | Male | Sheltered residence | Polite, easy to talk to. |
| **P8** | 25 | Male | Sheltered residence | Poor eyesight. |
| **P9** | 17 | Male | Primary school | Low comprehension level. |
| **P10** | 23 | Female | Sheltered residence | Support need (wants to talk in groups), suffers from Turner syndrome, concentration issues, active in sports. |
| **P11** | 21 | Female | Youth education | Suffers from stress, urticarial, shy of the camera (at first). |
| **P12** | 23 | Female | Sheltered residence | Difficulty expressing herself, talks quietly. |
| **P13** | 24 | Female | Sheltered residence | Low comprehension level, lively imagination. |
| **P14** | 17 | Male | Primary school | Distance from reality (imagination), control and structure are important. |
| **P15** | 17 | Male | Primary school | Social anxiety, one-to-one contact. |
| **P16** | 16 | Male | Primary school | Interaction issues (inappropriate, literal), uses humour as a defence mechanism (or a conversation starter?) |

| | | | | |
|---|---|---|---|---|
| **P17** | 16 | Male | Primary school | Not present much, ironic, condescending. |
| **P18** | 19 | Male | Youth education | Polite, shy. |
| **P19** | 18 | Male | Youth education | Low comprehension level, Jabbers, touches his fingers much, and rubs his forehead. |
| **P20** | 19 | Male | Youth education | Shy, low comprehension level |
| **P21** | 14 | Male | Primary school | Polite, easy to talk to, direct and firm in his statements. |
| **P22** | 17 | Male | Primary school | Social anxiety, trust issues, low self-esteem, psychological challenges, loneliness |
| **P23** | 17 | Male | Primary school | Overstimulation (needs breaks) |
| **P24** | 24 | Male | Sheltered residence | Concentration issues, restless |
| **P25** | 25 | Female | Sheltered residence | Language barriers (not Danish origin), temper (knows what she wants and does not want), 'grunt-tic', keep appointments (lack of flexibility). Social and cognitive deficiencies and skills. |

*Table 2 contains the characteristics and triggers of each study participant.*

#### 4.2.2.1 Youth

There are different views regarding the age interval in which one is considered young. The United Nations (UN) and the World Health Organisation (WHO) define 'youth' as the 15–24 age group, 'adolescents' are individuals in the 10–19 age group and 'young people' covers the age range of 10–24 years (United Nations Youth, 2014). However, the UN Youth defines 'youth' as the 15–32 age group (United Nations Youth, 2014). A Danish report from 2006 recognises that it may not be valuable to divide individuals strictly into age categories, as values, habits and experiences are not necessarily limited to specific age groups (Gundelach and Nørregård-Nielsen,

2006). As such, our understanding of youth is quite broad and includes ages ranging from 14–27 years, which does not substantially go beyond the age interval provided by the UN and the WHO. There were no specific age limitations for the inclusion of participants in our study; the age interval was set after the ages of the participants who wanted to join the study were determined. As such, the age groups at the institutions established the age interval.

### 4.2.3. SAMPLING AND SAMPLING SIZE

The primary investigator (PI) who had contacts at the primary school carried out the sampling at the Danish institutions. Snowballing was used to some extent, as the contact to the primary school opened the possibility of establishing a connection with the youth programme that the primary school was in contact with because this solution is a natural step education-wise. In addition, the contact at the youth programme opened the possibility of establishing a connection at the sheltered residence. Contacts at the youth programme recommended the sheltered residence because of good collaborations and experiences with this institution; some students were even involved in the youth programme and knew people from there. The three institutions were selected as they represent the institutional (and educational) stages that youth living with cognitive disability usually go through in their youth and adult life. Therefore, an inclusion criterion for the study participants was that they attended one of the institutions for youth living with special needs.

Another inclusion criterium of the sampling was voluntariness. The sample size was determined by the possibility of including participants at the three institutions and their desire to join. Participants were recruited during an informal information meeting about the PhD project, hosted at each collaborating institution by the PI and me. At the meeting, the student and residence at the collaborating institutions were given information about the project and the participants contributions. After the meeting, students and residents could ask questions, and if they wanted to be included in the study, they approached the researchers, or the resource persons connected to the project. We did not choose any of the study participants directly. This sampling strategy is similar to other sampling strategies used by Scandinavian researchers within disability studies (Borgström, 2021), while some have used more purposeful sampling to obtain rich information for generating theory (Ågren Alfredsson et al., 2020b; Söderström, 2009). Implications of having a sampling strategy based on voluntariness may be that the participants who were the most capable and the most extrovert chose to participate in the study, and therefore, they may also have a more social behaviour and be more digitally capable. For this reason, our findings may not be representable for individuals with more severe cognitive disabilities, or individuals who experience a high level of anxiety or other psychological impairments together with their cognitive disabilities. This matter is discussed in Paper 3. At the youth

education, the resource persons had some students in mind who did not attend the presentation of the project for personal reasons, and the resource persons asked them if they wanted to participate. As such, our sampling strategy entailed elements of purposeful sampling.

We did not exclude anyone who wanted to join. For example, at the shelter residence, a participant expressed an interest in joining the study halfway into the first round of fieldwork and was invited to join the study. We included eight participants from the primary school, eight from the youth education and nine from the sheltered residence. At the youth education, participants were not considered from the K and A groups (cf. Section 4.2.1), as they were deemed to be too unstable psychiatrically and too severely disabled, respectively, to participate in the study. As such, these constituted exclusion criteria as we merely included participants from the X and U group.

In most qualitative interview studies, the number of participants usually included in research has been assessed by researchers to be $15 \pm 10$ (Kvale and Brinkmann, 2015). The principle of 'information power' was used in this study in deciding the sample size (N=25). Information power means that the larger the information power the sample holds, the lower the number of participants needed in the study (Malterud et al., 2016). Malterud et al. (2016) suggest that sufficiency of information power (i.e. how large a sample needs to be) depends on the following factors: 1) study aim; 2) sample specificity; 3) theoretical foundation; 4) quality of dialogue in data collection methods and 5) analysis strategy (Malterud et al., 2016). The arguments for the need for a rather large sample size in this study are as follows. First, the study aim was broad enough to allow exploratory and inductive data collection, which makes the phenomenon under the lens more comprehensive. Second, the participants' characteristics were specific to the study aim, as they were limited to individuals living with cognitive disabilities (a specified study population) and not, for example, physical disabilities or Nero typical individuals. Thus, we had a broad diagnostic understanding and included participants living with multiple cognitive disabilities, which makes a large sample size necessary, as we wanted to present a broad spectre of individuals living with cognitive disabilities and not merely individuals on the autism spectrum, for example. Third, a specific theoretical framework was not used to deduce the research design, as we wanted an inductive research approach. The Vygotskyan perspective and participatory research approach were determined from the beginning, but the theoretical framework for analysing the data was chosen after the data collection process. Fourth, regarding the quality of dialogue, the communication between the researcher and the participants was structured around their use of and meaning attributed to digital technology. However, the dialog was open and unfocused within this matter and, therefore, required a larger sample size. The fifth and last argument for a rather large sample size was that we wanted to be able to address a variety of perspectives and to make sure to obtain rich descriptions from participants, as well as to be able to generalise the empirical findings and develop strategies not only for the study participants but for the study population in general.

This required a larger sample size (Borg et al., 2015; Caton and Chapman, 2016; Seale and Chadwick, 2017), as the analytical strategy was meant to explore tendencies and patterns in the empirical findings, as opposed to a narrative story, for example (Malterud et al., 2016). The raw data were analysed thoroughly for each participant, but the dissemination was not geared towards a narrative representation but narrative examples.

## 4.3. DATA FOUNDATION: MAPPING DIGITAL COMMUNITIES WITH THE PARTICIPANTS

The triggers and needs of participants made it necessary to have a creative and flexible research approach and to use visual tangible artefacts (VTAs) to interact with the participants and include their perspectives in the study (Kanstrup and Bertelsen, 2016). The VTAs were developed by the research team using inspiration from other VTAs in the research field (Baykal et al., 2020; Bødker et al., 2017; Brandt et al., 2012; Gaver et al., 1999; Harper and Harper, 2002; Jung et al., 2008; Murphy and Cameron, 2008; Shinohara and Tenenberg, 2007). The inclusive VTA tools were Talking Mats, digital snapshots, inspiration cards and the users' own digital technology (cf. Paper 5). The VTAs were used to map, communicate, and validate the findings with the participants, as well as to inspire reflections about future technology use and activities. As such, they provide great experimental and emotional value (cf. Section 3.1.1) as they stimulate memory, reflection, and emotions about the participants' digital technology use. The roles of the VTAs were evident in the data collection and dissemination process, as it would not have been possible to extract and present these empirical findings without these tools and techniques (cf. Paper 5).

The VTAs have been described in detail in Paper 5. Therefore, they will not be explained thoroughly in this section but merely touched upon. Instead, the different data sources (the data foundation) are described in detail. Table 3 provides an overview of the various data sources used in the study before describing them in detail.

**Table 3: Data foundation**

| Data source | Content | Purpose |
|---|---|---|
| Information sheet | Pre-fieldwork. The information sheet contained information about age, need for the resource person to be present, potential triggers and needs, and current use of digital technology (when, where, how long | Familiarisation with participants and guidelines for fieldwork and interviews. |

| | | |
|---|---|---|
| | and for what purpose the digital technology were used and whether the use was alone or together with someone) | |
| Pilot visit | Pre-fieldwork. A full day at each institution, following daily routines and activities of participants. | Familiarisation and development of interview-guide. |
| Interview | Part of fieldwork (one week). Video recorded, informal and unstructured interviews, inspired by an 'Interview to the double' approach (tech tours) where participants show and tell about their digital lives using their digital platforms (Nicolini, 2009; Ylirisku and Buur, 2007a). 'Talking Mats' were used to facilitate interviews. This method supports conversation using the mat as a focused space (Andreasen and Kanstrup, 2019a; Cameron and Murphy, 2006). Conversations were conducted individually or in groups based on participant wishes and advice from resource persons. | Facilitate in-depth insights and descriptions of participants technology use tailored their needs. |
| Observation with and without video | Part of fieldwork (one week). Observation of participants (Wadel, 1991). 3 video recorded sessions were obtained and few informal sessions. Field notes were turned into descriptive accounts after leaving the research setting. Informal meetings and visits at institution, with informal conversation with resource persons and participants took place from June 2018 to January 2020. | Observe non-verbal and indirect communication and behaviour and build rapport with participants. |
| Video diaries | Post-fieldwork. Participants carried out video diaries with resource persons and me. Diaries were structured around three questions, guided by findings from interviews, and lasted 5-15 min. | Capture the participants everyday use of digital technology |

| | | |
|---|---|---|
| | | for social interaction |
| Workshop | Post-fieldwork. Findings from fieldwork guided a participatory workshop with participants and resource persons. Visual means including a digital profile (the digital snapshot) for each participant, and the Talking Mats, were used to converse with participants about their digital social life. Viewpoints from resource persons were included from workshops. | Communicate and validate preliminary findings with participants and resource persons. |

*Table 3 is an overview of the data foundation (the data sources used in the project).*

### 4.3.1. PILOTING

Research has emphasised the importance of conducting a pilot study before fieldwork (Majid et al., 2017). In our case, this was not so much a pilot study as a pilot visit, which was carried out for one full day at each institution to get a sense of the institution, familiarise myself with the participants and start building rapport (confidentiality). I had informal conversations with the participants about their everyday activities and interests, told them about the research project and determined how they would prefer to interact. I visited the common rooms at the institutions and attended classes and breaks. At the sheltered residence, it was possible to visit the participants' personal rooms, which was an effective way to build rapport, as they enjoyed showing their rooms. Some needed to warm up, while others were already open at the outset. For example, P10 and P13 hugged me at the first visit and kept doing so during the fieldwork. Prior to the fieldwork, the participants filled out an information sheet with data regarding their age, need for the presence of a resource person, potential triggers and needs, current use of digital technology, when, where, how long and for what reason the digital technology was used, and whether they were alone or with someone during the usage. This sheet was used during the interviews to support the conversations.

The pilot visit enabled a test of the 360 cameras (used to record) and find out how the participants responded to them. I also tested the method of probing with digital artefacts (described in the following Section 4.3.2). It would have been beneficial to pilot test the Talking Mats and digital snapshots, but these were not defined in the pilot visit. Had we been able to do this, this would have enabled the adjustments of these methods, not least regarding the digital snapshots (cf. Section 4.3.5).

### 4.3.2. INTERVIEWS: TALKING MATS AND PROBING WITH DIGITAL ARTEFACTS

Creating and using visual maps to facilitate data collection and data analysis is a standard and essential approach and tool for researchers investigating artefact ecology (Bødker et al., 2017; Jung et al., 2008). These visual maps are created from empirical findings, often via a twostep process: 1) intuitively in the research setting with participants, and 2) by the researchers after a thematic analytical of the empirical findings (Bødker et al., 2017). This technique is used to process and reflect on the data, to retrieve a comprehensive list of artefacts that individuals interact with and to stimulate descriptions about the use and meaning of the artefacts. In the mapping process, rich pictures, post-its (mock-ups) and contextual designs (Bødker et al., 2017) can be used. This study used the visual and tangible mapping and communication technique of 'Talking Mats'. Talking mats are characterised as both a low-technology tool, visual framework (to build a picture of your view), procedure, technique, resource, and a method (Stans et al., 2019). Speech and language pathology researchers from the UK developed the method to support people with cerebral palsy. Researchers within different academic fields have since used the method to interact with many different groups who experience communication challenges (Stans et al., 2019). It is commercially available and was familiar to the institutions we collaborated with. They had been using them in their social training with the participants. The Talking Mats are widely used as a generative communication tool to support research with individuals living with disabilities (Brandt et al., 2012; Bunning et al., 2016; Murphy and Cameron, 2008; Stans et al., 2019). The Talking Mats breaks down topics into smaller units to help people process the concepts under the lens, and reduce distractions, memory issues and cognitive load (Stans et al., 2019). It is a flexible and dynamic process which reflects a peoples' opinions at a specific time in their life (Stans et al., 2019).

The process of using the Talking Mats is as follows: 1) The participant and the researcher decide a central topic they want to discuss and place a symbol of the topic at the bottom of the mat – in our case, digital communities. 2) The researcher selects and presents a set of options symbols (in our case, digital and social technologies and activities). 3) The researcher chose and presents a scale illustrating positive and negative feelings at the top of the mat (in our case, using smileys to illustrate whether the participants liked, disliked or were indifferent to the icon under the lens.). 4) The visual summary (the mat) is used to confirm the information on the mat. The researcher takes a picture of the mat (Stans et al., 2019).

The Talking Mats were tailored to this particular study and utilised accordingly, using this flexible framework to adjust the stepwise approach to discuss digital activities

and communities with the study participants (cf. paper 5). Figure 8 shows an example of a Talking Mat used in the conversation with P16.

**Figure 8: Talking Mats**

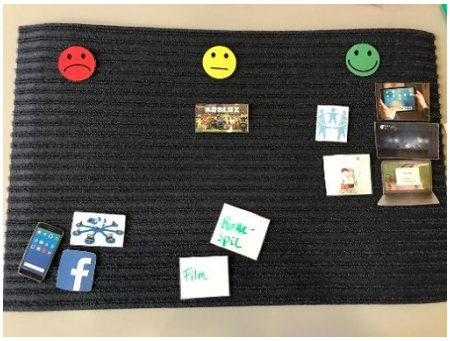



*Figure 8 is an example of the use of a Talking mat by a male participant from the primary school. Photo by Ditte Lystbæk Weber.*

In the Talking mat in Figure 8, the participant does not like using phones or connecting with people on Facebook. These were the items placed under the red smiley. He sometimes plays Roblox, watches movies and engages in role play at the primary school, but he does not care much about these particular items and placed them under the yellow smiley. He likes to use his iPad, mostly to watch others play 'Hollow Knight', and his computer to play a particular game at home. In addition, friendship and networking are important to him. These items were placed under the green smiley.

The process of mapping the digital behaviour with participants started with an interview but continued over a series of follow up interactions as it was difficult for several of them to participate in conversations for more than 20 minutes.

Using icons of the technology under the lens was a form of photo elicitation (Harper and Harper, 2002) meant to stimulate emotions and conversation about digital technology. As seen in Figure 8, some elaborated on technologies or events, which was not discovered during the pilot visit. These digital activities or relations were written on blank icons, as mentioned in Paper 5.

Other visual and tangible tools used were the participants' personal digital technologies through probing with digital artefacts (cf. Paper 5). This technique was inspired by Nicolini's (2009) 'interview to the double' (Nicolini, 2009). As discussed in Paper 5, the users' personal technologies, particularly their devices, were used to demonstrate and discuss their use of digital technology. As such, the technology became the method used to support the research of technology in the participants'

everyday lives (i.e., we start from where the participants are and what they want to show and tell, cf. Paper 5). Probing with digital artefacts meant that the users' own digital technology and devices were used to examine their digital use and relationships, as these show how they use their digital technology and for what purpose. Some examples were P23 and P12, who used their **phone** as a conversation starter. P23 showed me funny gimmicks he has sent or received from his friends, while P12 wanted to show what she is doing on her phone:

> Ditte, look at what I am doing (she leans forward eagerly to show me what she is doing on her phone while I am talking to P13).

At another encounter, I used her phone to take a tour with the participants using the QR codes, which were posted at the sheltered residence. These QR codes contained the videos made by the participants: some with discussions on bullying, a participant illustrating how to clean up a mess in one's room, and so on. In Figure 9, P14 shows me a home page he has made himself using his computer as the probing tool (personal technology). Using the technique of technology tours made the participants feel safer in displaying their technology use, as they were on home ground.

**Figure 9: Probing with users' digital artefacts**

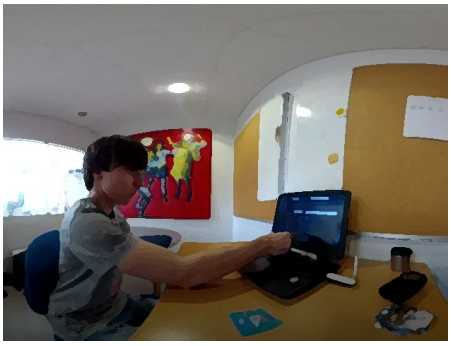


*Figure 9 is an example of probing with users' digital artefacts. In Figure 9, a participant use his computer (personal device) to demonstrate his digital use. Photo by Ditte Lystbæk Weber.*

The two visual and tangible mapping techniques were used in combination during the interviews and video diaries. In a typical interview situation, I would place the mat with the smiley categories at a table where the participant(s) and I were sitting. The participant(s) would sit with their device next to me with a pile of laminated icons, which the participants have expressed that they used during the pilot visit, and the blank icons. I would choose a random icon from the pile and ask the participant(s)

how they felt about using a particular device or how they felt about a specific encounter. The participant would answer and use the device to show how the icon was used and for what purpose. This would most often trigger further intuitive questions. During the informal interviews and technology tours, I made sure to acknowledge and recognise what the participants were saying and showing. This was especially important for P15, P14, P10, P22 and P11, who obviously sought this recognition and were very creative in their digital work, making the acknowledgement a natural part of the encounters.

Other tangible probing artefacts were the visual calendars for fieldwork, termed 'visual planning', so the participants could see when they were to meet with me and for how long. These visual planning tools hang in their joint rooms at the institutions.

### 4.3.3. OBSERVATIONS

A manual for observations and how to ask questions during interviews was developed prior to the fieldwork to help conduct the interviews and observations. The manual was adjusted continuously throughout the fieldwork's duration. The manual contains sensitive information and, therefore, has not been included in the PhD thesis. Three formal sessions were recorded at the sheltered residence and the primary school: a game night session, where participants at the sheltered residence tried out original Nintendo games, a Makerspace session at the primary school and a movie session at the primary school. Details of the video sessions are provided in later methodological and empirical sections. Besides these formal sessions, it was possible to record informal sessions at the sheltered residence and primary school, for example, of P22 playing Rocket League with a resource person, of P12 and P13 making their video recordings in the hallway at the sheltered residence and of P13 making her music videos with the camera or having informal conversations with me. It was not possible to record any formal or informal sessions at the youth education due to video-recording restrictions and privacy. However, interviews were possible to record for all participants at the youth education.

In Figure 10, we see P13 making a music video to the left in the common room at the sheltered residence, where she raps about her FIFA gaming skills. In the picture to the right, she uses the microphone and audio recorder as a Wakee Talkie and also sings a song about me and the DiGi project into the microphone.

**Figure 10: Informal video sessions**

*Figure 10 portraits informal video session with P13 and P12. Photos by Ditte Lystbæk Weber.*

### 4.3.4. VIDEO DIARIES

The purpose of the video diaries was to understand and map the participants' everyday use of and experiences with digital technology, as well as to give the participants a chance to elaborate on sensitive and personal matters regarding the use of digital technology to interact with others. Video diaries took place when and where the participants felt comfortable, and they were carried out individually. The venues ranged from their room at the sheltered residence, the classrooms, the interview rooms or elsewhere. The resource persons and, in some cases, myself, carried out the video diaries with the participants. At first, we anticipated that the participants could (and preferred to) carry out the video diaries themselves, but it turned out that they wanted and needed the resource persons to be present during the video diary sessions.

As an inspiration for the conversations, we formulated three questions: 1) What did you do on your device today? 2) Have you done something interesting or fun with others online? 3) Have you experienced any challenges with others online? These three questions were formulated after the interviews were conducted and were meant to capture both their negative and positive experiences online on a daily basis. In addition, the laminated cards that each participant had used during the interviews were on hand (cf. Figure 11).

**Figure 11: Video diaries**

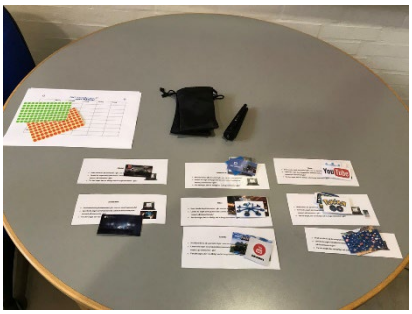


*Figure 11 illustrates the preparation of digital diaries. Photo by Ditte Lystbæk Weber.*

Thus, the video diaries did not fulfil their full potential and purpose. The method required much more support from resource persons than initially anticipated and, in many cases, became a checklist structured around the three questions for all participants that had to be ticked off every day, as both the support staff and the participants were busy. One resource person even said, 'We have to stick to the questions' when a participant started to jabber on, which he often does.

A few support staff would ask questions about issues that would not have been shared had they not reminded the participants to elaborate on these matters because of their familiarity with the participants' digital lives. On the other hand, we learned from the interviews that participants did not always like the presence of the staff and would rather talk to the first author alone. As such, the role of the support staff was important to consider during the video diaries, as they may either be a barrier or support.

In addition, the timeslots for making the video diaries were too limited. This made consistency in making the daily diaries difficult for many of the participants. We needed a sufficient amount of time to go in-depth in the conversations with the participants, as well as be able to plan for the unforeseen, which is why the interviews and workshops were a better fit for the participants and the research purpose. During the video diaries, many participants repeated what they did and used digitally every day, which served as a confirmation but not a forum for elaboration. This explains why Table 4 indicates 'Confirms technology use and behaviour' for many participants. The laminated cards were disposable but rarely used during the video diaries, which may have been helpful in making the conversations flow. In addition, a few support staff were not clear about how to do the video diaries. The lesson learned in this regard was that time and timing are crucial when researching technology in action with people living with cognitive disabilities, along with proper handover if using resource persons in the video diary sessions.

To encourage more independent use of the video diaries, we considered providing the participants with a GoPro camera so that they could film when they wanted to and what they wanted to in a private and personal arena. This was deemed difficult by the staff and the researchers but could constitute a future initiative.

**Table 4: Video diaries characteristics**

| Participants | Number video diaries | Interest points |
|---|---|---|
| **P1** | 4 | Tells about her dreams to become a YouTuber |
| **P2** | 4 | Confirms technology use and behaviour |
| **P3** | 5 | Confirms technology use and behaviour |
| **P4** | 5 | Re-established contact with an old friend |
| **P5** | 5 | There is a lot happening with her socially, dramatically, also online, the phone is constantly bibbing, something always happens in her life. |
| **P6** | 4 (3 with P8 and P7) | Development: internet connection improvement. |
| **P7** | 5 (3 with P8 and P6) | Confirms technology use and behaviour |
| **P8** | 4 (3 with P6 and P7) | Shares very personal content |
| **P9** | 0 | Confirms technology use and behaviour |
| **P10** | 4 | Confirms technology use and behaviour |
| **P11** | 5 | Diary 3: Tinder (new app), This works as a diary. |
| **P12** | 4 | Confirms technology use and behaviour |
| **P13** | 4 | Development: uses snapchat now |

| | | |
|---|---|---|
| **P14** | 1 | Confirms technology use and behaviour |
| **P15** | 2 | Confirms technology use and behaviour |
| **P16** | 2 | Confirms technology use and behaviour |
| **P17** | 0 | Confirms technology use and behaviour |
| **P18** | 5 | News: Has an app where she can embroider |
| **P19** | 5 | Confirms technology use and behaviour |
| **P20** | 5 | Development in behaviour: Opens up, talks about using many apps. |
| **P21** | 4 | Confirms technology use and behaviour |
| **P22** | 1 | No video. |
| **P23** | 5 | Repeats the same every day. |
| **P24** | 3 | Not interested in doing the video diaries. |
| **P25** | 4 | Confirms technology use and behaviour |
| **All** | 90 | |

*Table 4 illustrates the characteristics of video-diaries. Number of video-diaries and points of interest among participants.*

### 4.3.5. WORKSHOP: DEVELOPING A TOOL TO VALIDATE EMPIRICAL FINDINGS AND STIMULATE DISCUSSION

**Developing tools** for the workshop started with a brainstorm in the research team on what participatory techniques and tools could aid support for collecting data about the participants' digital aims and to validate empirical findings with the participants. The PI has extensive experience in the field of participatory design. I had started a drawing process of each participant's digital use and behaviour from a comprehensive data analysis (more on this in Section 4.6) (cf. Figure 12). The drawings and methodological insights inspired thoughts on how to present the digital use in a simpler and more tangible way while keeping the visual presentation, that is, using tangible and visual artefacts (Kanstrup and Bertelsen, 2016).

**Figure 12: Iteration of a digital snapshot**

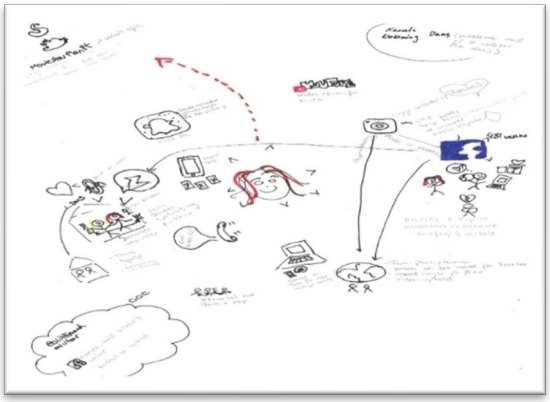


*Figure 12 portraits the first iteration of a digital snapshot with information from P5.*

'Digital snapshots' is not a new concept as it has been used previously to examine the role of tools in a community and how these tools influence communities in different ways (Wenger et al., 2009h). It also serves as a toolkit to examine indigenous youth through media art (Lindquist, 2018). As such, digital snapshots are not new tools to investigate digital technology, but the structure in our digital snapshots is unique to this study and this particular study population. In addition, Lindquist (2018) does not provide a visual structure of a digital snapshot, which is the most essential element in our digital snapshots.

The digital snapshots were meant to capture each participant's individual digital use and relationships. This was our way of mapping what Jung et al. (2008) refer to as *personal ecology of interactive artefacts* (Jung et al., 2008) in this mapping of artefact ecologies (cf. Chapter 2).

In Figure 13, we see an example of P19's digital snapshot. The circles in the digital snapshots are divided by colour and contain similar information as the properties and layers in the artefact ecology framework (Jung et al., 2008). In the inner circle are the physical artefacts (devices), in this case, a phone and a console. In the middle circle are the informational artefacts (applications and platforms), in this case, GTA, FIFA, FaceTime, Messenger, Facebook, Snapchat, SMS and YouTube. In the outer circle are the relationships mediated by digital technology (the function of the digital technology). In between the inner and outer circles, it is possible to detect how the digital technologies mediate and are used to create and maintain relationships. In this case, the participant uses GTA and FIFA to game with his friends; FaceTime to talk to his best friend at the youth education centre; the calling function to call his family;

and Facebook, Messenger and Snapchat to interact with friends and famous football players.

The digital snapshots constitute the main methodological contribution of the study as they were developed by the research team.

**Figure 13: Digital snapshot**

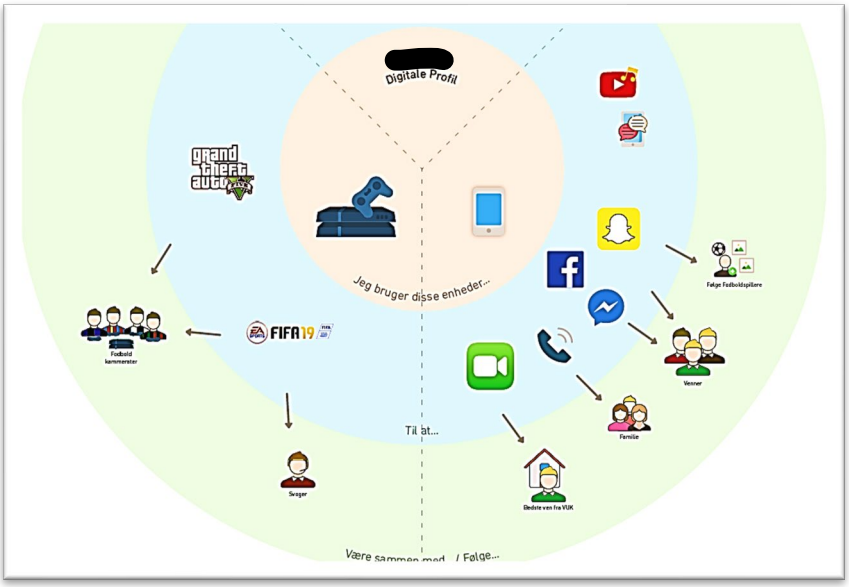



*Figure 13 shows a digital snapshot of one of the participants, P19's. His name has been anonymised to respect confidentiality.*

**Workshops** were inspired by future workshops (Brandt et al., 2012), using our digital snapshots and 'inspiration cards', which were developed to present the participants' digital use and behaviour to themselves and stimulate conversation about digital technology (cf. Paper 5). The workshops were held at each institution, lasted for 3–4 hours and comprised two main group exercises. The workshop started with a joint breakfast attended by the participants, DiGi researchers and resource persons. Afterwards, the schedule for the day was announced, and the DiGi research team was introduced. Then, the preliminary findings were presented to the participants, namely, what technologies they used and referred to make this tangible for the participants to grasp. I also asked the participants to define a digital community, which they found

difficult. Recognising that the digital community is a difficult subject to discuss, I presented my digital snapshot to the participants as an example of a personal artefact ecology and gave them their personal digital snapshots, which had been developed individually for each participant (cf. Paper 5). The participants were asked if they understood the structure and information on the digital snapshot and whether the information therein was correct and up to date. What we learned here was that some of the participant changed their digital usages and relations since the interviews, albeit not extensively. There were minimal changes, for example, using a new application or no longer playing a particular game. This will be elaborated further in Chapter 4 under 'dynamic digital behaviour'. In many cases, the devices, applications or relations that the participants wanted to add or remove from the digital snapshots were not discussed during the interviews or, in a few cases, because the name of a game was misspelled. At the primary school, it was necessary to change the names of some participants, which we got wrong. Fortunately, the participants and the resource persons joked about the errors in a friendly manner at the workshop, but the incident was unprofessional and should have been avoided. Nevertheless, the digital snapshots made it possible for the participants to elaborate further on technology and behaviour, which they had not had the chance to discuss or forgot to elaborate on during the interviews.

Following the handover of the digital snapshots, the participants were divided into predefined groups of 3–4 participants, with a DiGi researcher and a resource person from the institution. They were asked to do **the first group exercise** (30 minutes) called 'tune in on digital technology', wherein the participants looked at each other's digital snapshot and identified the technologies they had in common and the ones that were different to inspire collaborative learning. In addition to the digital snapshots, the Talking Mats and laminated icons were reused to sort the technologies which the participants had in common and the ones which differed, as illustrated in Figure 14.

During the exercise, humour was an essential conversation starter, as it had been a while since we met, and this helped lighten the mood. An example was when P16 played with the Danish words for 'mat' and 'had to':

> Ditte: I brought my mat with me again today.
>
> P16: You had to bring it (in Danish, a 'mat' has the same meaning as 'had to').

**Figure 14: Comparing technology use with Talking Mats**

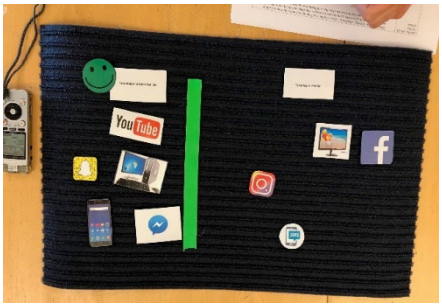



*Figure 14 shows a Talking Mat used at the workshop to sort technology use among participants. Photo by Ditte Lystbæk Weber.*

After the first exercise, there was a joint summary of the exercise and then a break.

**The second exercise** (30 minutes) 'digital aims' was intended to stimulate thoughts on what the participants aimed for in their digital relationships, communities and lives. To help facilitate this reflection process, the Talking Mats were used again, and the participants were asked to turn over their digital snapshots, which had an illustration of a thought bubble at the back (cf. Figure 15). The thought bubble was empty, which was the case for many participants, as digital aims are a difficult configuration to discuss.

**Figure 15: Talking Mats and thought bubbles**

*Figure 15 portraits a Talking Mats and a thought bubble. The Talking Mat is to the left and the backside of the digital snapshot with an empty thought bubble is to the right. Photo by Ditte Lystbæk Weber.*

In line with the thought bubbles at the back of the digital snapshots, inspiration cards were used to stimulate inspiration among the participants (cf. Figure 16). The inspiration cards contained visual and written information regarding all the digital activities carried out by the participants, such as 'game with my friends online', 'watch YouTube videos with my friends', 'make international friendships online', 'share pictures online', 'be nice to each other online' and 'like others' pictures online', as illustrated in Figure 16. As such, it was not necessarily the activities done by the particular participants in the exercise but by other study participants at the three institutions. The inspiration cards were picked up from a pile in random order by the DiGi researchers or the resource persons, and the participants replied 'Bingo' if they liked the activity on the inspiration card. After conversing about the particular digital activity in question, the inspiration cards were arranged on the Talking Mat according to the reactions and responses provided by the participants (again, using smileys). If the participants felt inspired by the activity on the inspiration card, the card was placed on the mat.

**Figure 16: Inspirations cards**

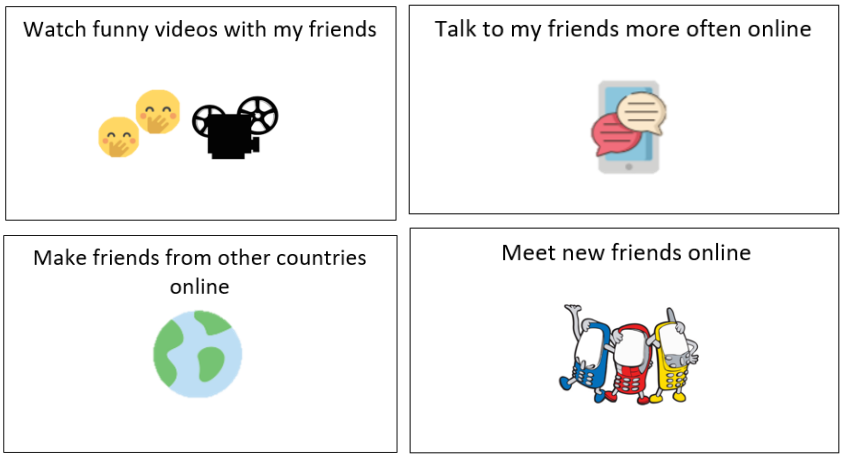



*Figure 16 illustrates four examples of inspiration cards with activities performed by study participants, for example watching funny videos online, talking to friends more often online, make friends from other countries online, and meet new friends online.*

The exercise ended with a summary of the discussions following a break and a joint lunch in the common rooms at the institutions.

The workshop exercises are illustrated in Figure 17. At the workshop, we learned that big gatherings and group work worked out quite well as long as the participants had familiar faces among them. Some participants even managed to present discussion points in front of all participants. The resource persons at the institutions and I decided on the groups. In addition, breaks and short exercises were essential, which we incorporated into the programmes following recommendations from the resource persons at the institutions.

**Figure 17: Workshop exercises**

*Figure 17 illustrates examples of workshop exercises. Photos by Ditte Lystbæk Weber from workshops at the three institutions (the primary school in the top, the youth education at the bottom left and the sheltered residence at the bottom right)*

The digital snapshots were a strong VTA, but there are elements that could still be improved. A way to further develop the digital snapshots may be to make them more personal, for example, by not merely including the participants' names but also an illustration that looks like them or has their characteristics.

We used standard icons, for instance, a mother looks the same in all digital snapshots. This was a way to balance the personal information and the anonymity of the participants. The icons of the relationships could be personalised further to incorporate the characteristics of the participants' personal relationships and, thus, become a more personal snapshot. This would require a more extensive collaboration in the development of the digital snapshots with the participants than the one conducted in this study.

The digital snapshots also have the potential to add a more advanced structure, for example, by adding more spheres than the ones suggested in this study, thereby contributing to the ongoing development of approaches to understand the layers and dynamics in users' complex interactions with multiple technologies (Bødker et al., 2017).

## 4.4. IMPORTANT ROLES IN DATA COLLECTION

### 4.4.1. TRAINEE VS. EXPERT ROLE AS RESEARCHER

As the aim of this particular research project was to understand the participants' digital relationships and communities, I undertook the role of a trainee, which put the participant being featured in an expert role (Wadel, 1991). This was done through the use of the visual and tangible tools and techniques described in Section 4.3. In this sense, we adhered to a competency-based approach (Bayor, Bircanin, et al., 2019; Bayor, Sitbon, et al., 2019) by putting the participants in an expert role.

In addition, it was important to keep an open structure, which allowed the participants to elaborate on their discussion preferences during the conversations. In this regard, there is always an inherent risk of putting words in the participants' mouths with this study population (Brewster, 2004), as well as manipulating the research setting, which we tried to remedy by letting them take the lead as much as possible. Some examples of instances in which I, as the researcher, manipulated the research setting was when a female participant (P13) was made aware by another friend and female participant (P10) that the former did not respond to her friend request on Facebook or that a third friend and female participant (P12) no longer uses an application (Snapchat) and, therefore, did not answer. In this sense, I, as the researcher, manipulated the female participants' digital contact and awareness. This was not necessarily a negative manipulation. I also inspired a participant (P12) to play a game with me, which she would not have known about had it not been for me. Again, I, as the researcher, manipulated the participants' technology use. Another example of this manipulation of technology use and behaviour was when I played 'Rocket League' with P22, which was his preferred game. I noticed that he was not playing as aggressively and scoring as many goals as when he played with one of the pedagogues at the primary school. When I confronted him, he admitted that he played more poorly to spare me. This was a very considerate and thoughtful behaviour but did not give an authentic picture of how (well) the participant played the game. After the confrontation, he played with his usual adeptness and scored goal after goal. The last example of technological behaviour manipulation was when P1 and I used the QR codes at the sheltered residence. It was his first time using the QR codes, which hung at every room in the sheltered residence. Had we not conducted the technology tour with the QR codes, he would likely not have used them.

Additionally, there was a misunderstanding regarding my role as a researcher. One Friday at the sheltered residence, P10 asked if I could help her solve a technical issue (accessing Viaplay so that she can watch movies on her computer) because, according to her, 'You are knowledgeable with electronics', which was not the case.

### 4.4.2. AM I A PSYCHIATRIST, A FRIEND, OR A RESEARCHER?

During the data collection process, it was reasonably easy to take a friendly role toward the participants and build rapport – my age was close to many participants, and I was just as modest as them due to my lack of experience in some areas of their digital activities. In addition, I shared personal and digital activities during data collection, which made me relatable to most of the participants. This made it easier to discuss sensitive issues such as romantic relationships.

While engaging with the study population at a high reflection level, there were cases wherein my roles as a researcher, a friend, and a psychiatrist were blurred (cf. Paper 5). On the one hand, this helped build rapport; on the other hand, it was difficult to determine when a line was crossed in the researcher - participant collaboration.

Two participants, P1 and P22 (cf. Table 2), had severe psychological traumas from personal experiences, and they were both incredibly lonely. They elaborated on personal matters like bullying and family issues, which had nothing to do with the technological perspective and were beyond the scope of the planned interviews. I sometimes stayed for more than an hour longer to converse with the two participants during the data collection period. The interpretation was that the participants missed talking with another person and sharing their personal issues, as supported by a quote from P22:

> It doesn't really matter who I talk to. I just want to talk to someone when I'm sad and feeling lonely.

Two of the girls at the youth education also shared a lot of personal information regarding their love life, family life, bullying and conflicts in school. The two girls were not lonely, but they felt the need to unload a great deal of personal information.

As such, I paid attention to the four participants and were on neutral ground; their conversations were confidential, and I had no connection to either the institutional staff or their family members. It was a private sphere for them. As such, there was no harm done, and these sharing moments built rapport between the participants and me as the researcher. However, I harboured a constant fear of mishandling their personal matters, as I did not have the professional competencies to provide psychological guidance (Booth, 1998).

Had there not been 25 participants to represent during this study, these four individuals could have easily been used for a narrative.

Regarding crossing the line between friendship and professionalism, this issue emerged when P24 asked if we could be friends on Facebook, and I intuitively replied, 'Of course we can'. Another participant, P25, who was quite challenging to engage with and needed a 'carrot' to converse, wanted to send me a picture and made a friend request on Facebook. Accepting the friend request so that I could see the picture was a way to connect and build rapport with the participant, but it may have crossed a line between friendship and professionalism.

### 4.4.3. THE ROLE OF RESEARCH PRACTICE

It is well recognised in qualitative research that the research should be done and understood in practice, which relates to the physical place and, most importantly, to the culture, habits, values and actions in the given practice where the research object and phenomenon takes place (Johansen and Larsen, 2019; Kuutti and Bannon, 2014; Porter, 2011; Rieber and Carton, 1993). As such, the digital sphere is the practice of this research study, as we seek to analyse how our participants act in relation to digital technology in different situations and contexts and how digital technology is integrated into their everyday lives (Johansen and Larsen, 2019; Wenger, 1998a; Wenger et al., 2009d). This creates a focus on how the individuals act with the digital technology rather than the digital technology itself (Johansen and Larsen, 2019).

The physical setting is particularly essential to consider with a study population experiencing triggers and vulnerabilities to make them feel safe and at ease. At the sheltered residence, many interviews were conducted in their rooms, which made them feel comfortable. The setting was also more authentic, as we could follow how and when they actually use their digital technologies and for what purpose. At the primary school and youth education centre, the interviews took place in a shielded room where we could speak peacefully. This was an unnatural setting, but we were able to observe classes (Makerspace and video sessions) and breaks in the common rooms. At the youth education centre, many go to the common room when they get a break. They hug, sit together in couches, or play the guitar. Others go into rooms where they can be alone or be with fewer people.

### 4.4.4. THE ROLE OF THE CAMERA

Video as a medium has proven beneficial for collecting and presenting the views of individuals living with cognitive disabilities (Rojas and Castros, 2011). Ethnographic

videos have the ability to communicate and capture the complexity of interactions between the participants and me, as the researcher, as well as the interactions between the participants and the object under investigation (in our case, the technological applications and devices), and the culture and attitudes of the participants. As such, using video with this study population made it possible to communicate a broad set of issues and capture the non-verbal communication used by the participants and me, which is beneficial with this study population (Rojas and Castros, 2011; Ylirisku and Buur, 2007a, 2007b).

In our case, the video camera worked as both a door opener and a closer for researching technology in action with the participants, as some enjoyed being video-recorded and were impressed by the camera, while others were intimidated and did not want to be video-recorded. It was primarily the participants who experienced anxiety (P22, P16) who did not want to be video recorded. These interviews merely contained audio data. P22's comfort with the camera was eminent during a video recording of the students and participants at the primary school watching a movie during class. I had been allowed to video record the session, and the camera was in another room, standing on its own, as I watched the movie with the participants. P22 kept checking the camera, looking at it more than 20 times during the 1.5-hour film. Clearly, it distracted him from following the movie.

Meanwhile, P11, who was comfortable making TikTok videos, did not want to be video recorded initially but opened up after the first talk and did not mind the camera afterwards. She just needed a familiar ground to feel safe. Two participants at the sheltered residence (P8 and P7) expressed that they were quite impressed with the functions and design of the 360 cameras (cf. Figure 18), which made the video interview sessions easy to conduct.

**Figure 18: Cameras**


*Figure 18 illustrates the two different cameras used to record the participants statements. We see the YI 360 camera to the left and the portable camera in the middle and to the right, held by P13 and I. The left photo by YI Technology, Shanghai, China. The middle and right photo by Ditte Lystbæk Weber.*

The portable camera was used when I needed to move around, as the 360 camera needed to be placed on a flat surface. The portable camera created much more awareness than the 360 cameras, as it was more obvious that the participants were being filmed, as opposed to the 360 cameras, which was placed on a table near the participants during interviews and was more of an invisible artefact. In Figure 19, we find a participant, P15, waving at the portable camera used during a Makerspace session and making a face. It seems the camera did not make him uncomfortable despite the fact that it was definitely not invisible and captured attention and, as such, affected the natural environment in the research setting.

**Figure 19: The role of the camera**

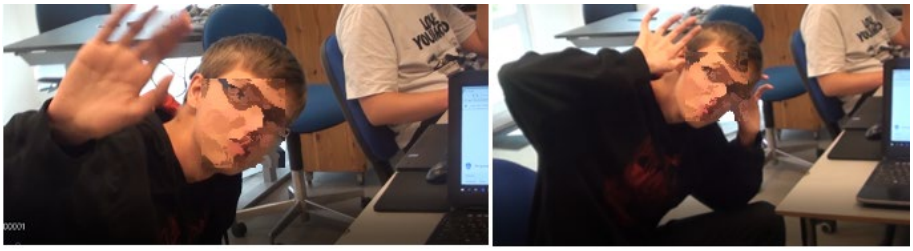


*Figure 19 illustrates the influence of the camera during fieldwork, where P15 waves in the left photo, and makes a face in the right photo. Photos by Ditte Lystbæk Weber.*

The 360 cameras were sometimes used as a means to start the conversation with participants who needed to warm up, often comparing it to the device used in the film *Men in Black* to erase people's memory to lighten the mood.

The disadvantages of using the 360 cameras were that it merely lasted for an hour and needed a battery change during some interviews, which created unnatural interruptions. Thus, it was only possible to have an interview lasting for more than an hour with very well-functioning participants who did not seem affected by the interruption.

## 4.5. CHALLENGES IN MAPPING DIGITAL COMMUNITIES WITH THE PARTICIPANTS

Despite the use of VTAs, there were inherent methodological challenges in communicating and presenting the data with the study participants, which was identified as part of the data analysis (cf. Section 4.6). These challenges were general

tendencies related to overstimulation, self-awareness, literal communication, concentration, accountability, flexibility, reflection level, imagination, language barriers, misunderstandings, and distancing (cf. Paper 5). We go through each challenge in the following subsections.

### 4.5.1. OVERSTIMULATION AND SELF-AWARENESS

Before the interviews, the resource persons informed us that we could not conduct interviews with the participants for more than 20 minutes at a time. This was the case for some, but many were able to converse for more than an hour, especially because we were not speaking the whole time but looking at their respective devices. Interviews worked better at facilitating these individual needs, as we could plan and take breaks in accordance with the individual, as opposed to group-based workshops. For example, P3 was so exhausted that she claimed to almost fall asleep during workshops: 'I'm just so tired. I'm on the verge of falling asleep. I better not'.

As mentioned in Paper 5, many participants were shy and needed to acclimatise to my presence before opening up to me. Some were also very self-conscious and found it difficult and overstimulating to interact with others, including myself. The technology tours helped in this regard, as the participants who felt this way could 'disappear' into the digital world. Another way to get a glimpse of the participants' social behaviours was by observing them during their elective class (role play) where they played a board game similar to Dungeons & Dragons. Herein, participants can take on different fictitious characters and roles. P16, who was quite overstimulated due to his literal interpretation of everything being said, shared that the role-play classes were a place where he could relax and feel at ease because he could act as he pleased and not according to how everyone expects him to act in real life.

### 4.5.2. LITERAL COMMUNICATION AND CONCENTRATION

In Paper 5, it was discussed that a communication challenge was that several participants (especially P16 and P14) were highly literal, which gave rise to communication challenges and misunderstandings between the participants and me. The quote below is an example of a literal interpretation of 'conversation' which, in this case, was a video diary involving a male participant at the primary school:

> This is what you call a proper conversation... Now, I'm thinking, is this even something, is there some special word for conversation when it concerns the Internet? Or is conversation some kind of 'multi-word', a word that fits under both things? Because now I'm interested in finding

> out if there is some kind of special word for, or version of conversation, with one concerning the Internet and the other concerning reality.

Another example from P16 was when I said 'film' instead of 'video', and P16 wanted to know the distinction. He also found it weird that there was a Facebook dislike icon next to the Snapchat icon on his digital snapshot. We had used the Facebook dislike icon to illustrate the dislike of certain social media applications. P16 expressed laughingly, 'It is almost like it is Facebook that does not like Snapchat'.

Concentration was another challenge, with this participant and many others having trouble staying focused on the research topic, changing the focus or 'babbling on' and bursting into self-oscillation. This happened with P16, P5 and P19, as the quote below indicates:

> Eh, what's it called… Sometimes, I often take snaps of myself. I actually do that every day. When I am on, every day, when I am on the bus on my way home, eh, I go and take pictures of myself where I, like, write that now I am sitting on the bus on my way home after a lovely day in school, including, and including how lovely it is that it is the weekend. Yeah, that's what I write. (P19)

During the workshops, two female participants, P3 and P5 from the youth education centre, lost their concentration at the end and started laughing and had trouble stopping, which affected the whole group dynamic as the rest of the group members also started to laugh. This was disturbing for the group conversation but was also a sign that they could not stay focused for long, which is something worth considering.

### 4.5.3. IMAGINATION

As discussed in Paper 5, especially for two participants, P13 and P14, it was quite difficult to determine whether they were telling the truth or making up stories, as they sometimes narrated what they wanted to happen instead of what actually happened. Sometimes, the untruths were easy to detect, for example, when P13 told us that she was best friends with the Danish minister or that she was going to a concert that did not take place at the given time and place. Meanwhile, P14 was very good at programming. As such, it was difficult to detect when he was exaggerating or claiming to do something which he did not actually do because of my lack of technical skills in this regard. The boundary between imagination and reality was detected by the assistance of one of the key resource persons, who called out P14 when he was not being truthful. The resource person even confronted P14 during the workshop, saying, 'You have to be careful that what you say does not get too random. It sometimes does'.

Thus, this was not a challenge but more a note for analysis and interpretation of the empirical findings from these two participants, as the study aim was not to find the actual truth about the participants' digital behaviour but the participants' reality and truth. From the participants' perspectives and lifeworld, the stories were true, making them legitimate and meaningful to the study findings. According to Wenger (1998), imagination is a mode of belonging which expand the reality of the social world and ones' own identity (Wenger, 1998b). He defines imagination as:

> … the creative process of producing new 'images' and of generating new relations through time and space that become constitutive of the self (Wenger, 1998b, pp 177).

As such, the imagination used by the participants is a way to expand themselves by creating new images of the world and themselves (Wenger, 1998b), which enable participation in events, relations and communities of practice.

### 4.5.4. ACCOUNTABILITY AND FLEXIBILITY

Accountability was challenged by the mental states of some of the participants. For example, a few were not able to participate in the workshop due to the worsening of their mental states and one participant left during the workshop because he had an anxiety attack (cf. Paper 5). P22 never wanted to make an arrangement on when to meet for the interviews as he was not sure how he felt and if he had been up all night gaming. Therefore, we needed to play it by ear and consider the time and timing, which were crucial to engage in conversations with the participants, as well as the clarity of the activities. Some examples were participants who found the research aims and activities unclear, asking 'What is this (the research and the digital snapshots) for?' and 'Why do we have to make them multiple times (referring to the video diaries)?', which may have affected their motivation to share their perspectives and show up to our meetings.

As tackled in Paper 5, a participant (P25) was especially unpredictable and stubborn, which made for a complicated interaction and a need for extensive creativity in the interactions. Data collection was a process wherein communication was sometimes possible and sometimes not at all, as she would keep quiet when asked a question regarding her technology use and the meaning she accorded the technology in her everyday life. I learned that sometimes, I could negotiate with the participant by helping do the dishes while talking to her, making her tea, getting her napkins when she was sick, helping her with something technical, playing a game with her while we talked or simply keeping her company. Interaction via gaming was not an opener for a conversation, but we got to spend time together and establish some rapport. The following illustrates how the interaction between P25 and I took place during the data collection:

In the first picture in Figure 20 (to the left), P25 and I are playing Bubble Shoot Pet. P25 showed me how to play the game. She helped me play by moving my finger and guiding me to only use one finger. P25 even moved the camera herself so she could show the game to the camera. In the second picture (to the right), I was given more freedom to play the game by P25.

**Figure 20: Interactive video session 1**

*Figure 20 shows an interactive video session with P25 via a game. Photos by Ditte Lystbæk Weber.*

I had the mat and icons with me, and while we played the game, I asked where Facebook should be placed on the mat (green, yellow or red), as P22 had mentioned using Facebook to follow friends during the pilot visit. She did not answer. I asked about the computer that P25 had expressed earlier that she wanted to purchase. Again, there was no answer. I then asked what music P25 preferred because she listened to some Vietnamese music during the pilot study. P25 finally answered: 'There is music in this [game]'. I learned during this process that P25 was merely interested in discussing matters related to the game, either because she was caught up in the moment or could not comprehend and reflect upon the other questions. Trying to recognise P25, I asked: 'Is it a bit difficult to answer?' P25 replied: 'Mmh'.

I asked if it was possible to play the game with someone else. P25 nodded, but when I asked her if she played with anyone else, she did not answer. I continued to ask questions, but P25 was preoccupied with showing me how she plays. I asked her what she liked about the game, but she still did not answer. At some point, I found out that she does not play the game with others. When asked about other matters regarding the game, for example, what level she is at or how to shoot a chicken, P25 answered the questions.

In the third picture in Figure 21, I am playing the game on my device (my phone). P25 helped me install the game by spelling out its name, writing it on a sheet of paper and giving the paper to me.

**Figure 21: Interactive video session 2**

*Figure 21 illustrates the second interactive video session with P25 via a game. Photo by Ditte Lystbæk Weber.*

After playing the game for quite some time, I started to ask questions related to Facebook and YouTube again. P25 replied, 'I don't have anything to talk about. I just think it is more fun that we do this [play Bubble Shoot Pet] together'. She asked if I did not feel like playing anymore and seemed a bit frustrated and looked like she wanted to find a new game for me to play on my phone. I tried to negotiate with P25 by agreeing to play the game again and then discuss. P25 nodded her head. We played a bit more and then decided to go to P25's room, as she was feeling sick, but she still wanted me to come.

In the fourth picture (to the left) and the fifth picture (to the right) in Figure 22, the scene has changed to P25's room. Our roles also changed. There, I helped P25 take a screenshot and use it as a background picture on her iPad (picture four) and send a picture via Messenger during their last encounter (picture five).

**Figure 22: Interactive video session 3**

*Figure 22 illustrates the third interactive video session with P25 via a game. Photos by Ditte Lystbæk Weber.*

In picture four, P25 wanted me to get her phone, which was in the common room where they had previously been. While I was gone, P25 visited Facebook page. When I came back, we played the game together on our separate devices. We talked about P25 being sick, and I again tried to discuss her laminated cards. I told her about our last conversation about the videos that P25 watches on YouTube, but she did not answer. I asked about the big screen in the common room, where they saw Robinson yesterday, but P25 merely said that she did not watch anything on the big screen. I suggested that we speak tomorrow and that P25 can use my computer to visit Facebook, as she expressed a wish to use my MacBook. P25 assented to this suggestion.

During the last encounter, I asked P25 if she sends pictures to others. She nodded but did not answer. I asked again what she uses Facebook for. P25 replied: 'Not so much. I would like some more tea'. P25 watched a Vietnamese show during the last encounter, and the process of talking about something else and her not answering at all continued to the point where I actually got a bit annoyed and decided to stop the conversation.

Later, I tried to go for a walk with P25, but she still did not want to talk about her technology use and social relationships.

### 4.5.5. REFLECTION LEVEL

The reflection level of P16 in the quote regarding the use of words for conversation in Section 4.5.2 is quite high, which was not the case for several participants, even though tangible and stimulating artefacts were used (cf. Paper 5). This especially concerns the conversations about the digital aims and digital communities. During both the interviews and the workshops, the participants were asked if they could elaborate on what a digital community meant for them, and almost everyone had trouble answering this and interpreting the concept. P15 expressed during the workshops (after we had conducted interviews) that he did not know what a digital community was. P21 agreed. This was the situation at all three institutions. Therefore, I tried instead to ask more specific questions regarding the participants' technology use both during the interviews and the workshops, which was beneficial in starting the conversation. Some of the questions were 'Do you call anyone?', 'Do you write to anyone?', 'Do you game with anyone?' and 'Have you interacted with anyone who watches your videos on YouTube?' In addition, asking them to define a friendship was much more tangible than defining a community.

In general, and for several participants, it was challenging to go from concrete to abstract questions. For example, I asked P12 why she uses Snapshot, and she simply replied, 'I don't know'. Other examples were between two of the male participants from the sheltered residence and me, as exemplified by the conversation below:

> P7: It happens much less [misunderstandings on social media] when you sit together in the same room. Then it's different.
>
> P6: Mmmh.
>
> P7: It is worse when you Skype.
>
> P6: Yeah.
>
> P7: Or something like that.
>
> Ditte: But how can that be? Is it because you can't see each other quite as well or… What do you think?
>
> P6: Hmm, I actually don't know.
>
> Ditte: How is it like speaking via Messenger in a group as opposed to sitting together, like, physically?
>
> P7: It is very different.
>
> P6: Mmmh.

Ditte: What is the difference?

P6: That I actually don't know.

P7: I actually don't know either. Well, we can see who we talk to when we talk to them on Facebook or Skype.

A technique that worked in making sure that the participants understood the question was to ask the same question but in different ways many times.

Memory was also a challenge for some, for which we used the screen time function when available and feasible.

### 4.5.6. LANGUAGE BARRIERS AND MISUNDERSTANDINGS

We only encountered language barriers with two participants (P12 and P25), but this did not hinder the conversation; it just made it more challenging and necessary for me as a researcher to listen carefully both during the interviews and the data analysis. In one case, the language barrier created a misunderstanding between me and P25, who wanted a Bubble Shoot Pet as a background photo on her iPad, which took me some time to understand.

### 4.5.7. DISTANCING

A few participants used different methods to distance themselves from others. P22 distanced himself mentally when we discussed different issues regarding his social interactions, saying 'I don't care' very often, even in matters that were assumed to be important to him. This was interpreted as a way of shielding himself from being let down on matters which were actually very important to him.

P17 distanced himself physically and mentally by staying home from school most of the time. He merely went to school when he received a reward from home, and when he was there, he sat with his phone and exhibited rough and careless behaviour when he interacted with the staff at the primary school and me. P11 also had a seemingly rough attitude when discussing sensitive issues, even though she cared a lot about the personal matters she elaborated on. Again, this was interpreted as a behaviour intended to shield her from getting hurt.

## 4.6. ANALYTICAL STRATEGY

To ensure that we will give a fair and honest presentation of our participants' points of view (Blomberg and Burrell, 2003), it was important to perform an in-depth, thorough and systematic data analysis. This process was timely but was evident to ensure the validity of our empirical findings. With an enormous amount of video-recorded data, an analytical approach that would allow a comprehensive, systematic and iterative analysis was chosen: the five-step framework approach (Pope et al., 2006). The framework approach is by its nature highly similar to meaning condensation (Malterud, 2013), and it is an extension of the widely used thematic analysis (Braun and Clarke, 2006). I analysed the data but discussed the emerging findings continuously with my co-researchers in the DiGi team.

**Step 1** in the framework approach is 'familiarisation'. Here, I watched the raw video material from the interviews and diaries immediately after the data collection to identify initial themes, systematically looking for recurring, emerging and contradictory themes (Malterud, 2013; Pope et al., 2006). Afterwards, the video material was transcribed following the standards for video analysis (Davidsen and Kjær, 2018; FitzGerald, 2012; Ylirisku and Buur, 2007b, 2007a). The video material was transcribed by moving between fine-grade and coarse-grade transcriptions, depending on the relevance for the project aims and objectives (Davidsen and Kjær, 2018). Parts of the video material were analysed using multimodal conversation analysis (Davidsen and Kjær, 2018; Goodwin, 2013; Mondada, 2018). However, the nonverbal interactions were difficult to interpret. It was challenging to give meaning to signs and facial expressions, as many participants had tics related to their disabilities and not necessarily signs that they were uncomfortable, for example.

**Step 2** is 'thematic framework identification'. From a comprehensive coding process of the raw material from the video interviews and diaries using the qualitative video data analysis software Transana, an initial thematic framework (or map) was identified for the participants' digital relationships and communities. The coding process was inductive to ensure that the participants' perspectives guided the analysis (Malterud, 2013; Pope et al., 2006). Specifically, the initial codes were generated by labelling interesting sections of the transcribed raw data material with codes to present their content. The initial coding was done systematically across the entire data set (Braun and Clarke, 2006). For some sections, the codes were specific (for example, 'followers'), for others, general codes were used (for example, 'external digital communities'). Afterwards, codes were refined and structured into themes in the final thematic framework (Malterud, 2013; Pope et al., 2006). This thematic framework consisted of the following emerging themes: 1) communities around digital technology and 2) communities via digital technology, with subcategories of individual digital relationships, digital groups, and peripheral digital participation in society under these two main themes. Furthermore, the main themes were 3) external digital communities; 4) internal digital communities; 5) adverse digital interaction and

6) non-digital communities. Each theme had sub-codes (cf. Appendix B, code tree 1 and 2).

The data collection process entailed two steps (first, via interviews and diaries and second, via workshops). Familiarisation (step 1) and thematic framework identification (step 2) were first carried out for the interview data and then for the workshop data. The thematic framework identified from the systematic coding of the raw material from the interviews and diaries was used to code the raw material from the workshop while allowing for emerging themes to arrive. This coding process was, therefore, both inductive and deductive. An emerging and main theme from this coding process was the digital aims with associated sub-themes (cf. Appendix B, code tree 3). The emerging themes regarding digital aims were improving digital competencies, extending digital relations and proper digital behaviour.

**Step 3** is 'indexing'. The raw data material, including all empirical data from the interviews, diaries, and workshops, were systematically and deductively re-coded using the identified thematic framework (cf. Appendix B, code tree 1, 2 and 3). This re-coding process was done to ensure that the preliminary themes were consistent with the empirical data, which was particularly important since the data collection and coding process was twofold (Pope et al., 2006).

After re-coding the interview, diaries and workshop data, the data were coded from a methodological angle, with codes concerning data collection (cf. Appendix B, code tree 4). These were identified as humour, creativity, acknowledgement, negotiation, support, and narrative storytelling. Other methodological codes concerned challenges regarding data collection. These were concentration and abstraction level, unclear research aim, accountability, flexibility, language barriers, video dislike, literal communication, imagination, jabber, shyness, warm-up, therapeutic researcher role and distancing (cf. Appendix B, code tree 4).

**Step 4** is 'charting'. After the coding and re-coding process, the emerging themes were structured further into categories and condensed descriptions and quotes which explain the key findings (Pope et al., 2006). The artefact ecology and community of practice framework (cf. Chapter 3) was used to synthesise and restructure (reanalyse) the empirical data into a meaningful presentation of the emerging findings. The research design was not influenced by the theoretical framework, but the analysis of the empirical findings.

**Step 5** is 'mapping and interpretation'. Lastly, the findings were structured into different 'matrices' (tables and figures in the PhD thesis), which organised and condensed the empirical results even further, making the findings easy to present and illustrate.

### 4.6.1. THE ROLE OF DIGITAL SNAPSHOTS IN DATA ANALYSIS

Aside from supporting the communication about digital behaviour with the participants, the 25 snapshots were used to complement the qualitative data analysis. We used the snapshots to identify patterns of digital behaviour for each participant, as well as across participants. This way, the digital snapshots helped sort out the comprehensive data material into recognisable patterns and tendencies in step 2 of the framework approach.

We analysed the digital snapshots by placing the printed digital snapshots on a large table that could contain all 25 snapshots. The first step was to analyse the digital snapshots individually to obtain an understanding of each participant's digital behaviour. The digital snapshots gave rise to a process of counting digital technologies in the middle sphere to see how many participants used a particular application, and then identifying the range of the digital technology used. This process highlighted the comprehensive use of multiple devices and applications by these young people (more on this in Chapter 4) and made it possible to identify themes and pursue details of the themes in the audio and video materials. For example, analysis of the outer sphere across the 25 snapshots identified multiple types of relations mediated by digital technology in the young participants' everyday life and whether these were internal (inside their institutional circle) or external (outside their institutional circle). We also used digital snapshots to investigate the types of use by specific applications. For example, zooming in on specific applications in the middle sphere and looking for patterns in use across the 25 mappings provided insight on the specific types of technologies and their meaning and use for this study population. An analysis of the middle sphere made it easy to detect divergent digital behaviour.

The use of digital snapshots as an analytical tool was an important aspect of our user study as it complemented the analysis of audio and video recordings from the participant interviews with a mapping created and validated in cooperation with the participants. This process of combining mappings with rich material from interview transcriptions has also been employed by Bødker et al. (2017) in their mappings of community artefact ecologies (Bødker et al., 2017).

## 4.7. ETHICAL ASSESSMENT

Ethical assessment in a research project is always important, but it is especially crucial when doing research with vulnerable groups. The inherent risks that we considered in our research design and process were to unintentionally discriminate, be paternalistic, have a 'solutionism' approach instead of considering the participants' needs and wishes and misinterpreting and misrepresenting the participants' perspectives. We considered and assessed the ethical values and norms that were relevant for the

identified risks and on how we conducted and designed our study: vulnerability, justice, humidity, autonomy, and privacy. These values and related norms have been formulated by researchers working with ethical technology assessment (Børsen, 2021). We did not consider all ethical values and norms, only those deemed necessary for our research study.

1. Vulnerability and justice

Ethical clearance was obtained from the Danish data protection law. Regarding the values of vulnerability and justice, one of our norms was that we emphasise the *inclusion* of participants in the research design and process. We did this by considering how to involve the participants in the research design and by identifying their digital lives and needs via interviews and workshops, so they will not be included by proxy and considered as bystanders. We also believe that it is important to involve resource persons for justification and assistance. Vulnerability and justice are considered from a norm of *equality*; we treat participants from the view of 'defectology', that is, as equal and capable human beings. Lastly, *transparency* is a norm ensuring that vulnerability and justice are considered. First, we ensured that consent was obtained and the participants were fully informed and knew that they would be anonymised. We obtained written and verbal consents from the participants (for the informed consent form, see Appendix C). They were given the needed information about the research process and were made aware of their right to refuse and withdraw at any stage of the project for any reason. Initiatives have been made to obtain consent from individuals living with cognitive disabilities using the Talking Mats (Cameron and Murphy, 2006). We did not find this necessary, as the resource persons were the ones administering the consent forms. Second, the dissemination of empirical findings via reports, project website and participation in conferences and public forums were an approach to amplify the voice of a vulnerable group that is not necessarily able to speak for themselves, as well as to influence relevant stakeholders to advocate for their (digital) rights. The openness and continuous contact with the participants and institutional staff in the research process also ensured that they were presented with respect and justice. Lastly, the thorough data analysis helped ensure that the participants' views were not misinterpreted and misrepresented.

2. Humility and autonomy

The most important norm regarding the value of humility and autonomy was *to reflect on one's own role* in the research design, data collection process and data analysis. Using the 'trainee role' and a flexible research approach was a humble way to ensure that the participants' views and needs were at the forefront, as well as our views of the participants as equal, capable youth.

3. Privacy

We were very thorough in ensuring privacy and anonymity among the participants, both because of their vulnerability and because many participants requested it. This meant that we did not publish any pictures or video materials without consent from the participants. Moreover, in the published pictures, the participants were anonymised to the level where they could not be identified by blurring their faces and using pseudonyms instead of real names. As such, there was no risk of harm. The raw data material was transferred from the cameras and dictaphone to a password-secured drive immediately after finishing the fieldwork each day and deleted from the devices. The data was kept in the drive, which the research team had access to, and in a physical password-secured hard disk to back up the data material. The data material was not stored in Transana (the analytical program used to analyse the data material) so we had to open the drive, or connect the hard disk, to be able to use Transana.

## 4.8. SUMMARY

This chapter examined, among others, the fifth methodological research objective: to examine how to include the study population in researching their rich digital activities and communities. In conclusion, including young individuals living with cognitive disabilities in research about their technology use and the meaning they give to this technology use comes with certain methodological challenges (overstimulation, self-awareness, literal communication, concentration, imagination, accountability, reflection level, language, misunderstandings, distancing) and ethical challenges (discrimination, paternalism, solutionism, misinterpretation, and misrepresentation). Nevertheless, it is possible to include the study population in researching technology use and meaning using traditional qualitative research methods of interviews, video diaries, observation, and participatory workshops. This is possible using a flexible approach to, and view of, inclusion and considering the role of the researcher, the role of practice, the role of the camera when recording, and the ethical values of vulnerability, justice, humility, autonomy and privacy and norms of inclusion, equality, transparency. Using VTAs to communicate and validate empirical findings with the participants is proven to be effective and respectful, as well as putting the participants in an expert role. Lastly, a thorough data analysis ensures an honest presentation of the participants' points of view.

# CHAPTER 5. DIGITAL TECHNOLOGY USE AND VALUE

*'If I live without electronics for 24 hours, I will die' ~ P11*

In this chapter, the digital technologies that the participants use in their social and everyday lives, their digital activities, and the value that they give to digital technology, are examined, addressing research objective 1 (What characterises the digital technology use, activities and value of young individuals living with cognitive disabilities). As such, the properties and values of the physical, informational and interactive aspects of user perceptions towards different types of artefacts in Jung et al.'s terminology are introduced (Jung et al., 2008).

## 5.1. DIGITAL TECHNOLOGY USED BY THE PARTICIPANTS

In our case, the physical artefacts of artefact ecology refer to the digital devices that the participants use, such as PC, MacBook, PlayStation, consoles, iPad, desktop computers, smartwatches, and mobile phones. The participants use a multitude of informational artefacts via these physical artefacts. We use the informational aspects to describe the applications and platforms that the participants use, as these contain digital contents that are of value to the participants.

As illustrated in Figure 23 and Table 5 and as addressed in Papers 1 and 2, the participants use a wide range of digital technology (informational artefacts) in their everyday life (Andreasen and Kanstrup, 2019a, 2019b) (cf. Papers 1 and 2). This extensive use of a multitude of digital technology was a general tendency for all participants, and this finding was important to complement the literature stressing a digital divide among youth with cognitive disabilities and their non-disabled peers (Chadwick et al., 2013; Dobransky and Hargittai, 2016; Duplaga, 2017; Lussier-Desrochers et al., 2017). Our analysis across the digital snapshot identified that, on average, the participants use eight digital applications each. The smallest usage among the participants was three and the largest was seventeen. The most popular digital applications were YouTube, Facebook (including Messenger) and Instagram. The most popular games were FIFA and Counterstrike. The participants at all institutions used these applications. Only the participants at the primary school, who were all males, used programming tools and blogs, and it was the same two participants who used these.

The list of digital technologies is not exhaustive as there may have been some digital technologies that were not mentioned by participants during the fieldwork and their technology use has likely changed from the time of the fieldwork to the present. We elaborate on changing or dynamic technology use later in this chapter (Section 5.4).

**Figure 23: Participants' digital technology use**

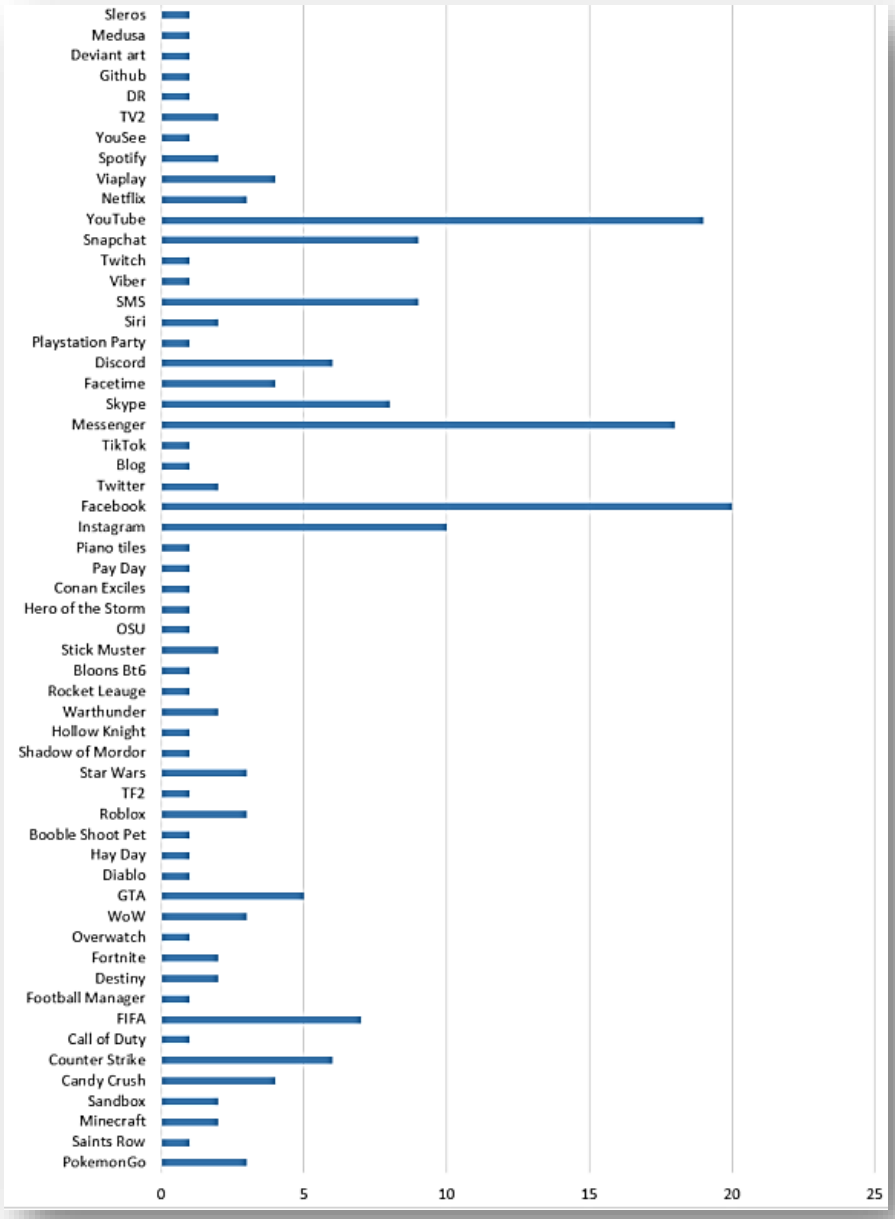



*Figure 23 illustrates the digital technologies (information artefacts) used by the participants.*

As illustrated in Figure 24, informational artefacts are divided into five categories: online and offline games, communication technology, social media platforms, developmental programmes, and video channels. This also illustrates the division of use among these technological categories, where online and offline games and communication technology are used the most.

**Figure 24: Technological categories**

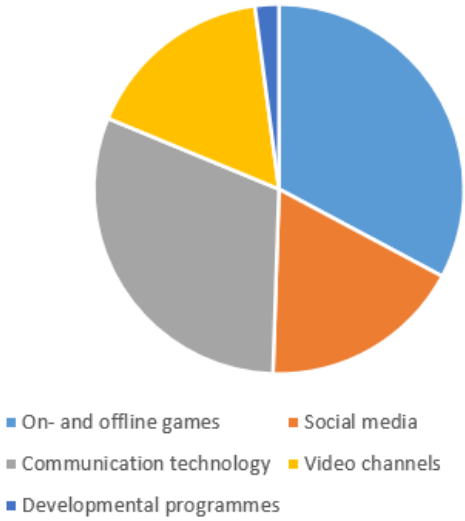



*Figure 24 illustrates the technological categories (on- and offline games, communication technology, developmental programs, social media, and video channels)*

In Table 5, which has been published in Paper 2 (Andreasen and Kanstrup, 2019b), we see which informational artefacts have been assigned into which informational category, as well as which technologies are used by which institution. We see that all three institutions have a diverse use of digital technologies across all five technological categories.

The digital snapshot in Figure 25 demonstrates an example of comprehensive use of digital technology among the participants.

## Table 5: Categorised technology use

| Applications | Number | Primary school | Educational program | Sheltered home |
|---|---|---|---|---|
| **On- and offline games** | | | | |
| PokemonGo | 3 | x | x | x |
| Saints Row | 1 | | x | |
| Minecraft | 2 | x | x | |
| Sandbox | 2 | | x | x |
| Candy Crush | 4 | | x | x |
| Counter Strike | 6 | x | x | x |
| Call of Duty | 1 | | | x |
| Fifa, Football manager | 6 | | x | x |
| Destiny | 2 | | x | x |
| Fortnite | 2 | x | x | x |
| Overwatch | 1 | | x | |
| World of Warcraft | 3 | | x | |
| Grand Theft Auto | 5 | | x | x |
| Diablo | 1 | | | x |
| Hay Day | 1 | | | x |
| Bobble Shoot Pet | 1 | | | x |
| Roblox | 3 | x | | x |
| Team Forthtress 2 | 1 | | | x |
| Star Wars | 3 | x | | x |
| Shadow of Mordor | 1 | | | x |
| Hollow Knight | 1 | x | | |
| Warthunder | 2 | x | | |
| Rocket League | 1 | x | | |
| Bloons Bt6 | 1 | x | | |
| Stick Muster | 2 | | | x |
| OSU | 1 | x | | |
| Heros of the Storm | 1 | x | | |
| Conan Exciles | 1 | x | | |
| Pay Day | 1 | x | | |
| Piano tiles | 1 | | x | |
| **Social media platforms** | | | | |
| Instagram | 10 | x | x | x |
| Facebook | 20 | x | x | x |
| Twitter | 2 | | x | |
| Blog | 1 | x | | |
| **Messenging technology** | | | | |
| Messenger | 18 | x | x | x |
| Skype | 8 | x | x | x |
| Facetime | 4 | | x | x |
| Discord | 6 | x | x | x |
| Playstation Party | 1 | | x | |
| Siri | 2 | | x | x |
| SMS | 9 | x | x | x |
| Viber | 1 | | | x |
| Twitch | 1 | x | | |
| Snapchat | 9 | x | x | x |
| **Video Channels** | | | | |
| Youtube | 19 | x | x | x |
| Voice comparison | 1 | x | | |
| Netflix, Viaplay, TV2 play, DR | 7 | | x | x |
| Spotify, YouSee | 1 | | | x |
| OR-codes | 2 | | | x |
| TikTok | 1 | | x | |
| **Others** | | | | |
| Github | 1 | x | | |
| Diviantart | 1 | x | | |
| Medusa | 1 | x | | |
| Java Scribt | 1 | x | | |
| Sleros | 1 | x | | |

*Table 5 illustrates the technology use in categories. Technology use is divided into informational categories and institutional sphere (published in paper 2).*

**Figure 25: Comprehensive technology use**

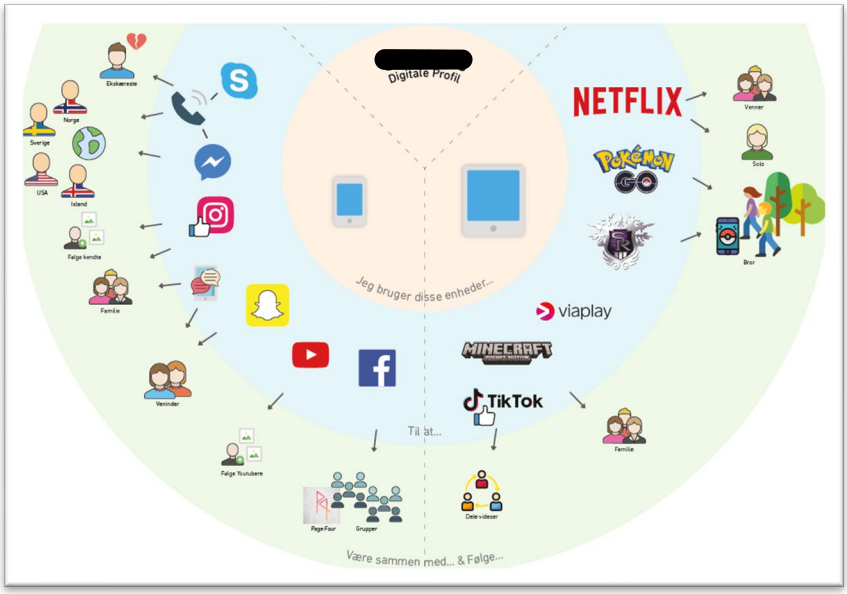



*Figure 25 shows an example of a digital snapshot with a comprehensive use of a multitude of digital technology by a participant, P11.*

## 5.2. CORE AND PRIMARY TECHNOLOGIES

As mentioned in Section 3.1.1, the computer was valued as the core and primary physical artefact in Jung et al.'s artefact ecology framework (Jung et al., 2008). For many of our participants, the phone was the core and primary physical artefact. During the workshops, the participants placed the phone icon in the 'technology we like the most' column on the Talking Mats. In this regard, they were asked if they could live without their phone for 24 hours, which was deemed impossible by three participants at the sheltered residence (P1, P7 and P24) and all participants at the youth education centre. One female participant from the youth education centre answered, 'Never in my life!' (P11) to the question and further elaborated that 'If I live without electronics for 24 hours, I will die'. She stated that it was only possible to do without her phone if she could use her iPad as a replacement for the phone. This was also the case for another participant (P18), although it was the computer that could be used as a replacement (P18).

Jung et al.'s artefact ecology framework is from 2008. Our study findings indicate that the view of core technology has likely shifted from the computer to the phone, at least in the youth population.

Aside from the phone, many informational artefacts were also greatly valued by the participants. The quotes below attest to the value of the informational artefacts. In the first quote, a participant gives a summary of the workshop exercise with the purpose of identifying which technologies the groups had in common and which were different. The phone and computer are still at the core, but other informational artefacts were important as well, namely, Google, YouTube, and Deviant Art:

> Well, we cannot do without our phones and Google or the computer and all that because then we would go crazy. We also cannot do without YouTube. P23 and I cannot do without making videos. I use Deviant Art a lot. That's where I make my YouTube videos. P21 cannot do without DR.dk (P21 repeats 'also not without YouTube' twice).

Similarly, YouTube was important to the other participants, who stated the following:

> I use YouTube every day and many times a day. I use it approximately five times a day, at least. (P11)

> I use it (YouTube) more times; it is almost always open (on my computer). (P18)

One participant is particularly excited about using Netflix, claiming, 'I don't do much else' (P7). For P10, Candy Crush is a primary technology. 'I play a lot - and I mean a lot - of Candy Crush'. For P11, Messenger was highly valued. She said, 'Messenger is my life'. In another study with a similar focus and study population, Bayor et al. (2018) find that some participants claim to be addicted to Facebook and value it greatly (Bayor, Bircanin, et al., 2019).

In conclusion, digital technology is an important part of the participants' everyday lives with high emotional value. They are digital natives, and technologies are an integral part of their lives.

### 5.2.1. GENDER-BASED TECHNOLOGY USE

During the interviews, we identified a gap (digital divide) between which applications the females used and which ones the males used, particularly for online games. Both genders play online games, but they differ in their gaming choices. For example, a female participant (P10) saw Minecraft as a 'boy's game', while another female (P4) expressed, 'Boys play games; girls talk about boys'. Females from the residency and

the youth education centre expressed these viewpoints, as there we no females at the primary school.

There were cases wherein females played games such as Saints Row (P11) and Fortnite (P5), which were mainly played by the male participants. When P11 plays, she has a seemingly rough behaviour, which was reminiscent of the way a male would behave in a game. The quote below supports this somewhat stereotypical point:

> (Saints Row) is about stealing things, fighting evil people, and just having fun. It is funny. If you get upset then it works, too… I beat people up if I am upset […]. I also hit old ladies with my car […]. My friend is worse than I am. She hits everything. I hit things when I lose control. Otherwise, the cars are not that difficult to manoeuvre. It depends on how bad the brake mechanisms are and how torn the car is.

P11 knows the prices of the cars, and she has a hand gesture in the game, which is supposed to denote 'fuck off'. One of the researchers asked if she also shows the hand gesture to people she likes and if they do not get upset. Her reply to the question was 'Yeah, it doesn't matter. I just beat them to the ground'.

P5 claims to have a male-like behaviour, which the quote supports:

> I can play with cars and stuff like that. I am not what you would call the girly type […]. Many may look at me and think that I am girly, but I am actually not because I like cars and motorbikes and all sorts of stuff. (P5)

### 5.2.2. NEGOTIATING CORE TECHNOLOGIES

During the workshops, the exercise wherein the participants were supposed to categorise what technologies they preferred to use ended up becoming a negotiation on norms. Here, non-users of a particular technology may experience pressure from users of the technology to turn them into active users (Kiran et al., 2015). That is, they try to negotiate what the core or primary digital technology should be among the participants. Some even engaged in a mild form of peer pressure, as exemplified below. In the first quote, the PI had just asked the participants to consider one more digital technology that they liked the best:

> P11: Messenger.
>
> P18: Computer.
>
> PI: If you have to choose one more thing [digital technology] that you like best, what would it be?

(P18 whispers): Computer.

P11: No!

From the conversation quoted above, it is clear that none of the participants wanted to change their preferred or core digital technology. This point was also stressed when P18 was surprised that P11 uses Skype. She claimed, 'I use Skype if I want to!', which indicates that nobody should tell her which technology she should use and which she should not. Thus, the conversation between the two participants maintained a proper and playful tone. The negotiation of norms continued among the participants at the youth education centre, where P11 and P18 tried to influence a friend to use Discord and Minecraft:

P11: I use that (Discord).

P18: I use that, too. P4, come on!

P4: What should I use it for?

P11: To talk to people like we do.

P4: Shut up over there […]. What is it with you and Discord?

P11: It is because it is a good place to be. P4, try it.

P4: No, thanks!

As the dialogue demonstrates, P18 and P11 tried to influence P4 to use Discord with statements such as 'You want to do what we do' and 'You will be more social'. P18 also used statements such as 'Do it, do it!' to try to influence P4 to use Minecraft. Nevertheless, her friends were not able to influence P4, as she did not see the point of using Discord or Minecraft. P18 also stood his ground with a firm 'No!' when P11 wanted to choose 'TikTok' as their favourite application during the workshops.

P16, who did not like or use social media, tried to influence the others in the digital community *not* to use social media:

P16: Hey, P14, you do not have any dislikes on them (Facebook and Instagram) […]. How can you not have disliked them?

Ditte: Do you dislike Facebook?

P14: I don't know.

In this case, the negotiation of norms was turned around, as it was the non-user (P16) who was seemingly pressuring P14 not to become a user but to become a non-user,

particularly a 'disliker' of social media. In addition, P16 saluted a participant who agreed with him about disliking social media:

> Ditte: You (P16) don't like Facebook and Instagram that is why there is a pile down.
>
> P21: Me neither.
>
> P16: That's it, P21!
>
> P21: It is a waste of time.

P16 further exclaimed, 'We've got a traitor among us!' when P14 asked why Fortnite was among the applications brought to the workshop, a game of which P16 was not a fan.

### 5.2.3. BROAD TECHNOLOGICAL UNDERSTANDING

P14, P15 and P23, who were all male participants from the primary school, as well as P1 from the sheltered residence, have a broad technological understanding. This means that they knew many different technologies and what their meanings were in the digital sphere. An example would be memes, as mentioned in the quote below:

> It is like the bread and butter of YouTube and the Internet […]. There are many popular memes on the Internet […], some more stupid than others. (P23 laughs) [...] It is always the dumbest things that become memes. (P15)

They are all knowledgeable about the technologies and competent in using and producing them:

> P23: I once tried to make one (memes).
>
> P14: It is not very difficult to make memes.

This technological understanding may influence both their ability to use the technologies and their motivation for using them. As for the rest of the participants, they were skilled in using their preferred technologies. What stood out for P1, P14, P15 and P23 was that they knew the digital world well, including all the different technologies that they did not necessarily use or prefer themselves.

## 5.3. INTERACTIONS WITH DIGITAL TECHNOLOGY

The difficulties experienced in the virtual world by individuals living with cognitive disabilities, specifically in terms of digital technologies and their concomitant challenges, were identified via a systematic search in Paper 3 (for the detailed search protocol, see Appendix A). Some of these challenges were related to accessibility and usability (ease of use of the functions on the physical device). A challenge for the study population is that standard IT protocols are not tailored to the needs and abilities of individuals living with cognitive disabilities who are not able to understand and use the interface design on digital platforms and technologies (Ågren Alfredsson et al., 2020b; Bayor, Bircanin, et al., 2019; Chadwick et al., 2013; Rajapakse et al., 2018; Shpigelman and Gill, 2014). Thus, these issues may not necessarily be related to the usability of the device but the digital abilities (or disabilities) of the user. For example, literacy was a major concern for usability and accessibility among this study population (Ågren Alfredsson et al., 2020b; Bayor, Bircanin, et al., 2019; Louw et al., 2019; McClimens and Gorden, 2008; Newman et al., 2017).

Generally, the participants in our study found it easy to use their digital devices (the physical artefacts). The challenges experienced were related to the applications (informational artefacts), which were not that many. Those who experienced issues regarding usability found solutions such as using assistive technology, which is in its nature an act of personal infrastructuring (Rajapakse et al., 2018). Some examples include using the Voice-to-Text feature in Messenger for those who could not spell and write and Google Translate for the ones who were not fluent in English but needed to play with international gamers. In these examples, assistive technology is, in fact, assistive to the technology used and does not replace the technology for these participants.

There were two unsolved cases regarding the interface. A participant (P25) experienced difficulties sending a picture on Messenger and changing the background picture on her iPad. Another participant from the sheltered residence could not play Star Wars because he had poor eyesight; the features were simply too small and complex for him to grasp. In this sense, he could still play a game that he preferred despite his disability, but the interface of the physical and informational artefact could not accommodate his poor eyesight (cf. Paper 3).

Authentication issues, specifically forgetting passwords, constituted another interactive issue identified in the literature search (Bayor, Bircanin, et al., 2019; Feng et al., 2010). In our study, only one participant, P25, expressed that she ‘doesn’t even know what her Facebook password is’. Bayor et al. (2019) conducted a training workshop, where participants living with cognitive disabilities were taught how to use the digital media that they had trouble with, for example in terms of remembering passwords (Bayor, Ploderer, et al., 2019). A training workshop focusing on usability and accessibility would not have been relevant for our group of study participants,

who were more occupied with developing their skills regarding dissemination of digital content further, which will be elaborated on in Chapter 7.

Moreover, a reason for some participants not being able to access the gaming platforms that they preferred was economic, such as poor internet connection, which was related to economic accessibility. Not being able to afford technological devices or licences, for example, is another challenge for many individuals living with cognitive disabilities, as many do not have much economic latitude (Chadwick et al., 2013; Newman et al., 2017) (cf. Paper 3).

An interesting finding regarding interactivity was that the male participants (P6, P7, P8 and P12) found it challenging to use the old Nintendo games brought by the institutional staff during the fieldwork (cf. Chapter 3). The male participants use gaming platforms such as Team Fortress, Destiny, Diablo and Call of Duty. All of them found both the interface and the rules much more complicated in the old Nintendo games than in their gaming platforms (cf. Paper 5). The Nintendo games could only play one game per unit and, as such, merely contained one task, whereas the virtual world and tasks in the games that the participants were used to were much more complex yet easier for them to grasp.

## 5.4. DYNAMIC TECHNOLOGY USE

As discussed in Paper 5, an essential point from the empirical findings was that digital technology use was dynamic. This means the participants' digital use, relationships and preferences change over short time intervals. In our case, we were able to detect these changes over a period of three months from the interviews to the workshops and, in a few cases, from the workshops to a later encounter. The digital snapshots were essential in detecting these dynamic changes in the participants' digital use and relationships, as illustrated in Figure 26. In the top digital snapshot, we see a digital snapshot handed down to a participant (P6) at the workshop. During the workshop, P6 and many other participants wanted to adjust the items on their digital snapshots for which we used post-its (cf. Paper 5). After the workshop, I visited the three institutions to give the participants their updated digital snapshots. In the case of P6, he stopped playing GTA and got a girlfriend, as illustrated in the bottom digital snapshot. Notably, some participants wanted adjustments even after the second visit, which supports the argument that digital technology use and digital relationships are dynamic among the participants (cf. Paper 5).

**Figure 26: Dynamic technology use**

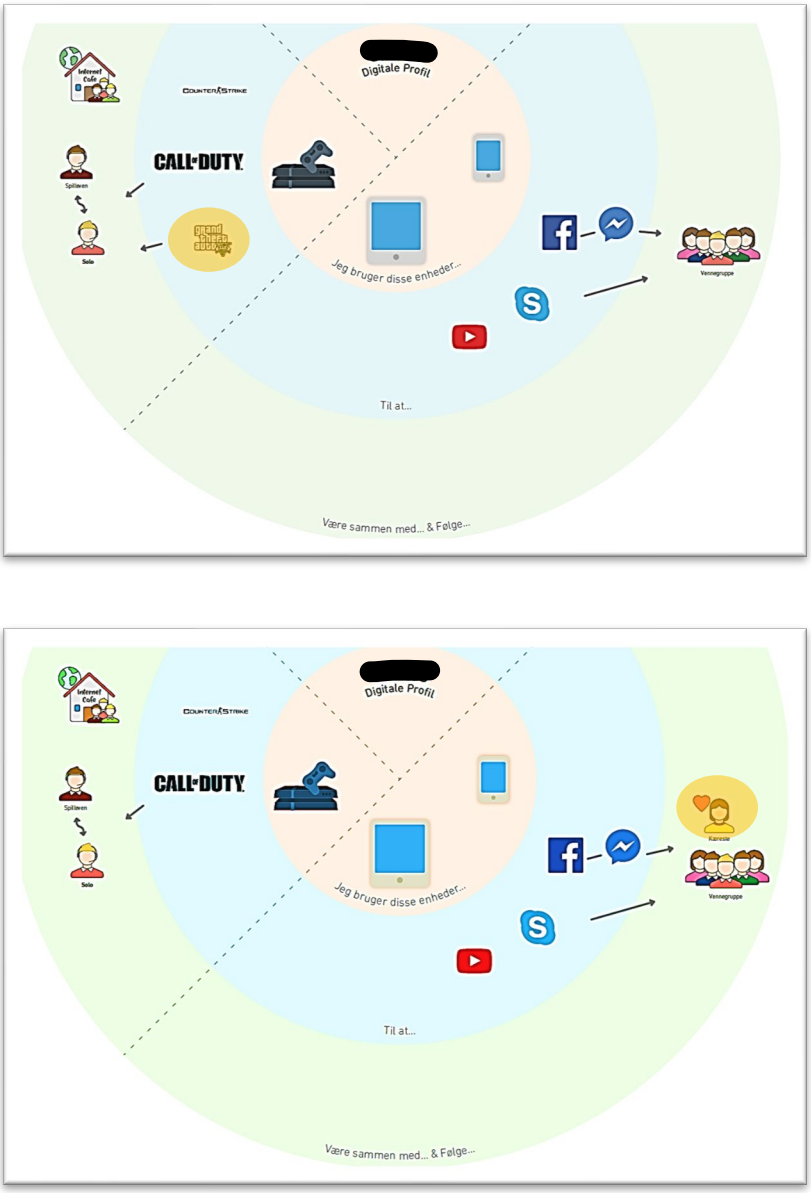



*Figure 26 shows an example of the dynamic technology use. We see P6's digital snapshot before (top) and after the workshop (bottom). The changes are marked with yellow in the two digital snapshots.*

Another element illustrating that the technologies are dynamic is the participants' use of the same technology for different purposes. One participant mentioned that she uses Facebook to connect with her close friends, while on Instagram, everyone can follow her peripherally:

> The ones (who follow me) on Facebook, they are people I know. I am friends with them. On Instagram, I am indifferent about who follows me in there, but when it is Facebook, then it should be someone I prefer, someone I know.

Lastly, the digital aims of the young participants likewise changed from the interviews to the workshops (cf. Paper 5). For example, at the workshops, some participants expressed a wish to use (or use more) applications that they were told about or had not used before, such as Skype (P25), audio books (P10), Snapchat (P10, P13), Home Scapes and YouTube (P12). Therefore, the digital aims are also dynamic, that is, a *snapshot* of the young people's reality at this particular time of their lives.

## 5.5. SUMMARY

In this chapter, the physical (digital devices), informational (applications) and interactive (ease of digital technology use) aspects of artefact ecologies have been addressed. This means that we examined research objective 1: What characterises the digital technology use, activities and value of young individuals living with cognitive disabilities? It should be emphasised that artefacts are interconnected and allow users to create a network of artefacts that are mutually connected and used for different purposes and with different people. The participants use a wide range of digital technologies, and their use, relationships and aims are dynamic (change over time). The participants negotiate about which technologies are at the core of their lives and are the most important, but all of them agree that it is hard to live without digital technology. Digital technology has great value and meaning in the participants' lives (especially the phone), and they do not experience any tremendous interactive challenges when using digital technology.

In the following chapter, we focus on the communities created via and around ecologies of artefacts (digital technology). Furthermore, we determine their functional properties and corresponding values in the exploration of digital relationships and communities.

# CHAPTER 6. DIGITAL RELATIONSHIPS AND COMMUNITIES

*'It is very important to be social' ~ P11*

In this chapter, the functional aspects of artefact ecologies in the participants' digital lives are addressed using Wenger's notion of communities of practice, as the relationships and communities developed and maintained around and via digital technology are the main focus of this study. This includes identifying what properties they have and how participants value these digital relationship and communities. In this regard, all layers in Jung et al.'s artefact ecology framework is under the lens: 1) the (social) purpose of digital technology use; 2) the context in which these technologies are used; 3) the subjective meaning given to these relationships; and 4) people and collaboration, the last layer incorporated by Bødker et al. There is no division between relationships and communities in the dissemination of the empirical findings. The concepts are used together to emphasise the importance of the relational orientation in the study and analysis. This means that we examine part of research objective 2 in this chapter: How does digital technology form the digital relationships of this study population?

In Papers 1 and 2, we established that the participants create personal relations, interest-based groups and national and global networks via and around digital technology (Andreasen and Kanstrup, 2019a, 2019b). There are three types of communities of practice, each having shared characteristics, repertoire, mutual engagement via a common enterprise and orientation, and a history of learning. The participants are not limited to only one of these communities of practice. They participate and are members of all three types of communities in their own ways.

In these communities, the interaction dilemma proposed by Wenger et al. (2009) is evident, as the participation in these digital relationships and communities is organised around physical and conceptual artefacts (reification), which is exemplified in the following.

An interesting finding from the examination of our empirical work is that these digital relationships and communities can be divided into internal and external digital relationships and communities of practice. By internal digital relationships and communities, we mean that the participants interact with the individuals within their institutional sphere, for example, participants from the same residence or school or individuals whom they met at the Youth Club they attend or at their workplace. This

implies that these digital social circles consist of other individuals living with cognitive disabilities. By external digital relationships and communities, we mean that participants interact with individuals outside of their institutional sphere.

## 6.1. INTERNAL DIGITAL RELATIONSHIPS AND COMMUNITIES

The internal digital relationships and communities primarily concern the identified personal digital relationships in Papers 1 and 2, which the participants maintain via and around digital communities.

When asked to define what friendship is, most of the participants mentioned that togetherness, intimacy, closeness (long-term relationships) and cosiness are important elements in a friendship. What characterises some of these personal relationships are mutual engagement and meaningful experiences given to long-term or personal connections with others. The social value is the shared enterprise of some members in internal communities (a relational orientation) and not a specific interest or activity. Other internal digital relationships and communities are formed around specific interests or activities. The following conversation between two female friends, P11 and P4, at the youth education centre is an example of this division between a relational orientation vs. a common interest:

> P11: That thing about having, what you [Ditte] said, about having something in common, I think that is quite important. If you sit with someone and you don't have anything in common, then it is really difficult. It is much easier if you have something in common.
>
> P4: Why?
>
> P11: Yeah. Try to think about if you were right next to someone and you did not have anything in common and you just…
>
> P4: Well, I have someone whom I don't have anything in common with.
>
> P11: And how is that going?
>
> P4: It is going fine.
>
> P11: For me, it would not.
>
> PI: Then you just laugh together or what?
>
> P4: Yeah.

> P11: That's where it goes wrong for me because I have someone, I don't have anything in common with, and it goes terribly.

The two female participants have different views on what is important in a relationship: common interest vs. relational orientation. In the following, the different internal digital relationships and communities are elucidated.

### 6.1.1. COMMUNITIES AROUND DIGITAL TECHNOLOGY

As addressed previously, the importance of the geographical element of a community of practice has faded with the progression of digital communities. While this is the case, the physical arena around digital technology has been identified and examined in this study (cf. Papers 1 and 2). This means that the participants find ways to be together physically using digital technology. Therefore, there is a physical artefact that mediates participation and relationships *around* a particular digital technology. Some empirical examples of these digital communities around digital technologies are watching movies, communities around gaming and Makerspace.

#### 6.1.1.1 Communities around movies

Most people like watching movies with others, but other prefer watching videos and movies by themselves to relax. P13 sometimes watches movies with her boyfriend and friends in person. At the three institutions, they arranged different movie sessions during the fieldwork, which were video recorded. At the primary school, it was during class when the participants and other students watched a historical movie as part of their lesson. In Figure 27, we see participant P22 in front of an office chair and P23 and P14 on the couch (P23 on the left side and P14 on the right side). P22 is looking at the screen, while P16 (not visible in the picture but is on the couch near the two other participants) looks at P14. P14 is laughing at something P23 says, and P22 turns his attention towards the three other participants, looking back at the couch where they were sitting but staying quiet. After 10 minutes, the sound vanished, which elicited a laugh and a glance between P14 and P23, who also removed a pillow from the couch to be funny. After a minute and a half, P16 said, 'Then we should just make the voices ourselves', which triggers immense laughter from P14 and P23. P23 expressed eagerly: 'P14, P14, P14. Now I just feel like saying… (what is being said is unclear, but the two laugh together)'. After a few more minutes, P23 and P22 exchange glances and laugh. Then, P22 laughs towards the rest of the participants and moves his chair a little closer to the couch. After 15 minutes, the sound returns but

vanishes again for another 10 minutes, which makes P22 say sarcastically to the room, 'I don't think it has anything to do with the movie'.

What is essential in the picture and in the movie session is that many participants are not comfortable in large gatherings, but during the movie, the participants were comfortable being in the same room with many others around the television and interacted around this technology, especially the technological flaws (missing sound on the device). This was the case for P22, who normally has difficulties interacting with others.

**Figure 27: Community around movies**

*Figure 27 illustrates an example of a community around movies. Photo by Ditte Lystbæk Weber.*

At the youth education centre, they had a class called 'the genius body', which they watched together in groups. Some follow the programme, some laugh, and some ask questions. At the sheltered residence, the participants would watch a movie or a football game in groups in the common room or in a separate room with fewer people. During a football game that was played on the big screen in the common room, the participants sat on the couches and watched the game. Only a few took out their phones during the game. When P10's phone rang, she answered it. As soon as there was a break, everyone started using their phones to play Candy Crush or scroll through Facebook.

For the activity of watching movies, it is common interest in (or obligation to carry out) the activity that drives the participants to join more than the relational orientation.

### 6.1.1.2 Communities around gaming

Gaming communities are a big part of many of the participants' lives, both digitally and physically. Physically (more on the digital gaming communities later), some participants host their own Local Area Network (LAN) parties with a friend (P18) or with a group of friends (P19). Other participants (P6 and P7) often sit for a couple of hours and game together, as the quote below suggests:

> P6: Yes, that's when you play the game. You game with friends and, yeah, have a nice time together.

P14 sometimes plays Minecraft with his friend when they are together; P20 plays FIFA with a friend.

P7 and P24 sometimes go to Internet cafés to game. Thus, this is a more peripheral community, as they do not necessarily know each other each, but they are physically present in the same room and have a joint interest to game using the devices that the Internet café provides.

The last gaming platform under the lens comprises the computer rooms at the primary school and the youth education centre, which have been elaborated on in Paper 3. At the youth education centre, P2 plays for fun, as well as trains for participation in Geeks Grown Wild, a tournament at Gigantium where different youth clubs from Denmark engage in a physical tournament against each other.

In the physical gaming communities, the common interest is gaming and the particular game preferred is essential for membership. However, togetherness and intimacy among friends are also important to the members, who obtain social value from these communities.

### 6.1.1.3 Lurkers in communities around gaming

P11 and P5, as well as a female participant from the youth education centre (P3), mentioned that they like to watch 'the guys' when they play, for example, FIFA. This is to be able to spend time with their male friends or boyfriends and because, as P5 said, she does not mind being a bystander when it is her *friends* that she watches playing. If it were someone that she did not know, she would not be interested. For these females, the motivation for using this technology and becoming a member of this community does not revolve around technology and gaming interest but on their

relationships with their male friends. The quotes from the females below underscore this point:

> I played it [FIFA] with some of my friends. It is not because I play it alone but when I am with someone, then I can […]. It depends on what kind of people I am with. When I was with my ex-boyfriend, we gamed a lot together, ehm, football, such as FIFA and stuff like that […]. And then (friend's name), I gamed with him a lot. I also game with PlayStation and stuff like that […]. It depends on how I communicate with people […]. If it is someone whom I am really close to, they can get me to play right away […]. What it is really about is that you have to get to know me, deeply, then you can get me to participate in something which I would otherwise say no to. (P5)

> My boyfriend also plays FIFA at home when I am with him. I watch or sit with my phone while he plays. Just for the cosiness. (P3)

> You [P18] can have a LAN party now and invite me. Then I will sit and keep you awake. That sounds really nice, and I do not care if only guys will be there. (P11)

As such, their interest in gaming is a 'passing enterprise' and not something that the friends have in common. However, their friendships give them great social value and these girls care greatly about them. They have friendship in common, and they exert effort to fit in. Thus, they do not identify with the content of the activity or negotiate about this matter.

#### 6.1.1.4 Makerspace

During the Makerspace session (for detailed information, see Section 4.2.1), the participants sat at their computers and were very focused on the activity: making a keychain in the programme Tinker cad, cf. Figure 28. The teacher and resource person in charge of the Makerspace session explained the procedures multiple times during the session while the participants listened. Afterwards, they did it by themselves and were instructed to call for help when needed. Therefore, the teacher works as a 'technology steward' in this particular community around Makerspace. He takes care of a community that wants to learn together and facilitates the development of technical abilities among the participants (community members).

**Figure 28: Makerspace 1**

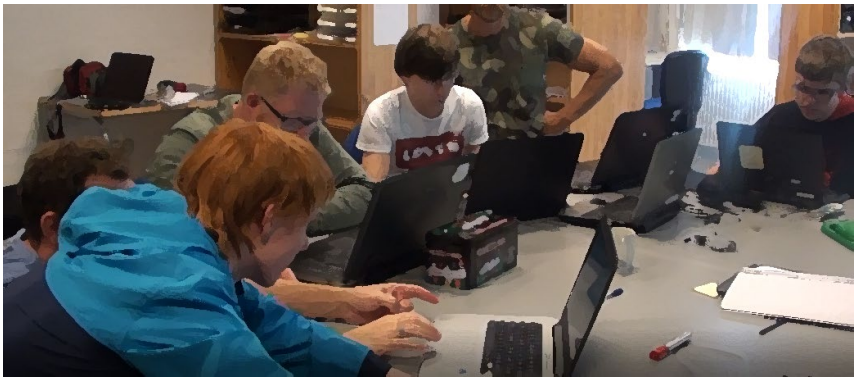


*Figure 28 shows an example of the Makerspace class. Photo by Ditte Lystbæk Weber.*

At some point, P15 asked for help but managed to solve the problem himself by leaning over to see what P16 was doing before the teacher came over. Thus, he was able to learn from P16. This made P15 very proud. He expressed, 'By the time you (the teacher) came to help, I have already figured it out myself'. With this, he takes on some semblance of responsibility in the community and evolves, for which the teacher (the leader) appreciates and acknowledges by saying, 'Okay. Then I will just go have some cake and coffee (the teacher has a big smile on his face)'. P15 asked for support a couple of times, but he also wanted to make the teacher aware that he was good at the task and could do it independently. P15 sought acknowledgement when he (and P14) showed the teacher his output. P15 was very eager to hear what he thought, asking multiple questions, such as 'What do you think about it up until now?', 'But does it look nice?' and 'Am I not just really quick in learning this?' Therefore, he expressed a need for recognition, but he was also very confident in his work, as the quote suggests:

> I made this all by myself with no help […]. The programme I use to make models in Minecraft is similar to this (programme). And it (the programme he uses) is much more difficult than clash, hack, crash and much slower. This is easy compared to that because this is much, much easier to use (he explains some details about Minecraft). I have played Minecraft for many years, so I am very adept at it. I think this is why I learned how to use Tinker cad really fast.

Later, during the session, P15 called me to show the figure he made (the scary cupcake from the movie Five Nights at Freddy's). He started to make this figure in Tinker cad (cf. Figure 29), thereby taking ownership of the product by making it his own and identifying with the product. This displays independence and represents an entry to

the community of practice in his own way. When one of the assistant teachers came to look at P15's work and suggested that he try to play with the colouring, P15 seemed annoyed and firmly replied, 'I did not learn yet how to change colours'. The assistant teacher tried to explain, but P15 interrupted and said, 'I will wait for that guy (the primary teacher) to come back'. Evidently, the assistant teacher seemed to have crossed a line with P15.

**Figure 29: Makerspace 2**

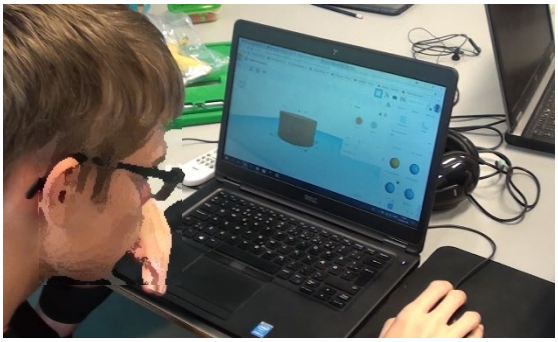


*Figure 29 illustrates a Makerspace class where P15 is in the process of making his scary cupcake. Photo by Ditte Lystbæk Weber.*

During the Makerspace session, P14 found that one can chat in Tinkercad and comment on another person's work. He was able to identify a communication channel for the participants and expand their communication possibilities, thereby unveiling that the community orientation is more than the product; it also involves relationships. The participants interacted by looking at each other's screens, although there was limited talk. At one point, P16 looked at P15's screen and stated, 'Oh, you did make the cupcake'. P15 responded, 'Yes, of course'. As such, there was a form of mutual learning between P15 and P16 during the Makerspace session. At one point, P16 made a joke, which could also be interpreted as a sign of mistrust: 'I would not be surprised if anyone made a viruses'. It was most likely meant as a joke. P14 also interacted with the other participants when trying to help them. P15 and P16 put their figures on their 'My Education' page. The participants interacted with the teachers and me. I was operating the camera, but I was also interacting with the participants.

Makerspace is a closed community around a common enterprise and a product orientation to develop technical abilities. It is just as much about competency development and learning as togetherness, with the objective of developing competencies to match the competencies in the community.

P23 came in after 25 minutes and asked if he could join until lunch was ready. He entered this particular community as a non-member but became a member by demonstrating the ability and motivation to fit in. He asked what they were doing (expressed an interest), joined the class and behaved according to the norms in the Makerspace community. He sat with his own computer and solved the problem/activity of making a keychain.

Later, we learned that two of the participants, P15 and P22, did not find the Makerspace session useful. They did not feel that the sessions made sense. The two participants had some very narrow personal interests, namely, P22's Rocket League game and P15's YouTube videos, which made the sessions difficult to tailor to their particular needs and interests. Although the two participated actively in the session described above, they were not motivated to continue the course. As such, they exited the community and found new ways to fulfil their needs for their technological development (Davidsen et al., 2021). P22 did not find the Makerspace sessions useful and showed signs of insecurity, for example, by expressing, 'If he [P14] needs help, then I think I do, too' while leaning over to see P14's output. He also had to be reassured by one of the assistant teachers that his work was okay. Other than that, he seemed calm and satisfied during the sessions, and he was not disturbed by the camera.

In conclusion, Makerspace is in some way a formal and temporary (passing interest) community created in a formal setting (school) around formal activities. What makes it a community of practice is that it developed to become a space where participants who are interested in developing their technological abilities come together to learn together during their breaks and free time. The space for this initiative was a computer room, which the 'technology steward' initiated setting up in continuation of the Makerspace community. Here, the participants could sit by themselves and game. They could even create games in, for example, Roblox, as described and elaborated on in Paper 3. What was essential was that the participants learn together in this computer room by helping each other build games, formulate strategies, and so on while maintaining their individual space and participation (more on this in Chapter 6).

#### 6.1.1.5 The community around the phone

During the breaks at the youth education centre, it was easy to spot the use of the phone as a mediator for conversations and relationships among the participants.

In the U group, two participants, P5 and P3, talked in the hall about checking their phones. They looked at it and exclaimed, 'I thought he was fat… and it is a guy'. Later, P5 showed her phone to some of the guys because she was annoyed at someone who kept writing to her.

In the X group, the students, and participants (often the same students) gathered in a common hall room. At these encounters, the phone was often used as a mediator. One example is provided in the following: P11 and P4 sat together on the couches. They were sitting around a table with chairs and three couches. All seats were taken. P11 sat with her phone for a while but mostly talked with the others. She told P4 that she could not sleep because she had too many thoughts. Afterwards, she asked one of the males if he uses Twitter and what the platform is about. He explained that you use it to follow famous people, such as Trump. He read her some posts from Trump's Twitter profile. P11 laughed. She looked at me and asked when they would video-record again, but she got distracted. At one point, P11 asked one of the other girls if she was okay, as she looked sad. P4 did not say much but seemed worried about P11 when she told her that she could not sleep. P2 sat with his phone. He showed a football match on his phone to two of the other students.

### 6.1.2. MAINTAINING PERSONAL RELATIONS AT A DISTANCE

Since the interviews, three of the participants moved to a new residence, which gave us the opportunity to investigate if and how the participants maintain relationships when they move from one institution to another aside from what we had already learned in previous conversations with them. Two participants (P10 and P12) explained that they use FaceTime on their iPad and phone to talk with two female friends who still live at the old institution, including P13. The friends appreciate FaceTime meetings because they can access a living practice through a virtual space. As explained using P13's own words:

> I use FaceTime. It is more fun to talk when you can see each other instead of just talking […]. Even though you are not together at each other's home, you still feel like you are there.

P10 and P12 (who moved away) also shared during the workshop that they sometimes use Messenger to write to P13. During the workshop, P10 thoughtfully reassured P13:

> P10: You (P13) are welcome to write me if you get upset out here or call me.
>
> P13: Yes, yes.

Before P10 and P12 moved, the three female participants had a Messenger group, where they would send each other heart emojis, for example. P10 explained that she enjoys conversing via group chats: 'It's cosy. You can talk to all sorts of people. You are not one, you are more'.

Notably, P10 began using social media, particularly Snapchat, at a lesser degree after she moved to the other residence. The change in context changed her digital use, and she may be in the process of exiting this personal community, which challenges the maintenance of friendships.

Another female participant, P11, explained that messaging technologies are important when you have friends who live far, such as her friend in Island. They use FaceTime, Skype, or Discord to communicate. P11 also uses Discord to talk with her friends at the youth education centre.

Another participant, P20, uses Skype to stay in contact with friends and family when he is travelling.

While time and frequency are not eminent to be a member of a community, frequent interaction with friends (active participation) and being available were important to some of the participants who interacted on a daily basis. As shared by male participant P19:

> So, I can talk to him while I am in the car on my way home and when I come home, then we can talk with each other… We talk every day.

Meanwhile, some participants at the youth education centre elaborated:

> P11: I receive Snaps from him all the time, right P18?
>
> P18: Yeah. That's because I'm bored sometimes.

An observation made was that the assistive technologies, in this case, the microphone in Messenger chat, made it possible for a male participant at the sheltered residence, P7, to send a chat message to his friend (D), where he asked D to add him to a platform so they can game together (cf. Paper 3). As such, the assistive and digital technology enabled digital togetherness between this participant and his friend.

Two of the participants (P10 and P13) also engage in a form of peer-learning activity, where they help each other by requesting or sending each other lives in Candy Crush. They do this with each other and with their colleagues.

The members of internal communities described above have an orientation towards relationships (especially long-term ones) more than a particular activity. These close and personal relationships are maintained via written, verbal or visual messaging technology, for example, FaceTime, Messenger or Snapchat. The interactions happen from room to room, from class to class, or with other people who used to go to the school or live at the residence. Research with the study population has shown that Facebook is used to maintain and enrich existing relations formed online, whereas Instagram and Snapchat have the potential for creating new relationships (Bayor,

Bircanin, et al., 2019). P5 supported this point when she stated that she is friends with the people on her Facebook account, whereas anyone can follow her on Instagram.

Although many participants believe that digital technology is important, some (P10, P12, P13) mentioned that they do not think it is essential to remain in contact with one's friends. When members of a community have a relational orientation it is not abnormal for the technology to become less relevant (Wenger et al., 2009f).

#### 6.1.2.1 Safety and surveillance

Digital technologies are perceived as a lifeline for many individuals living with cognitive disabilities as especially the phones give them direct access to resource persons regardless of the time and place (Söderström, 2011). A participant (P19) uses his phone to call his parents and friends if he needs help or to let them know that he is well. In this sense, the phone serves the purpose of making him feel safe and making his surroundings feel safe.

As a way of fostering safety, a participant (P3) mentioned that you can use Snapchat to keep an eye on your friends. P11 also had an app where her friends could see where she was (Senley) (cf. Paper 3), but she got tired of the app and deleted it, as she did not want her friends to know where she was at all times.

#### 6.1.2.2 Entertainment

For many of the participants, an element of entertainment is important when using digital technology. For example, when P2 was asked what the game he plays is about, he replied quickly:

> Having a good time (he replies very quickly and smiles). Well, it's also about having fun and winning. That, you sort of have to do.

Many of the participants use Snapchat to entertain themselves and others:

> P11: You can receive really funny pictures […]. The great thing about Snap is that you can make the silliest pictures of yourself. It is also great for keeping memories.
>
> P18: I can send, for example, a beef sandwich that I had yesterday to my brother. Then he would write 'Mean asshole' back to me (laughs).

> P11: It's like when I send Mac to my friends. Then they just write 'Fuck you' back.

Sending Snapchats while being in the same room was found by P19 to be amusing. P7 sends funny pictures of cats to his friends, while P10 and P18 enjoy sending funny pictures of themselves. The other participants (P10, P23 and P11) send funny videos, gimmicks, or memes to their friends in a Messenger group, while P8 likes having conversations with internal jokes among friends. As such, the Snapchat application has both social, emotional, and experimental value, as it stimulates feelings of joy and memories with friends. To one of the participants, P13, these acts of entertainment are viewed as friendly digital teasing, which she finds important in a friendship. Other research with the study population confirm that sharing animated and satirical photos of daily activities and videos on Snapchat is highly prioritised and valued by individuals living with cognitive disabilities (Bayor, Bircanin, et al., 2019), along with other leisure activities (Baric et al., 2018).

## 6.2. EXTERNAL DIGITAL RELATIONSHIPS AND COMMUNITIES

Some participants mostly interact with people from their school, residence, youth club or work, but many of them also interact with people from outside of the institutional sphere, particularly international encounters. Some participants even prefer these external digital relationships and communities, as underscored in the following quote by P9:

> I think Danish people are boring when you meet them on the Internet. They are not as fun as people from America or Sweden. They have more humour.

Likewise, P11 appreciates international relations and has a vast network:

> Everybody comes from different countries. I have a lot of international friends… where I sit and write with as well.

The common understanding and enterprise-oriented content is evident for the external digital relationships and communities, as the content (field/activity of interest) is what joins the members in these communities. This is not to say that internal relationships are not focused on a common enterprise or interest, but the basis and motivator for the encounter may be the closeness and long-term element as opposed to a particular activity or interest (a conceptual artefact which the participation is organised around).

### 6.2.1. INTERNATIONAL GAMING COMMUNITIES

Closeness and intimacy are not limited to the internal digital relationships and communities, as some participants (mainly P22, P1 and P18) managed to gain social value from friendships formed on international gaming platforms. These communities are external but not peripheral.

P22 enjoys playing Rocket League as something always happens on that platform. He has tried other gaming platforms, but he had to wait a long time for something to happen, which can trigger a feeling of loneliness. As such, this participant has an orientation towards frequency of meetings or activities (gaming) on this platform.

While the gaming community gives him a sense of belonging, he still needs to negotiate norms to fit in. For example, he needs to stay up at night and change his daily routine to game with other international gamers who live in other time zones (cf. Paper 3): 'When you are lonely, you do what it takes to fit in'.

On this gaming platform, another important element for P22 is that he can conceal his identity (his face and real name) whenever he likes because he is afraid that showing his true face and identity will scare people away (cf. Paper 3). This particular feature of hiding (and not hiding) one's identity is a good example of how community members can evolve in a community. He goes from hiding his identity (his face and real name) to showing his face to the members of the community with whom he games and feels safe when he gets to know them (cf. Paper 3). As such, he is a member of a peripheral community of practice on the gaming platform with shared enterprise and repertoire, as well as an intimate sub-community (the particular gamers he games with), which is not a peripheral community to him. He creates a social identity on the gaming platform and identifies as a gamer as he forms friendships there (cf. Paper 3). The gaming community evolved for this participant to incorporate physical meetings as well, as he met with one of the gamers in England (cf. Paper 3).

P1 uses the gaming platform Destiny 2 to shield himself from the load of negative thoughts and emotions that he carries around. In the game that P1 plays, there is a clan leader who games with the others (is a member) but, at the same time, takes on a leadership role and helps the others. His function is similar to the technology steward in the Makerspace session, as he facilitates collaboration and collaborative learning in the team. P1 speaks highly of the clan leader but other than that, belonging is not the main motivation for him to game. He is more interested in sharing a common interest (Destiny 2) with his team members. This interest, as well as his gaming abilities, is his way of fitting into this community of practice. P1 claims to not have any common enterprise with the other individuals at the sheltered residence and, therefore, finds it difficult to socialise with them and resorts to the Destiny 2 gaming platform. However, despite P1's claim, it was observed that he and P6 enjoy building Lego figures

together. They even went to Copenhagen with P6's mom to buy some new Lego sets. As such, he shares an enterprise with at least one of the residents.

P9 has physical friendships but also uses the gaming platform to extend his relations with digital relationships. His physical gaming community has evolved, becoming involved (participate) in a digital and more peripheral community while remaining in the physical gaming community. The quote below from P9 supports the argument that common enterprise is evident:

> Your friends sit and talk with someone, and you get invited to a conversation. You all talk, you are interested in the same thing, then you become friends […]. I just don't want to be with a person who does not have the same interests. What are we supposed to talk about? We would just sit and look at each other.

In conclusion, besides creating an online space for intimacy and togetherness, the gaming communities in which P22 and the other participants are part of provide an important element of peer learning, as the gamers use each other to strategize and communicate (more on this in Chapter 7).

### 6.2.2. PERIPHERAL PARTICIPATION IN COMMUNITIES

In peripheral participation in communities, members have an orientation towards content integration combined with access to expertise and open-ended orientation, where individuals find common understanding and interest and participate by following others or their content on digital platforms, particularly Facebook, Instagram, and YouTube. In these peripheral communities, the conceptual artefacts which the participation is organised around is particularly evident.

#### 6.2.2.1 Followers and recognition when sharing content

In these peripheral communities of practice, acknowledgement and recognition from a wider network are at the centre instead of intimacy and closeness among the participants, as illustrated in the conversation below:

> P5: I think I have around 3000 or something followers on Instagram.
>
> Ditte: So, you are actually the one who is famous (laughs).
>
> P5: Yeah. There are a lot who want to follow me, and of course, I just press accept.

Meanwhile, P11 is occupied with sharing the content she makes with her friends on YouTube, Instagram and TikTok and likes it when others follow her. She also follows others on YouTube, where she claims to be following 10,000 accounts. On TikTok, she follows 818. She likes and comments on the posts she enjoys, including the ones by the so-called 'influencers':

> I do that [like] almost every time Oscar (a Danish YouTuber) posts a video, and then I would comment […]. He advertises with his t-shirts that you can win, so I always write that I want one.

In these peripheral communities of practice, these influencers work as leaders who influence members in the periphery and create a learning process for them. People can access their expertise through the previously mentioned digital platforms.

However, not everyone is a fan of this influencer culture. P18 prefers following people who are more easy-going, and he merely likes and never comments on posts. His activities include learning to play the guitar using online tutorials. These tutorials make it possible for him to access expert knowledge.

Even P1, who is quite shy, shares stuff on YouTube. By contrast, for P15, Instagram is merely used to follow and not share content. He follows the people who make the faces he uses for his scary cupcakes and other figures. Like P18, he is oriented towards content and access to expertise.

Meanwhile, P14 appreciates his admirers on YouTube. He has an admirer who leaves many comments on his videos. The peripheral participation in these communities on different digital platforms enables an open-ended orientation, as members can share content or lurk, engage in discussions, and share opinions, thereby learning through active or passive participation in communities of practice. They may learn a specific skill, but they may also learn to identify with something or someone or experience personal growth from acknowledgement and recognition.

#### 6.2.2.2 Peripheral cultural participation

As addressed in Papers 1 and 2, P25 orients towards content by using music videos and series on her iPad to connect to her home culture, as she is from Vietnam. In Figure 30, we see a TV series that P25 follows in the left picture. In the TV show, the actors scream at each other in Vietnamese, and it is a very dramatic scene. In the picture on the right, P25 watches a music video of a male Vietnamese singer. This way, P25 participates passively as a lurker in these peripheral communities, but it gives her a sense of belonging.

**Figure 30: Peripheral cultural participation**

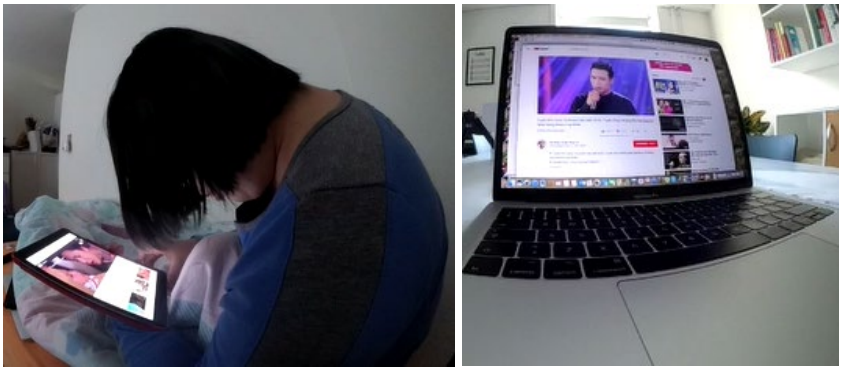


*Figure 30 shows an example of peripheral cultural participation. P25 watching a dramatic Vietnamese TV-series (left) and a music video (right). Photos by Ditte Lystbæk Weber.*

The cultural interaction is not merely peripheral but also personal and intimate for P25. During the workshops, we learned that she uses Facebook and Messenger to call her friends and family in Vietnam. This is the digital activity she prefers.

P5 incorporates other peripheral cultural spheres through Facebook via her family, as her stepmother and stepsister are from the Philippines:

> I know a lot of people from the Philippines […]. Some of them are just people who have friend-requested me [sent a friendship request on Facebook] because of my sister. They are very impressed that my older sister has a Danish stepsister, so just as soon as they see me, they request me, and I am just like yes, yes […]. It is not just my sister's friends; it is also other friends and their friends' friends who friend-request me.

The participants who game with international gamers learn the behaviours of people from the US, UK, Russia, and others. This way, they get a sense of other cultures, at least in the gaming sphere.

## 6.3. SUMMARY

This chapter examined part of research objective 2: How does digital technology form the digital relationships of this study population? The empirical findings presented in this chapter indicate that the study participants' community artefact ecologies are complex and manifold. They participate in different communities of practice and use a multitude of technology to develop and maintain meaningful digital relationships and communities. Their participation in digital communities of practice serves different purposes and has different meanings and contexts tied to them. Common to all these communities of practice is a purpose of commitment to relationships with people and collaboration in the communities (the fourth layer of artefact ecology suggested by Bødker et al. 2009). Specifically, the purpose of the internal digital relationships and communities is to maintain personal relationships in contexts via and around digital technology (around movies, gaming, Makerspace, the phone). The purpose of the external digital relationships and communities is mainly to develop relationships with individuals from contexts outside of the institutional sphere, such as in contexts of international (but close) gaming platforms or in the periphery. The participants find these communities of practice meaningful as they foster togetherness, intimacy, fun, peer learning, joint enterprise, and recognition.

The empirical findings in the following chapter go into further detail about the complexity of the participants' artefact ecologies and communities of practice.

# CHAPTER 7. MANAGING DIGITAL COMMUNITIES: PERSONALISATION AND INDIVIDUALISATION

*'A healthy community acts as a social container to make disagreements productive' ~ Etienne Wenger (2009)*

This chapter examines the second part of the functional properties and values of artefact ecologies, emphasising the digital challenges experienced by the study participants and how the participants manage these digital challenges using individualisation and personalisation. This means that this chapter addresses part of research objective 2 (how does digital technology challenge the digital relationships of this study population) and objective 3 (how do the study population manage their digital communities). As such, the functional aspect of artefact ecologies is a personalised and individual orientation towards technology. This is also the purpose and value given to use or non-use.

These challenges were identified in a systematic review in Paper 3. They were termed 'digital social challenges', as they concern the challenges experienced in digital relationships and communities. The challenges are elaborated in the following subsections, as well as how the participants manage the challenges in digital relationships and communities using different coping responses.

## 7.1. CHALLENGES IN DIGITAL RELATIONSHIPS AND COMMUNITIES

Togetherness, closeness, and intimacy are essential for the study participants, as mentioned in Chapter 5. The other important elements in a friendship are that friends bring joy, comfort, solitude, and kindness. Kindness was expressed in an incident where a participant (P8) gave a friend and fellow participant (P6) a game he knew he liked, as the quote suggests:

> P8: It is the latest version. I could not use it because I am not in PlayStation Plus, so I gave it to P6. He is very keen on Call of Duty, so I thought he could have it.

> Resource person: Then you helped a good friend.
>
> P8: Yeah, I did, so he could have it.

Trust and credibility are also essential in a friendship, according to the participants. It was expressed, for example, by being able to keep a secret or having someone whom you feel that you can approach with a problem. Two participants (P6 and P7) illustrate how you can *be there* for your friends digitally:

> P7: In this case, trust matters.
>
> P6: For example, if one of our friends is having a tough time, we are there for them.
>
> P7: And if you cannot be there personally, you can call […] because then you will be able to hear what they have to say, and you can try to solve it that way. If it is not possible for you to be there, then you have to do it that way.

These critical elements, namely, kindness, joy, comfort, solitude, trust and credibility, are not necessarily present in the communities which the participants are part of. The majority of the study participants, as well as other individuals living with cognitive disabilities, experience challenges in their digital relationships and communities. In Paper 3, we identified three main challenges in the participants' digital relationships and communities: digital harassment, digital exclusion and digital disturbance. These challenges were also identified in the systematic review to be prevalent for other individuals living with cognitive disabilities (cf. Paper 3). The digital challenges mostly occur in the periphery and in a few personal relationships. The difficulties are designated as challenges because the friendship elements described above are important for the study participants.

### 7.1.1. DIGITAL VICTIMISATION AND HARASSMENT

An emerging challenge from the systematic search conducted in Paper 3 was digital victimisation and bullying (Chiner, Gómez-Puerta, et al., 2017; Holmes and O'Loughlin, 2014; Iglesias et al., 2019; Normand and Sallafranque-St-Louis, 2016; Wells and Mitchell, 2014; Wright, 2017a). The study participants experienced this through the harsh online language and drama between the students at the youth education centre and the residence (cf. Paper 3). In particular, two female participants exhibited dramatic behaviours in both the physical and the digital spheres. An example was when P3 felt left out in a Messenger group. P5 and some other female friends had been writing together about an event where they were with their boyfriends, except for P3, who did not attend the event as she did not have a boyfriend

at the time. P3 was very upset that she was not invited and caused a violent scene in the hallway. She even wrote vanishing texts about the other girls in the Messenger chat.

### 7.1.2. DIGITAL SEPARATION

The incident cited above exemplifies challenges of both dramatic digital behaviour and digital exclusion of P3. Digital exclusion, or as Wenger et al. (2009) termed it, 'separation', entails separation from friends or other people, but also from digital platforms because of technological interactive issues, such as poor Internet connection (cf. Paper 3). Blocking and excluding others on social media platforms was a challenge identified in the systematic review (Chiner, Gómez-Puerta, et al., 2017; Iglesias et al., 2019), which one participant, P14, experienced. He was blocked from a Discord group because one of the group members reported him as being underage, which was not the case. Thus, he had to make another account on Discord.

At the residence, three of the female participants separated from one another unintentionally because of a lack of response. We learned during the workshops that P12 no longer uses Snapchat. Her friend, P10, did not know this and realised that this was the reason she did not answer when she sent a photo. P10 also forgets to answer P12 sometimes when she receives a heart from her in their shared Messenger group, as she is too busy writing to other girls at the residence. A third friend (P13) was made aware that she did not reply to Facebook friend requests sent by the two friends, P10 and P12.

#### 7.1.2.1 Normal? That's a store

As mentioned in Chapter 1, many individuals living with cognitive disabilities experience loneliness due to their communication and interaction challenges, which leaves them with a feeling of not fitting in (and being separated from the normal) in certain social arenas. The heading for this Section was a quote provided by P11. In Denmark, 'Normal' is, in fact, the name of a store. During a conversation, I asked P11 what kind of friend V was [a male student at the youth education centre]. P11 replied:

> P11: He is a bit weird and a good friend.
>
> Ditte: Is it good to be a little weird?
>
> P11: Yeah... There is nothing called normal. Many people ask me: What is normal? I would say: That's a store.

Ditte: What is weird then if there is no normal?

P11: It's us out here (at the youth education centre).

Ditte: Are you weird?

P11: Yeah. In our own way, we are all weird. We are good weird.

The quote suggests that P11 feels different compared with the others. In fact, she sees herself and the rest of the students at the youth education centre as 'weird' but in a good way.

#### 7.1.2.2 Loneliness and rejection

As discussed in Chapter 1 and Papers 2 and 3, loneliness is experienced by individuals living with cognitive disabilities and a condition experienced in particular by three of our study participants, P1, P14 and P22. When discussing the terms of a friendship, P14 states that it is not important whether the friendship has Danish, international or even online roots. He just wants to interact more with people at his institution:

Ditte: (taking an inspiration card from the pile) There is one about wanting to talk more to the ones we know, for example, on Discord, or these platforms or the phone…

P14: Yeah, I want that. I think […] it does not have to be from other countries […] because when you talk to someone from other countries that you do not see, then it is not the same because you cannot go home with them […]. The only one I talk to here (at the primary school) is A (a student). I would also like to talk to J (another student), but he does not want to talk with me […]. I don't quite know why.

Ditte: Then it doesn't matter what you talk about?

P14: No, I don't care about that.

In this example, P14 values and finds meaning in the social and physical elements of a relationship and not so much the common interest (topics examined in Chapter 5).

### 7.1.3. DIGITAL DISTURBANCE AND SELF-CONTROL

As mentioned in Paper 3, individuals living with autism and ADHD are particularly vulnerable to Internet and gaming addictions with consequential sleep deprivation and

social isolation (Becker and Lienesch, 2018; Gwynette et al., 2018). Notably, P5 and P11 shared that their phones disturb them during the night and sometimes even during the day. Indeed, I observed that P11 answered her phone during a cooking class, although they were not supposed to bring their phone to class at the youth education centre. Therefore, challenges on the participants' self-control regarding their digital artefacts were constantly encountered online as they were expected to be available at all times (Kiran et al., 2015) (cf. Paper 3).

Another incident involving the challenges regarding self-control with technological artefacts was P13, who took pictures of others at her workplace, which she was not supposed to do.

## 7.2. PERSONALISATION AND INDIVIDUALISATION

### 7.2.1. PROBLEM AND EMOTION-FOCUSED COPING

In this study, the act of developing and maintaining digital relationships and communities (togetherness) is perceived as a problem-focused coping response to digital exclusion or separation. As such, the empirical findings confirm the suggestion by Wenger et al. (2009) that separation is a prerequisite for experiencing togetherness (Wenger et al., 2009h). Therefore, it is not necessarily a negative pole if togetherness is found in some way or another, in this case, via digital relationships and communities. In the layer of togetherness and 'people and collaboration', the focus on collaboration is especially evident in a case wherein P15 turned harsh comments on his YouTube videos into constructive feedback, which he used to improve his videos. He employed a problem-focused coping response to manage the digital harassment and collaborated with other members in the peripheral community around his homemade YouTube videos to improve them (cf. Paper 3).

Other problem-solving responses made by the participants to manage digital challenges were to confront others' harsh language or behaviour (including digital separation) and block or mute them in games, for example (cf. Paper 3). Other participants used emotion-focused responses of accepting, avoiding and being cautious towards digital harassment, separation, and disturbance (cf. Paper 3). An evident emotion-focused coping response was to view the harsh online language as a shared repertoire in the peripheral community around gaming, Messenger, or other platforms. This way, the participants regulate their emotional responses towards a challenge by accepting the harsh online language and making it legitimate, as opposed to a morally unacceptable sign of selfishness and betrayal of the common bond (cf. Chapter 1), which other community members may perceive the behaviour to be. As stated by P22, people may write 'Kill yourself' (cf. Paper 3), but such is not perceived seriously because it is in writing. He would not be tolerant if people talked that way

in the physical sphere which, unfortunately, also happens from time to time. Some participants, P9, P11, P16 and P14, speak harshly themselves (cf. Paper 3), as exemplified in the following:

> P9: I do it myself (speak harshly).
>
> P16: You can say whatever you want without doing anything. The only thing that can happen is that you are blocked or something. But then you can just create a new account.
>
> P14: If it were in real life, then there would be consequences.

These participants are tolerant of this harsh tone because they speak harshly themselves. This attests to a deeply rooted language discourse or norm online, particularly in gaming communities. Harsh language use may also be age-related, as the younger participants at the primary school and the youth education centre find it more acceptable to speak harshly online than the participants at the residence do.

The following quote by P16 suggests that he feels different from other people. He formulates well the challenges faced by the study population in their social interactions and shares how he practices precaution as an emotion-focused coping response:

> I try to be perfect in conversations, like, make as few speech impediments as possible. Carefully, I try to organise conversations in such a way that they become good conversations. Right now, I am doing that thing where you end up having a fun conversation out of nothing; it is not something you can plan. […]. We are all friends here. The funny thing is that when you look, it reminds me a bit of myself, when I look at the students in class: shy, trying to stay calm, trying to stay back, trying to let the other person enter instead of them being the aggressive ones jumping in to try to make conversation. Instead, they hold back. […]. But then again, we stay back and when a person enters and tries to start a conversation with us, we jump in slowly. I am that kind of person. If I enter a new group of people, I stay calm, stay back, look at them and let them get used to the sight. You have to get used to the sight yourself, get used to it, build it up slowly. You should not aggressively try to start a conversation. It can go wrong if you fuck up the words because it is the first impression that matters for everything. A shy person, that is a person whom you want to help.

In the quote, it is evident that P16 and his fellow students and friends exert effort to fit in when they enter communities with caution. Another example of exercising precaution was when P13 chose not to bring her phone to work to manage her desire to take photos of her colleagues without permission.

For the participants, the problem- and emotion-focused coping responses are ways of managing the challenges experienced in their digital relationships and communities. They employ a strategy (a coping response) of personalising one's behaviour and orientation towards digital technology use and other people online or, as Rajapakse et al. (2018) termed it, 'personal infrastructuring' (Rajapakse et al., 2018).

The challenges and coping responses addressed in Paper 3 are illustrated in Figure 31. Chapter 2 and Paper 3 state that emotion-focused and problem-focused coping are intertwined. It depends on the cognitive reappraisal of an act or a situation whether it is labelled an emotion- or a problem-focused response. For example, blocking may be perceived as an emotion-focused coping response of avoidance, as you avoid someone by blocking them. The argument for labelling blocking as a problem-solving response in Paper 3 is that blocking someone in a game or a social media platform is, in fact, an active (and even aggressive) act and statement, as you are changing the objective situation by preventing the harasser to continue the undesirable behaviour in the particular game or social media account.

In Figure 31, we see that the participants use emotion-focused coping for all three digital challenges in their digital relationships and communities (termed digital social challenge in Figure 31 and Paper 3. While emotion-focused coping is a passive response to manage digital challenges vs. problem-focused coping as an active coping response, it is a way to shield oneself from getting hurt, which is an adequate response for many of the participants (cf. Paper 3). Therefore, the coping response may solve a problem for the participant as he/she changes the way that the challenge is appraised, but it does not change the objective situation to avoid or accept a challenge (cf. Paper 3).

**Figure 31: Digital social challenges and coping strategies**

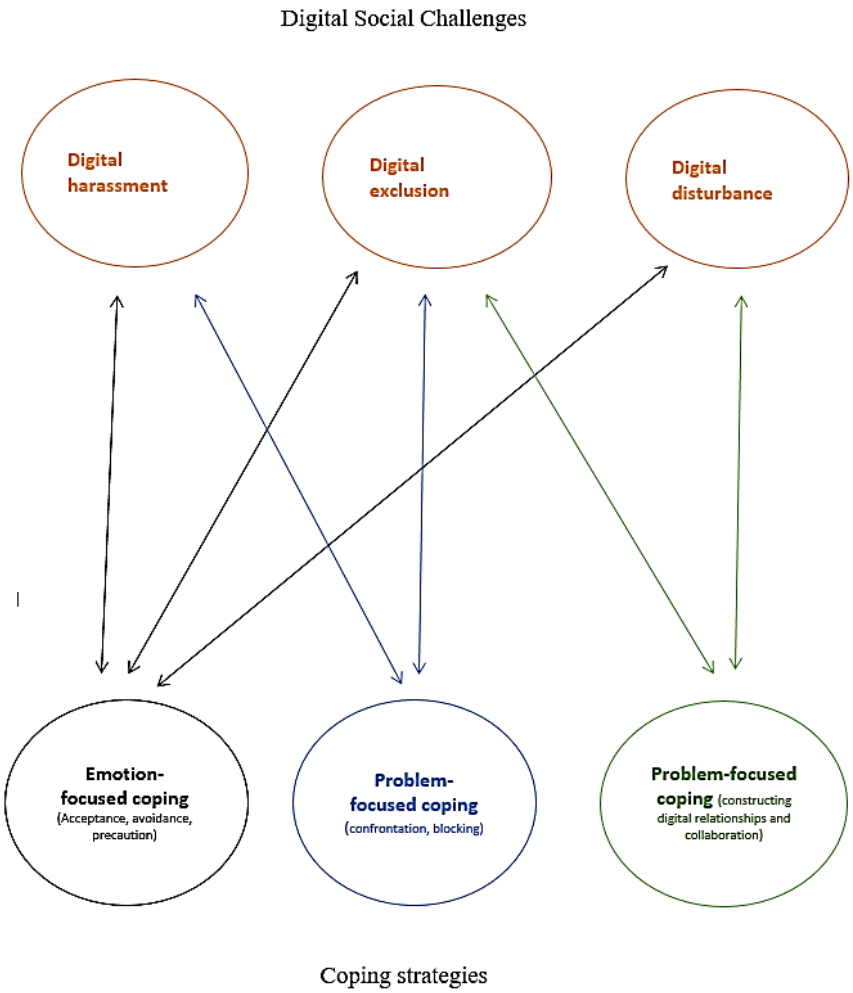



*Figure 31 illustrates the digital social challenges: harassment, exclusion (also referred to as separation), and disturbance, and the coping strategies: emotion-focused coping and problem-focused coping.*

## 7.2.2. INDIVIDUAL ORIENTATION AND NON-USE

Individualisation is, in a sense, a variant of personalisation, with a specific focus on the challenge of 'identity' (individual vs. group) formulated by Wenger et al. (2009). Here, the participants have an individual orientation as opposed to a group or

relational orientation. An example is when the participants sit with their phones while being in the presence of others (cf. Paper 3). This coping response can be both emotion- and problem-focused depending on the individual orientation towards the relational orientation; the one 'pole' is a prerequisite for the other in Wenger et al.'s (2009) argument.

There are different degrees of non-use or active resistance towards digital technology (Bødker et al., 2017) as an individual orientation and response. This is mainly because some participants disliked or stopped using certain social media and gaming platforms (cf. Paper 3). For example, P10 stopped using Snapchat and used other social media platforms to a much lesser degree after she moved to a new residence, as mentioned in Chapter 5. Another participant, P19, who was an active user of Instagram, suddenly deleted his account as he did not like it anymore. The non-use of digital technology was, in a sense, an emotion-focused coping response of avoidance, that is, avoidance of digital technology. On the other hand, P16 tried to negotiate about norms by trying to influence the other participants not to use social media (cf. Chapter 4), which is an active response towards changing others' incorrect behaviour, at least from his perspective.

Aside from these selective non-uses from four participants, there was one participant, P21, who stood out and had a distinct digital behaviour (cf. Figure 32). He had a strong and reluctant opinion against social media in general and the use of digital technology to connect with people. He formulates this in the quote below:

> I don't know. I don't have any digital communities […]. I just believe that you should be together. If you are to be social, then you should be together with them in the same room or something like that. I do not think that you should sit with your phone when you are together with someone […]. If you are going to be social, then you may as well just be social for real, not on the Internet. The Internet should be used for other things.

The 'other things' referred to by this participant include watching national TV and searching for information on the Internet. He uses Google to search for different information, especially historical. He watches videos via the national TV streaming service and YouTube. He has strong opinions about how social interaction should play out. He does not like social media and believes that it is a waste of time, which he reiterates multiple times during all conversations. As such, P21 avoids the digital challenges by steering clear of digital technology, but he also misses out on what might be meaningful digital relationships.

**Figure 32: Digital dislike and non-use**

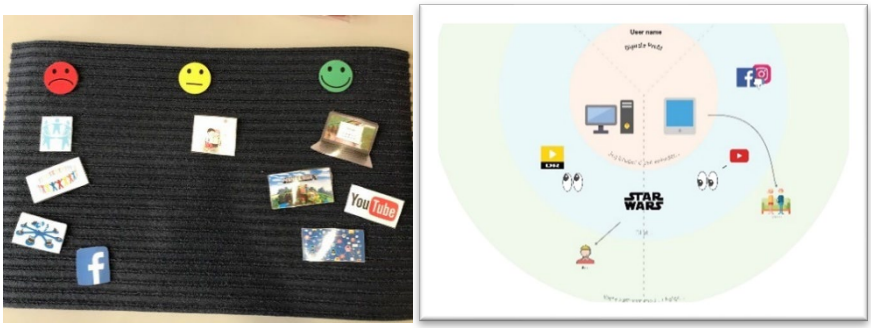



*Figure 32 displays examples of digital dislike and non-use via P21's Talking Mat and digital snapshot. These illustrates that P21's technology use differs from most of the participants technology use. Photo by Ditte Lystbæk Weber.*

P21 does not have a phone by choice (cf. Paper 3). During the workshops, P15 asked P21 if he was not old enough to have a mobile phone. P21 answered that he just did not want to have one. In this encounter, P21 was met with a lack of understanding as to why he does not have a mobile phone because it is an inherent part of his fellow student's (P15) digital life. Again, P21 became a 'deviationist' in P15's digital world.

Although some of the non-use by P21 are by choice, there are certain commonly known applications, games, and platforms that the participant does not know of, such as Messenger, Pokémon, Fortnite and Counterstrike. It is likewise implied that he has no knowledge of what Skype is (he repeats it and pronounces it in a different way). This may also be because he plays with the words and pronounces them verbatim. In this sense, the non-use may be influenced by a lack of technological understanding.

There was a consensus among some of the participants that it is better to be together physically rather than digitally. For example, one believes that it is better to talk to someone in person rather than behind a screen, or even worse, behind a profile picture. Another asserted that it would be better to game together rather than on an online platform. Thus, the participant depicted in Figure 32 was the only one who did not use digital technology for any social purpose and was against digital social relations.

## 7.3. SUMMARY

This chapter examined the functional aspect of artefact ecologies regarding the purpose of using an individual orientation towards digital technology use to manage communities and relationships. This means that we examine part of research objective 2 (how does digital technology challenge the digital relationships of this study population) and objective 3 (how do the study population manage their digital communities).

The participants use personalisation and individualisation to manage the challenges experienced in digital relationships and communities. The challenges faced by the participants are related to digital harassment, digital separation, and digital disturbance. The study participants manage these challenges experienced in their digital relationships and communities using problem-focused coping responses (togetherness and collaboration, blocking and confrontation) and emotion-focused coping responses (acceptance, avoidance, and caution), which are acts of personalisation and individualisation.

# CHAPTER 8. LEARNING POSSIBILITIES AND AIMS IN DIGITAL COMMUNITIES

*'What makes online interactions attractive and productive is the ability to learn together and experience learning friendships' ~ Wenger et al (2009)*

In this chapter, the fourth research objective is examined; What are the aims of the young individuals regarding their digital activities and communities? This means that we have examined the learning possibilities for the participants in their digital relationships and communities. The learning possibilities are connected to what the participants want to achieve in their digital relationships and communities, labelled as their 'digital aims'.

## 8.1. DIGITAL AIMS

In Paper 4, we identified three overall digital aims expressed by the participants. The participants aim to 1) develop their digital abilities further; 2) develop their digital relationships and communities further; and 3) obtain greater independence in their lives using digital technology (Weber and Kanstrup, 2021) (cf. Paper 4). The digital aims all stem from digital activities that the participants already carry out and want to expand and develop further, making the learning process particularly important to examine. Under each of the three long-term aims are diverse sub-aims, which are means to obtain the long-term aims. All of the participants' digital aims are somewhat oriented towards learning in a social context, at least regarding their long-term aims, which is addressed in Paper 4 and will be explained in the following sections.

### 8.1.1. LEARNING DIGITAL ABILITIES

#### 8.1.1.1 Producing video

A large proportion of the study participants values the use of video material. This may not seem surprising, as it was established in Chapter 3 that many individuals living with cognitive disabilities prefers visual communication channels. The surprising findings are the study participants' aim and ability to produce their own video content

and become 'digital producers' (Karadechev et al., 2021). Some examples are P10 from the sheltered residence, who expressed that she wants to improve her ability to make video diaries to share with her family (cf. Paper 4). Therefore, her sub-aim is to improve her proficiency in creating and producing videos, but her long-term aim is oriented towards learning in a social context, namely, to share knowledge about important matters in her life with family members (cf. Paper 4). Paper 4 addresses other examples of participants who use video as a tool or means to improve and utilise their abilities. P15 aims to improve his acting prowess in his YouTube videos, as he has a long-term ambition of becoming a professional voice actor. P11 also has a long-term aim to become a professional, by producing and distributing her TikTok videos. Her sub-aim is to improve her videos and attract more followers, which is a requisite for earning a profit on one's videos. P12 has a long-term ambition to become an actor and a rapper. Therefore, she records YouTube videos where she raps and dances to make her abilities known to the world (cf. Paper 1).

The participants' motivations for developing their video production abilities are different, but their aims are similar. P11 seeks acknowledgement from the peripheral participation and P10 from her intimate relations, while P15 wants to share content for others to benefit from (cf. Paper 4).

The participants' 'learning partners' (cf. Chapter 2) are the members they are inspired by and learn from in their respective communities of practice. For example, P11 learns from watching other people's videos and sometimes by making videos in collaboration with other TikTokers. P15 learns from community members' critical comments on YouTube, as discussed in Chapter 6.

#### 8.1.1.2 Learning abilities through gaming

In Paper 4, we addressed how P18 has a long-term aim to become a professional gamer and expand his social network. The two aims are again oriented towards learning in a social context. To become a professional gamer, P18 has to improve his 'game-sense' and his 'communication and strategy' abilities, which involves other members of the gaming community (learning partners):

> Again, this concerns the communication and team play you have to get a sense of before you can win. If you just play individually, then you might as well just give up.

P18 not only practices and improves his game sense with other gaming members as learning partners; he also uses a peripheral community to learn, namely, watching tutorials on YouTube (cf. Paper 4). As P18 improves, he can game with more people and expand his social network (cf. Paper 4). In this sense, he seeks to develop his social identity in the gaming community.

P9 supports P18's statement about the importance of teamwork and collaboration in the games; here, concerning Payday.

### 8.1.2. EXPANDING INTERNAL AND EXTERNAL DIGITAL RELATIONSHIPS AND COMMUNITIES

**Internally**, the participants aim to expand their current digital relationships and communities, primarily *around* digital technology. They aim to participate in and arrange movie nights, as well as LAN parties and game with friends (cf. Paper 4).

An example of an aim to expand one's communities around digital technology was expressed by P6, P7 and P8. They want to be able to play and talk with each other while on a gaming platform that is familiar to all of them while they sit in their separate rooms or are together in a room. At the moment, they can talk with each other on the gaming platforms, but they are not able to game together because they do not have access to the same gaming platforms and one of them (P6) has a poor Internet connection. Interestingly, P8 has been keen on playing Team Fortress 2 but when we talk about whether it matters what game they play together during the workshop, he (and P6) expressed that they are okay with playing all games as long as they are familiar with them. This indicates that the most crucial element is not the game itself but the company. In addition, P8 gamed more by himself before he came to live at the sheltered residence. Now, he participates more in physical activities and wants to game with his friends there.

P8 and P10 from the sheltered residence also expressed an aim to expand their personal digital relationships by calling their friends and families more often. P25 wants to play with others in a more indirect way by sharing lives in Candy Crush or the game she plays currently (Bubble Shoot Pet). This was a digital activity carried out by the other participants (P10, P12 and P13).

**Externally**, the participants aim to find a boyfriend or girlfriend via Facebook, follow and like more or new Instagrammers and YouTubers, share more digital content, participate in international communities and game online with people from other countries. P9 shared that he experienced a dynamic increase in new international friendships:

> Ditte: So, you already have friends from other countries?
>
> P9: Mmmh.
>
> Ditte: Would you like to have more friends from other countries?
>
> P9: Well, I get that all the time.

Although participation and not so much learning is mentioned explicitly in these aims to expand internal and external digital relationships and communities, these open up learning possibilities in a social context: to learn new skills *with* others, as well as *social norms, values and abilities*, by participating in communities of practice.

#### 8.1.2.1 Learning proper digital behaviour

The examples from Chapter 7 (Section 7.2.1) wherein the participants learn to cope with digital harassment by accepting harsh online language may also be interpreted as a learning scenario, as they learn to act and navigate the digital norms surrounding the language discourse online. Other participants are critical of this online language discourse and do not wish to be subjected to harsh online language. P5 wanted more control on Facebook regarding friend requests and anonymised calls. Interestingly, she has a non-digital aim to become a police officer. P1, P6 and P7 wanted to eliminate hackers in games. Other participants wanted to change online language use. For example, when conversing about harsh and inappropriate language online, P24 states:

> You should, you have to speak properly to each other [but] it is not always easy to take control.

P1, P6 and P7 agreed to this point during their conversations.

In the case of the proper digital behaviour, some of the study participants (want to) become learning partners in these peripheral communities or gaming communities. They want others to behave properly (or improperly) as they do themselves. Although their views on digital behaviour differ, they all have a stand, which offers excellent insights into their inner motivations and values.

### 8.1.3. INDEPENDENCE IN ACTIVE PARTICIPATION

Watching tutorials on YouTube or other people's TikTok videos or using Google to search for information can be interpreted as passive forms of participation in digital communities, where participants are 'lurking' (Wenger et al. 2009). Wenger et al. (2009) cite an example of active participation, such as 'posting regularly' (Wenger et al., 2009d), which is a digital activity carried out by most participants regularly. As tackled in Paper 4, the participants share information, opinions, pictures and homemade videos online (cf. Figure 33), they produce their own video material, they create their own games in Roblox Studio (cf. Chapter 5), they game with others, etc. All of these are active forms of digital participation. Not many are simply passive

'lurkers' (described by Wenger et al. as reading online). They participate passively from time to time and actively at other times; they move in and out of communities of practice and participate in different ways. Most importantly, they use passive lurking to acquire abilities to be able to participate actively in communities by producing their own digital content (cf. Paper 4) or participating in digital communities, which we see as independent digital behaviour. Studies support that access to information (particularly YouTube videos and Google searches) is central to empowering people to make independent decisions and achieve long-term aims (Sitbon et al., 2018). As suggested by Jung et al. (2008), 'Digital artefacts can empower users to freely control digital content by accessing, creating and editing them' (Jung et al., 2008, pp 206). In this sense, control is an important element for the participants' independence in their digital life.

The statements from P11, P15 and P18 about wanting to be professional in their respective field of interest are examples of the participants being quite ambitious. The digital sphere opens possibilities of expanding their abilities and independence.

**Figure 33: Productive and active digital participation**

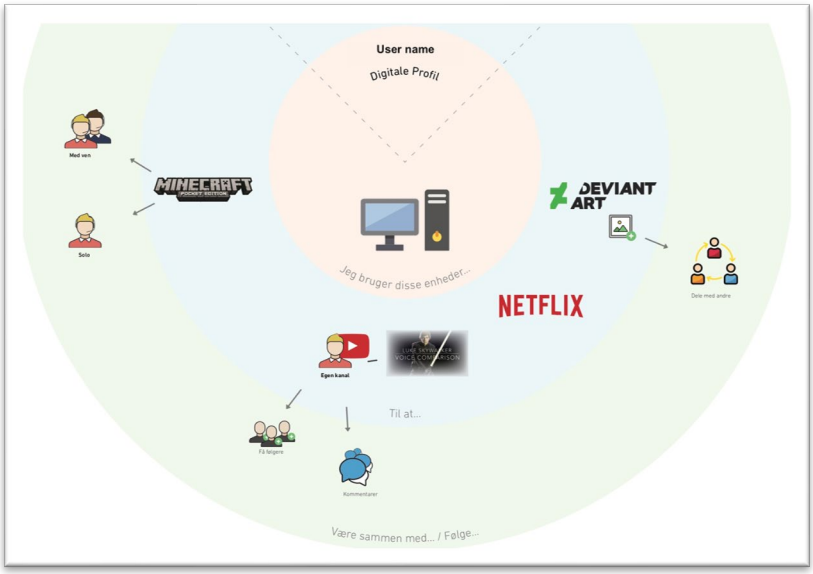



*Figure 33 displays an example of an active and productive digital participation in peripheral digital communities. P15 produces his own voice comparisons (comparing voices used by different actors for the same character in a movie). He also creates his own figures for some of his videos, using the program called Deviant Art.*

## 8.2. SUMMARY

This chapter examined research objective 4: What are the aims of the young individuals regarding their digital activities and communities? The chapter addressed how the participants aim for learning possibilities in a social context by developing their abilities to participate actively and independently in digital relationships and communities. They do this by producing digital content (particularly video material) and enhancing their gaming and social abilities to interact properly with peers and other important community members. In addition, we argue that the participants are ambitious and want to develop their abilities and learning possibilities in a social context and that their passive participation is a way to *learn* how to be able to participate actively.

# CHAPTER 9. DISCUSSION AND IMPLICATIONS

*'To **dis** is to trouble' (Goodley 2016)*

The aim of this PhD study was to understand and map how young individuals living with cognitive disabilities use digital technology to form and maintain relationships and communities. Specifically, the objectives were to examine 1) What characterises the digital technology use, activities and value of young individuals living with cognitive disabilities? 2) How does digital technology form and challenge the digital relationships of this study population? 3) How do the study population manage their digital communities? and 4) What are the aims of the young individuals regarding their digital activities and communities? Methodologically, a fifth objective was to examine how to include the study population in researching their rich digital activities and communities.

We determine what characterises the digital relationships and communities and the technologies and strategies used to participate in and manage these digital relationships and communities, as well as identify the digital learning possibilities regarding the digital aims of the study population. Understanding the complexity of the social arena of digital technology, participants' digital participation, behaviour, use, challenges, abilities, coping strategies and aims, as well as the possibilities for including them in researching their digital activities, was an essential prerequisite and contribution for future experiments with the study participants and to develop and implement digital interventions and initiatives for them in their institutional practice. The original contributions are mainly connected to the empirical knowledge concerning digital coping strategies and digital aims of the study participants (cf. Section 2.1). Methodological, our contribution is the VTAs to include the study population in research about their digital activities and communities (cf. Section 2.1).

The following sections elaborate on the core empirical and methodological findings in relation to existing knowledge elaborated in Section 1.3 (related work), concerning the complex mapping of digital communities, abilities and aims, support vs. protection, perspectives on digital divide. The sections further elaborate methodological contributions, specific recommendations for practitioners and researchers, and study limitations.

## 9.1. A COMPLEX MAPPING OF DIGITAL COMMUNITIES, ABILITIES AND AIMS

To our knowledge, a combination of the artefact ecology framework and the communities of practice framework has not been used in disability studies. Therefore, the analysis of the empirical data makes a theoretical explication as a contribution to the field of disability studies, but also PD and HIT, as summarised in the following.

From the empirical findings in Chapters 5, 6, 7 and 8, we learned that the physical (digital devices), informational (applications), interactive (ease of use of the digital technology) and functional (internal, external, and personalised digital communities) aspects all create a complex and comprehensive composition of an artefact ecology and community of practice framework. The layers of the framework for this study are illustrated using the template for the digital snapshots in Figure 34 (layers and properties of artefact ecology). Figure 35 illustrate the complex and comprehensive composition of the artefact ecology and community of practice framework. In Figure 35, we see that the artefacts are interconnected, allowing the study participants to create and manage a network (community) of digital artefacts. The artefacts may be connected via informational aspects (using the same application or platform in our case) or function (purpose of digital use). The artefacts are used for different purposes and with different people, but a common denominator for all digital relationships and communities is a purpose of commitment to create or maintain relationships with other people, collaborate in their digital communities, and participate in different ways. The digital snapshot in Figure 34 illustrates the digital use of a participant, and therefore, the composition of artefact ecology in Figure 35 illustrates how digital technology connects the *people* (relationships and communities) as well as the digital artefacts. Some individuals participate in internal digital relationships and communities of practice to maintain personal relationships in contextual layers via and around digital technology (movies, gaming, Makerspace, and the phone). Others participate in external digital relationships and communities to develop relationships and communities with individuals from contextual layers beyond their institutional sphere, in the periphery or in contexts of international (but close) gaming platforms. The participants find these communities of practice meaningful as they foster togetherness, intimacy, fun, peer learning, joint enterprise, and recognition.

The participants join different communities of practice and use a multitude of technologies to develop and maintain meaningful digital relationships and communities. They negotiate which technologies are the core artefacts, but for all participants, digital technologies are greatly valued and meaningful in their lives. Their use, relationships and aims are dynamic (change over time), but this does not alter the artefact ecology framework illustrated in Figure 35, as all elements are

changeable. Digital technology use may change but not patterns of digital use and behaviour.

Most of the participants find it necessary to personalise and individualise their participation in digital relationships and communities due to the inherent challenges in the digital relationships and communities (digital harassment, digital separation, and digital disturbance). As such, personalisation and individualisation are both means of purpose and value in the artefact ecology layers and properties illustrated in Figure 35. The study participants manage the challenges experienced in their digital relationships and communities using problem-focused coping responses (togetherness and collaboration, blocking and confrontation) and emotion-focused coping responses (acceptance, avoidance, and caution).

The layers in Figure 34 grow bigger in parallel to their importance in answering the study aims and objectives. An additional layer in the artefact ecology was added in this study to illustrate the learning element in digital relationships and communities (cf. Figure 34). This element is an important layer (or property) as the participants formulate aims for learning in a social context and practice by developing their abilities to participate actively and independently in digital relationships and communities by producing digital content (specifically video material) and enhancing their gaming and social skills to interact properly with their peers and other important community members. This additional layer and the whole illustration in Figure 34 are similar to Vygotsky's zone of proximal development although turned around with what the participants can (learn) to do in the outer circle (Porter, 2011; Rieber and Carton, 1993). This comparison does not have any theoretical meaning for interpreting the layers and properties of artefacts in Figure 34, but it is a tribute to the Vygotskyan approach to development and the study population.

**Figure 34: Layers and properties of artefact**

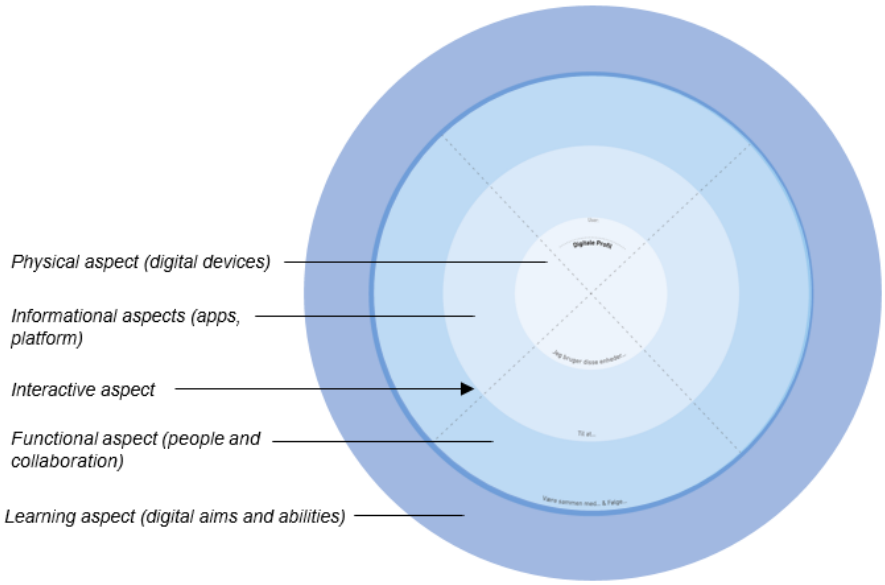



*Figure 34 portraits the layers and properties of artefacts from the empirical study findings, illustrated via an empty digital snapshot.*

**Figure 35: Composition of artefact ecology and community of practice**

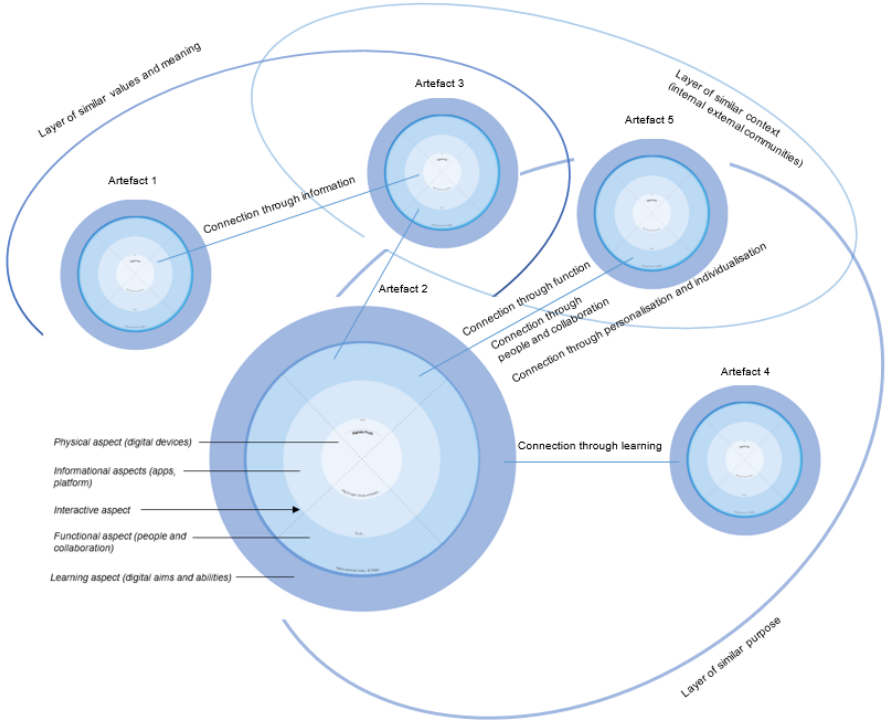



*Figure 35 portraits the complex composition of artefact ecology and community of practice in the study. The figure was re-made from Jung et al.'s (2008) artefact ecology composition, to illustrate the interaction between the properties, values and layers in the artefact ecologies and communities of practice framework in this study.*

From the related work (Section 1.3), existing research has contributed knowledge to understanding this complex social arena of digital technology. Mainly about the rights of individuals living with disabilities to participate in the digital arena (Ågren Alfredsson et al., 2020a; United Nations Human Rights, 2006), and how individuals living with cognitive disabilities use digital technology to develop and maintain social and romantic relationships and develop a social identity (Alcorn et al., 2011; Alper, 2014, 2017; Bayor, Bircanin, et al., 2019; Caton and Chapman, 2016; Darragh et al., 2017; Hjelholdt and Rasmussen, 2017; Löfgren-Mårtenson, 2008; Löfgren-Mårtenson et al., 2015; Näslund and Gardelli, 2013; Pinchevski and Peters, 2016; Ringland et al., 2016; Seymour and Lupton, 2004; Shpigelman and Gill, 2014; Söderström, 2009, 2011). Our findings complement and advance this knowledge with an understanding of the complex composition of layers, properties, values and

functions of the social relationships and communities of practice of a cohort of young individuals living with cognitive disabilities. This complex community perspective and understanding is one of our main contributions to the research field. Some of our findings not only advance but also contradict the view of the participants' digital relationships and communities in the related work. The comprehensive and complex participation in multiple digital relationships and communities, particularly the external relationships and communities identified in the PhD thesis, contradicts studies suggesting that digital technology mostly serves to support the maintenance of existing relationships and seldom develops new relationships with individuals outside of their institutional sphere (Bayor, Bircanin, et al., 2019; Burke et al., 2010; Hjelholdt and Rasmussen, 2017; Löfgren-Mårtenson, 2008; Seale, 2007), as well as literature suggesting that the study population engages with a small number of people online (White and Forrester-Jones, 2020). The participants in our study engaged in multiple internal and external digital relationships and communities using various digital technology to engage with many different people, despite their inherent communication challenges in the physical and digital arena.

Our empirical findings complement related work on digital challenges for youth living with cognitive disabilities regarding usability and accessibility (Ågren Alfredsson et al., 2020b; Bayor, Bircanin, et al., 2019; Chadwick et al., 2013; Feng et al., 2010; Rajapakse et al., 2018; Shpigelman and Gill, 2014), including literacy issues (Ågren Alfredsson et al., 2020b; Bayor, Bircanin, et al., 2019; Louw et al., 2019; McClimens and Gorden, 2008; Newman et al., 2017), victimisation (Chiner, Gómez-Puerta, et al., 2017; Holmes and O'Loughlin, 2014; Iglesias et al., 2019; Normand and Sallafranque-St-Louis, 2016; Wells and Mitchell, 2014; Wright, 2017a) and discrimination (Chiner, Gómez-Puerta, et al., 2017; Iglesias et al., 2019), including experiencing loneliness (McVilly and et al, 2005), as well as overstimulation and addiction (Becker and Lienesch, 2018; Gwynette et al., 2018). Other researchers have extensively explored digital challenges and our study contributes with a core focus on the challenges related to participating in digital relationships and communities: digital victimisation and harassment, digital separation, including loneliness, and digital disturbance and self-control, cf. Paper 3 and Section 7.1. Most importantly, our study contributes knowledge on how the study population is able to manage the digital challenges, which is elaborated in the following section.

### 9.1.1. TO DIS IS TO TROUBLE

The quote 'To dis is to trouble' by Goodley (2016) is essential in explaining how individuals living with cognitive disabilities are and have been dehumanised in many ways throughout history (Goodley and Runswick-Cole, 2016). The act of removing the 'dis' in disability either by using colouring (disability) or playing with words and concepts has been done extensively and with good reason, as it is an effective way to

underscore an important point. This study argues that it is imperative and relevant to consider removing the 'dis' when it comes to the digital sphere for our study participants, whether this concerns relationships and communities via or around digital technology. The empirical findings of this study emphasise that individuals living with cognitive disabilities do not necessarily have digital disabilities. The 'dis' in the participants' disabilities is not prevalent in their digital use and behaviour. Therefore, the definition of cognitive disability presented in Section 1.2.1 may not be applicable when addressing the digital sphere. 'Normal' is interpretable in this regard. For example, I did not merely take on a trainee role to enter the participants' digital world and let them be the experts; many times, I simply had to take on a trainee role because I was inexperienced with the digital platform, game or programme being discussed. Thus, I was 'digitally disabled' in certain domains of the digital sphere.

Subsequently, in addition to contributing a comprehensive and complex mapping of digital relationships and communities among youth living with cognitive disabilities, our study findings advance the argument made by other researchers that the participants are, and should be viewed and studied as, active, independent, and capable users of digital technology (Alper, 2017; Chadwick et al., 2013; Duplaga, 2017; Hjelholdt and Rasmussen, 2017; Karadechev et al., 2021; Löfgren-Mårtenson, 2008; Näslund and Gardelli, 2013; Ringland et al., 2016; Sallafranque-St-Louis and Normand, 2017).

Table 6 illustrates and summarises the participants' digital activities. These are perceived as digital abilities in this study in accordance with Bayor et al.'s (2019) 'competence-based framework' for this study population (Bayor, 2019; Bayor, Bircanin, et al., 2019). As such, Table 6 is meant to stress the point above about the participants being 'digitally abled' and not disabled. For example, we see that participants use social media or other digital platforms to communicate opinions, share digital content, and gain a stronger voice this way, as other studies suggest (Alper, 2017; Hjelholdt and Rasmussen, 2017). They also develop their digital abilities (e.g., by gaming) and produce their own digital content (e.g., YouTube videos), as suggested in other studies (Alper, 2017; Duplaga, 2017; Hjelholdt and Rasmussen, 2017; Näslund and Gardelli, 2013; Ringland et al., 2016; Sallafranque-St-Louis and Normand, 2017). These actions and activities stress the active behaviour of youth living with cognitive disabilities.

**Table 6: Competence-based framework**

| Digital categories | Applications | Digital purpose and activities |
|---|---|---|
| On- and offline games | Saints Row, Minecraft, Sandbox, Counterstrike, Call of Duty, FIFA, Football Manager, Destiny, Fortnite, Overwatch, World of Warcraft, Grand Theft Auto, Diablo, Roblox, Team Fortress 2, Star Wars, Shadow of Mordor, Hollow Knight, War Thunder, Rocket League, USO, Blooms Bt6, Piano Tiles, UNO, Stick muster Design, Pokémon Go, Candy Crush, Heyday, Bubble Shoot Pet | • Learn about strategy and communication (Game sense)<br>• Make own games<br>• 'game' with others, incl. international gamers<br>• Help friends complete games<br>• Address bad behaviour in games |
| Social media | Facebook, Instagram, Twitter, blogs, YouTube, TikTok | • Share posts (own and others)<br>• Follow friends and celebrities<br>• Video production<br>• Picture production<br>• Information search (incl. browsing google)<br>• Share videos (own and others)<br>• Share pictures (own and others)<br>• Write posts and comment on others posts<br>• Use tutorials to learn competences<br>• Recognise others via 'Likes' and comments |

| | | |
|---|---|---|
| Communication technology | Messenger, Facetime, Skype, Discord, PlayStation Party, SMS, Viber, Snapchat | • Send picture and emojis<br>• Develop new friendships via. Communication technology<br>• Write messages and chat with friends, family, and boy/girlfriends<br>• Maintain friendships via. Communication technology<br>• Call family, friends, and boy/girlfriends |
| Tv- and music channels | Spotify, Netflix, Viaplay, TV2, DR, You See | • Host movie nights with others |
| Developmental programs | Deviant Art, GitHub, Medusa, Sleros | • Programming |

*Table 6 display the digital use and related activities (abilities) for the study participants, which we term a Competence-based framework (Bayor, 2019; Bayor, Bircanin, et al., 2019).*

Bringing to the fore the perspective of individuals living with cognitive disabilities as digitally capable, our findings complement research focusing on digital challenges in disability studies (Ågren Alfredsson et al., 2020b; Chadwick et al., 2013; Chiner, Gómez-Puerta, et al., 2017; Holmes and O'Loughlin, 2014; Louw et al., 2019; Normand and Sallafranque-St-Louis, 2016; Wells and Mitchell, 2014; Wright, 2017a) with understanding and acknowledging how the study participants can manage the challenges experienced in their digital relationships and communities. Few studies have focused on managing the digital sphere and challenges (Ågren Alfredsson et al., 2020b; Borgström, 2021; Seale et al., 2013; Seale, 2007; Wright, 2017a). Wright (2017) proposes parental mediated technology (Wright, 2017b) to manage the digital sphere and challenges, while Seale (2007; 2013) addresses positive risk-taking to manage risks in the digital sphere (Seale et al., 2013). These two concepts will be elaborated on in Section 9.1.2. Alfredsson Ågren (2020) identifies word- picture-, and voice-based strategies to handle accessibility issues regarding the digital sphere, for example, using apps to enter a platform (picture-based strategy), notes for codes which are easily forgotten (word-based strategy) and voice controls such as Siri (voice-based strategy), as well as reduce numbers of devices and personalise them (Ågren Alfredsson et al., 2020b). Our study participants also use the picture- and voice-based strategies to manage accessibility issues, but more importantly, they cope with digital interpersonal relationships. This understanding of how the study participants use both emotion-focused coping responses and active problem-focused

coping responses is a main original contribution from the PhD thesis, which may result in long-term solutions to the digital challenges they encounter (cf. Paper 3). Simultaneously to our study on coping strategies, Borgström (2021) has conducted research with youth living with cognitive disabilities on negative online experiences, coping and support (Borgström, 2021). Borgström (2021) found that young individuals living with cognitive disabilities learn from own mistakes and from others' negative online experiences, termed 'a lesson to be learned'. The important role of siblings are addressed as well as the dilemma of support and negotiation of control (Borgström, 2021). While Borgström (2021) and our research uses the same concepts (emotion-focused and problem-focused coping, parental mediation, and positive risk-taking) to discuss the study populations coping responses to digital challenges (cf. Paper 3), our empirical findings differ. Our study findings show that young individuals living with cognitive disabilities are able to manage digital challenges without support from family or resource persons, as their social support system is found in the digital arena, rather than in the physical arena (cf. Paper 3). As such, our study participants do not need a lifeline to the extent suggested in other studies (Borgström, 2021; Söderström, 2011). Borgström (2021), on the other hand, finds that support from family, particularly siblings, is essential to managing negative online experiences (Borgström, 2021). In addition, there were no indication of participants using emotion-focused responses in Borgströms' (2021) study (Borgström, 2021), which was a main finding and contribution in our study. While Borgström (2021) cite 'Managing and addressing a problem by oneself may be understood as problem-focused coping' (Borgström, 2021, pp 15), our study compliments this finding with an extensive analysis and discussion of participants' emotion- and problem-focused responses to digital social challenges (cf. Paper 3). For example, our study distinguishes between *active* problem-focused responses (confrontation, blocking, constructing digital relationships and cooperation) and *passive* emotion-focused responses (acceptance, avoidance, and caution) and discuss how these responses foster self-protection and long-term management of digital social challenges (cf. Paper 3). A way to cope with digital harassment, which fostered self-protection, was to believe in own digital abilities, as done by P11. This way, the social arena of digital technology helps the participants to develop confidence, as Alper (2014) suggests (Alper, 2014).

Borgström's (2021) theme of 'a lesson to be learned' is interesting for long-term solutions to digital challenges, as coping is defined as a process by Lazarus and Folkman (Lazarus and Folkman, 1998d) and therefore, accumulated experience can be seen as a problem-solving resource, which can facilitate proactive responses to challenges. If a previously used coping strategy is applied to a similar challenge this can create a positive reinforcing coping circle if the strategy is successful, thereby facilitating the development of long-term coping responses.

The above studies have identified the active and ambitious digital activities of youth living with cognitive disabilities. In addition to the original contribution of coping

strategies, our study brings attention to explicitly formulated aims about their digital activities, abilities and communities (cf. chapter 8 and paper 4), which is an original empirical contribution to the research fields. The explicit formulating of research aims makes the learning possibilities more tangible for the study population and illustrates extraordinary abilities among them. Anchoring this digital understanding to the Vygotskyan perspective (cf. Section 4.1) is important for supporting individuals living with cognitive disabilities in carrying out their expressed future digital abilities and aims about being active participants and digital producers.

### 9.1.2. SUPPORT VS. PROTECTION

The capability perspective and argument in Subsection 9.1.1 that the study participants are not digitally disabled does not mean that the participants' disabilities should be disregarded; it is meant to stress that they are, in fact, able and capable digitally. For example, the resource persons at the institutions stated that they believe the study participants bring their disabilities into the digital sphere, which is a critical point to consider in trying to support the participants' digital lives.

As mentioned in Paper 4, it can be challenging for resource persons, as well as parents, to balance the need to shield the young individuals living with cognitive disabilities and to support them in their digital abilities, aims and independence. Nevertheless, the argument provided in Paper 4 is that it is important to foster a meaningful and independent life for individuals living with cognitive disabilities instead of treating them from a paternalistic point of view (Weber and Kanstrup, 2021). In Paper 3, the concept of 'positive risk-taking' is used and explored to address the risk management that study participants undertake when they participate in digital relationships and communities. The concept recognises individuals living with cognitive disabilities as independent individuals who can weigh benefits against potential harm when using digital technology to participate in relationships and communities (Holmes and O'Loughlin, 2014; Seale, 2014, 2007; Seale et al., 2013). This concept argues for a supportive approach towards individuals living with cognitive disabilities, recognising their independence. There are examples in the literature of parents who see the risk of their children experiencing loneliness as a more severe risk than for them to experience online abuse (Löfgren-Mårtenson et al., 2015). Therefore, they see potential in advancing their digital participation.

As mentioned, studies highlight the importance of support in accessing and managing the digital sphere from parents or siblings (Ågren Alfredsson et al., 2020b; Borgström, 2021). Another supportive, as opposed to protective, initiative addressed in Paper 3 and the literature is 'parental mediation technology'. Here, parents set the rules and guidelines for Internet use while maintaining an open dialogue with their children about such matters (Reilly et al., 2016; Wright, 2017a, 2017b), providing them with

at least some independence over their digital lives. In addition, there is potential for mutual learning when using this approach: the children can learn from their parents, and the parents can learn from what their children share about their digital lives.

This element of learning is crucial in the digital lives of young individuals living with cognitive disabilities. Family and institutional staff (resource persons) mentioned that they have not received any formal training in managing risks and promoting the safe inclusion of individuals living with cognitive disabilities in the digital arena and that they wish for such training to be designed and implemented (Chiner, Gómez-puerta, et al., 2017). Supporting this claim, a resource person at the shelter informed us that online conflicts, such as online safety issues regarding purchases and intrigues among female residence, are difficult to manage because there are no guidelines for solving such problems. Currently, resource persons handle such issues by intuition, which is not necessarily a long-term solution in their opinion.

In our research, we aim to dispense with the view of individuals living with cognitive disabilities as passive users in need of protection (Balasuriya et al., 2018; Boyd et al., 2015; Davies et al., 2015; Sonne et al., 2016; Washington, 2016). Alternatively, we argue that the individuals are in need of support in their digital abilities and aims rather than protection from the digital arena.

#### 9.1.2.1 Teaching material

Different training initiatives have been formulated to learn about the online behaviour of individuals living with cognitive disabilities, for example, web- and video-based ‘sharing communities’ (Bircanin and Brereton, 2016). In particular, YouTube has been beneficial in supporting the sharing of digital content and skill development of individuals living with cognitive disabilities. The study population can upload individualised content on YouTube for self-learning and for teaching others about their digital behaviours (Bayor, 2019; Bayor, Bircanin, et al., 2019). Our findings support these perspectives because our study participants use YouTube, specifically YouTube tutorials, for self-learning. Therefore, a suggestion for future initiatives has been made, namely, for the study participants to make their own tutorials about their digital competencies, for example, on how to manage online risks and challenges and promote safe inclusion online, by using the presented coping strategies in Paper 3 to inspire and teach their peers and resource persons. These coping strategies could be developed and adjusted to the practice that they will be used in.

In addition, teaching materials have been developed recently for digital behaviour, specifically for institutions for youth living with special needs in Denmark, which has earlier been addressed as a deficiency by both researchers (Bundsgaard, 2014, 2017; Søndergaard, 2013) and practitioners (resource persons) in the DiGi project. The

teaching material is developed by Sammenslutning af Unge Med Handicap (SUMH) and is called 'OSonline' (SUMH, 2021). This is an important development both in terms of providing equal access to information about digital well-being and behaviour and as a supportive tool for practitioners. Previously, practitioners had to use and customise the teaching materials and practical experiences about digital behaviour available for the general youth population in Denmark, which may not be sufficient for the study population.

**Figure 36: OS Online**

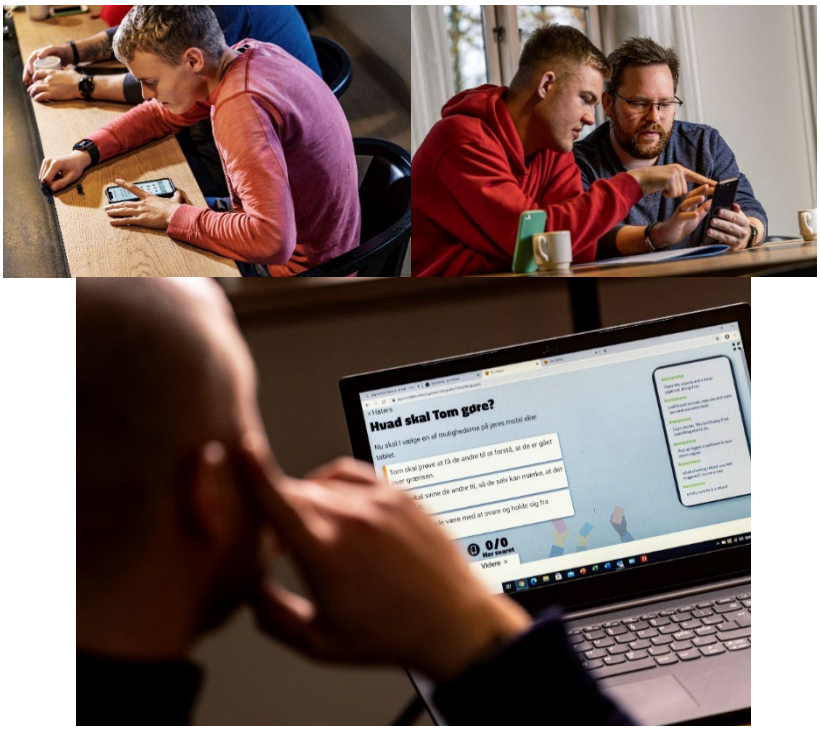



*Figure 36 shows photos of individuals living with cognitive disabilities who use the OS Online learning universe. Photos by Annette Haugaard from Sammenslutning af Unge Med Handicap (SUMH), Copenhagen, Denmark*

In conclusion, there are possibilities for resource persons to learn about the online behaviours of youth living with cognitive disabilities, ranging from formal teaching materials to learning from the study population themselves when they share their experiences via YouTube tutorials.

### 9.1.3. A DIGITAL DIVIDE? COMPARING THE DIGITAL USE OF INDIVIDUALS LIVING WITH AND WITHOUT COGNITIVE DISABILITIES

While the literature emphasises the existence of a digital divide among youth living with cognitive disabilities and their non-disabled peers (Ågren Alfredsson et al., 2020a; Chadwick et al., 2013; Dobransky and Hargittai, 2016; Duplaga, 2017; Lussier-Desrochers et al., 2017), our findings suggest otherwise, at least in a Danish context. Comparing our empirical findings with the work carried out by Johansen and Larsen (2019) on young people's media use, it was found that the technological use and its functions were highly similar between young individuals living with cognitive disabilities and their non-disabled peers in Denmark. The comparable tendency found by Johansen and Larsen (2019) was that youth living in Denmark use a multitude of digital technologies. In fact, youth in Denmark are among the ones with the highest technology use in Europe, according to Johansen and Larsen (2019), and their use changes rapidly (i.e., is dynamic). They use smartphones, tablets, online games, social media platforms and mobile applications for gaming, intimacy, friendship, sharing pictures, following YouTubers, and developing their identities (Johansen and Larsen, 2019). Comparable to our study participants, the non-disabled youth form social identities via media ('open-source networked identity') (Johansen and Larsen, 2019). In our study, digital relationships and communities are classified as individual or personal relations, interest-based groups, and national and global networks (cf. Papers 1 and 2), whereas Johansen and Larsen (2019) classify relations as 'strong ties' (intimate relations), 'weak ties' (sporadic interaction) and 'latent ties' (possibility for developing relations) (Johansen and Larsen, 2019). The classifications differ, but the characteristics are similar. Youth in Denmark create 'fan communities' around YouTubers (or 'micro celebrities'), characterised as 'followers and following' in the peripheral digital relationships and communities in our study. Comparable to our study participants, the non-disabled peers use 'likes' as a form of interaction and find it easy and fast to recognise others via likes. Thus, it is more important *who* likes your digital content than how many (Johansen and Larsen, 2019), which is the opposite for the participants who mentioned this matter in our study.

The non-disabled peers use Snapchat as a fun and creative medium to facilitate intimacy between friends, as do our study participants. These playful actions are also found in games, such as Star Wars, and are perceived to be important for development (Johansen and Larsen, 2019). The content of digital activities is not as important as the company which, in some cases, differs from our study but is nevertheless similar to some. The non-disabled peers stick to their 'own kind' and spend more time with people they know, which is also the case for some of our participants but different for others.

The non-disabled peers experience similar challenges online, for example, a constant pressure to be available. They regarded keeping a streak function as stressful, which is the same dilemma that our study participants have (cf. Paper 3). Other similar concerns are the sharing of one's location via an application, such as Snap Map, where our participants mentioned Senley. Cyberbullying was also a concern for the non-disabled peers, and people who are lonely seeking digital communities (Johansen and Larsen, 2019). As is the case for our study participants, the technological sphere is not a replacement for physical friendships for youth living without disabilities but should be seen as a supplement (Johansen and Larsen, 2019).

The non-disabled peers find inspiration from YouTube (which is a highly valued media platform) and produce their own YouTube videos, although they do not necessarily see themselves as producers. They want to share topics about their lives online even though it does not concern many people (Johansen and Larsen, 2019), which is also the case for our study participants, who actively produce and share digital content, but some find it important that the digital content reach a broad audience.

Other comparable tendencies are related to learning, namely, the number of males who game improve their language skills to a higher degree than males who do not game (Johansen and Larsen, 2019). The point about the study participants improving their language skills through gaming is addressed in Paper 3.

In conclusion, similarities regarding multiple and dynamic usages, digital relationships, celebrity culture, production, information search, social identities, entertainment, digital challenges, and learning were found between youth with and without cognitive disabilities. While this was not a formal comparative study, comparable points addressed in the literature and in our study were found. This comparison was meant to underscore that the participants are not digitally disabled and have the same digital use and behaviour as the general youth; they are all digital natives (Johansen and Larsen, 2019). The comparison also supports a view away from seeing the study population needing assistive technologies (Frauenberger, 2015) (Balasuriya et al., 2018; Boyd et al., 2015; Davies et al., 2015; Sonne et al., 2016; Washington, 2016). The study population wish to be online and use available digital technology, just like everyone else (Chadwick et al., 2013; Hjelholdt and Rasmussen, 2017; Löfgren-Mårtenson, 2008). This perspective does not mean that the addressed need for specialised teaching materials is not necessary but that this should be planned and considered according to knowledge about the study participants' comprehensive and complex digital use and behaviour, similar to the general youth in Denmark, in addition to their individual vulnerabilities.

## 9.2. METHODOLOGICAL CONTRIBUTIONS

The VTAs developed and used to support the inclusion of young individuals living with cognitive disabilities in this study constitute a major methodological contribution to the research and practical field. The VTAs opened up the possibility of discussing matters with the participants that would not have been possible to access otherwise (cf. Paper 5) to map and explain how young individuals living with cognitive disabilities use digital technology to maintain and develop relationships and communities. They help answer objective 5 of how to include the study population in research about their digital activities and communities, and as such, they contribute to an enhanced model of inclusive research, cf. Paper 5. They expand upon the already used and established VTAs in the research field (Baykal et al., 2020; Bødker et al., 2017; Brandt et al., 2012; Gaver et al., 1999; Harper and Harper, 2002; Jung et al., 2008; Murphy and Cameron, 2008; Shinohara and Tenenberg, 2007), as they make it possible to research a complex and abstract phenomenon of digital activities and communities. Talking Mats have been used to research television viewing (Bunning et al., 2016), but not digital activities in a broader social context. In addition, the VTAs make it possible to include the study population directly instead of by proxy (Benton and Johnson, 2015; Brereton et al., 2015; Druin, 2002; Foss and et al, 2013; Frauenberger et al., 2011; Seale and Chadwick, 2017) and to amplify their voice in research (Nind and Vinha, 2014).

In particular, the Talking Mats have been used in specialised fields by the collaborating institutions in this study and by various entities in other parts of the world (Stans et al., 2019). In addition, the VTAs were also found interesting by practice actors from different municipalities in Denmark working within the disability field (institutional staff and teachers, counsellors and disability organisations). I was invited to present the VTAs at two conferences held by the Danish disability organisation Foreningsfællesskabet Ligeværd, where I received positive feedback on using the VTAs to communicate with individuals living with special needs from practice actors working within the disability field. At one of the conferences, I hosted a workshop where I first presented the VTAs and explained their use. Afterwards, I showed the practice actors the empty digital snapshots, which I had uploaded in the CanVis application (cf. Paper 5). The CanVis application was introduced to me by other researchers working with inclusive technologies for individuals living with cognitive disabilities to expand upon the use and inclusive development of the digital snapshots by the study population. At the workshop, the practice actors had the template of the digital snapshots in front of them in the CanVis application, where they could add devices and applications to the empty digital snapshots, which they used themselves or by the individuals that they work with in their specialised fields. The practitioners found this to be an interesting and useful feature. As such, the tools and techniques may inspire use in practical settings in the specialised field and not just in a research context, as well as lead to the further development of the tools and techniques.

To sum up, the study findings contribute empirical findings regarding the understanding and mapping the complex digital activities and communities among youth living with cognitive disabilities and their digital competencies. The original contributions concern empirical findings of coping strategies to manage digital relationships and communities, explicit digital aims for digital abilities and communities, and methodologically tools and techniques (VTA) to include the study population in research about their digital activities and communities.

## 9.3. PRACTICAL RECOMMENDATIONS FROM STUDY FINDINGS

From our empirical and methodological findings, the research in this PhD thesis points toward tangible tools and techniques for supporting digital activities, abilities and aims for individuals living with cognitive disabilities. Overall, we put forth the following recommendations for practitioners and researchers working with the study population in paper 6 (Weber and Kanstrup, 2022):

- It is essential to understand the young individuals' digital activities, abilities and aims, before planning experiments or support strategies for them.
- Digital expertise is not required to support young individuals' digital activities - it is important to be curious.
- Let the young individuals be the experts in their digital lives and let them influence the dialogue and initiatives – see them as collaborators rather than informants.
- Visual, tangible, dialogue-based, case-based learning tools can profitably be used to understand and map the digital activities of the study population and embed knowledge among them. The existing digital support tools, teaching material tailored to the study population, and their own devices can profitably be used in the dialogue with the young individuals.
- Support strategies must engage, motivate, and acknowledge the study population and support their independence.
- It is essential to use and work from the young individuals' own and others' digital experiences in learning how to cope with digital challenges and produce digital content.
- Tailor the communication and initiatives to each participant and support each individual's needs, situation, challenges and ambitions.
- Let the work on supportive strategies be a continuous process, where evaluation helps to update the individuals' wishes and needs.

These recommendations have been communicated in paper 6 and at a seminar help for researchers and practitioners working with youth living with cognitive disabilities in March 2022. In the following section, the study limitations are addressed and discussed.

## 9.4. STUDY LIMITATIONS

Methodological limitations, such as those pertaining to the video diaries to fulfil their purpose, have been discussed in the methodology section. Therefore, they will not be elaborated further in the discussion. Instead, other implications are discussed regarding the participants' cognitive levels, investigating the study population as a homogenous group, the (non)inclusion of parents in the study, resistance towards in a focus on the digital sphere in a practical setting, and working interdisciplinary across research fields.

### 9.4.1. COGNITIVE LEVELS OF THE PARTICIPANTS

From our empirical findings, particularly those mentioned in Paper 3, it is clear that many of our participants have relatively high cognitive abstraction levels and are able to provide insightful answers to describe and explain their digital relationships and communities. In addition, all participants can communicate using spoken language, making the conversations about digital relationships and communities possible, at least with the use of VTAs. The literature claims that language equals control (Mcclimens, 2008; McClimens and Gorden, 2008). Therefore, this is an important prerequisite. If the participants did not have high reflection and cognitive levels, our empirical findings would likely have changed, as well as the possibilities for using the data collection tools and techniques in our particular study. The literature suggesting passive digital participation for individuals living with cognitive disabilities (Benton and Johnson, 2015; Brereton et al., 2015; Foss and et al, 2013; Frauenberger et al., 2011) and difficulties in navigating online norms and behaviours (Chadwick et al., 2013; Chiner, Gómez-Puerta, et al., 2017; Holmes and O'Loughlin, 2014; Louw et al., 2019; Normand and Sallafranque-St-Louis, 2016; Wells and Mitchell, 2014; Wright, 2017a) may have conducted research involving individuals living with more severe cognitive disabilities.

Nevertheless, our findings represent a sample of young individuals living with cognitive disabilities who experience communication difficulties in their own ways, and as such, are generalisable to the study population, with the perspective of a higher abstraction and cognitive level than some individuals living with cognitive disabilities.

### 9.4.2. A HOMOGENOUS STUDY POPULATION

Section 4.1.1 address how we have treated the study participants as a homogenous group diagnostically in our data collection and analysis, which is reasoned in our focus on digital and social behaviour and individuals triggers of participants. These aspects provided more prosperous and more informative insights into their digital activities and communities rather than their specific diagnosis.

While treating the study participants as a homogenous group diagnostically was a conscious and deliberate choice, we cannot compare the differentiated diagnoses. Our data analysis was not systematically differentiated into diagnostic groups, which would be a requirement to be able to compare and state behaviours related to the differentiated diagnostic subgroups. For example, we identified specific behavioural patterns for individuals living with ADHD and autism in the literature regarding overstimulation when using digital technology and increased risk of internet – and gaming addiction (Becker and Lienesch, 2018; Gwynette et al., 2018). Two of our study participants, who lived with ADHD, mentioned being overstimulated by their phones and having to be constantly available. However, this digital challenge was prevailing for most of the study participants and not specifically for the participants who lived with ADHD. Thus, we did not examine whether the consequences of being overstimulated were more significant for the two participants than for the rest of the study participants who mentioned this digital challenge.

While a differentiation in subgroups could be relevant to researching specific aspects of the study populations' digital behaviour, the subgroups of people living with ADHD and autism differentiate just as much within the subgroup, depending on where they are on the spectrum. Therefore, this would also need to be considered.

Conclusively, we did not see the value in a diagnostic differentiation of our study participants as we were interested in comparing and differentiating their digital activities and abilities, not their diagnosis, and we did not want to be prejudiced towards their digital behaviour from a diagnostic point of view. Instead, we argue that individuals living with cognitive disabilities need to be treated and supported according to their individual triggers, needs, abilities and ambitions when planning digital activities and studying their digital activities.

### 9.4.3. WHAT ABOUT THE PARENTS?

Researchers in Sweden have extensively examined the role of parents to individuals living with cognitive disabilities. They found, among others, that parents see potential in using the Internet for their children (Ågren Alfredsson et al., 2020c), cf. Section 9.1.2, for example, to meet peers and discuss their disabilities (Molin et al., 2015;

Sorbring et al., 2017). We label this as 'internal digital relationships and communities'. However, parents also fear that their children are more sensitive to certain contents and relations online, which our findings support to some extent, or that participating in the digital society will exclude them from the physical society (Chiner, Gómez-puerta, et al., 2017; Sorbring et al., 2017).

In this study, we recognise that parents play an essential role in the development and well-being of young individuals living with cognitive disabilities (Sousa, 2011), also in their digital lives (Löfgren-Mårtenson et al., 2015; Molin et al., 2015; Sorbring et al., 2017). The social, cultural and digital resources in the home influences the study population's experiences and success in the virtual world (Alper, 2014; Alper and Goggin, 2017; Seale, 2007). Therefore, it would have been relevant to include the parents' perspectives on the participants' digital social lives. This was outside the scope of this particular study, as the research took place at the institutions where the young individuals live and go to school, which complicated the involvement of parents. Furthermore, the majority of the participants were at a life stage wherein they were moving away from home. Therefore, the parents may have more peripheral or indirect influences on the participants' digital lives than the teachers and staff at the residences.

### 9.4.4. LET'S TALK ABOUT TECHNOLOGY

A critique that is often cited in relation to young individuals' technology use is that it is not something that should be promoted (Johansen and Larsen, 2019). This is also a criticism that this study has encountered from our audiences at conferences. Questions such as 'Do you really think that it is better to be together digitally than physically?' and 'Don't you think that it is important that individuals train their communication skills in real life?' have been raised. The aim of this study was not to argue for the promotion of the use of digital technology but to investigate and understand a phenomenon that is inevitable in the youth population, as it is an inherent part of the lives of almost all young individuals (Johansen and Larsen, 2019; Verbeek, 2015), including young individuals living with cognitive disabilities. In this sense and in understanding technology as a mediator for social relationships (Verbeek, 2015), it is implied that we have a pre-understanding of the phenomenon under the lens, although an inductive empirical research approach was used to interpret how the individuals interact with technology. The argument is that this is inevitable in trying to understand the young individuals' social relationships and communities and that it is better to try to understand their digital lives instead of disregarding it (Verbeek, 2015). This way, we may be able to positively influence this digital arena for young individuals living with cognitive disabilities. More importantly, many of the study participants use digital technology in a physical context (labelled as relationships and communities around digital technology) and find their physical relationships more important than

the digital ones, which argue that many are able to balance and combine their physical and digital relationships and communities. In addition, the understanding of technology is very broad, as all digital technologies used by the participants are under the lens. They determined which digital technologies were included and discussed in the study. They also set the agenda.

### 9.4.5. WORKING ACROSS RESEARCH DISCIPLINES

The interdisciplinary research field in which the PhD thesis is positioned (cf. Section 2.1) makes the communication of contributions complex, not at least identifying scientific journals to publish in. Nevertheless, the interdisciplinary research field was a prerequisite for understanding the phenomenon of digital activities and communities among the study population. Insights into the different research fields are crucial to explain and inspire the phenomenon under the lens manifesting and contributing to the empirical and methodological research findings in the PhD thesis. We did not simply have a technological focus as part of the related work (cf. Section 1.3) but painted a shared image of the study population and their technological activities, abilities and aims.

While the contribution to the HIT field is minor, it is crucial as research within this field does not focus much on cognitive disabilities, as mentioned in Section 2.1. There are studies concerning individuals living with dementia (Hendriks et al., 2014), and other cognitive disabilities (e.g. autism) and sensory impairments, but most research concerns health professionals (Hendriks et al., 2014, 2015). The research contribution to PD is also limited as there are no explicit design phase – no collaborative prototyping, but merely PD activities of fieldwork, workshops, and evaluation (Bødker et al., 2022b). Besides evaluating (validating) the empirical findings with the study participants, the resource persons were also included in the evaluation of the DiGi-project, its empirical findings, methods, and strategies to support digital activities (Weber and Kanstrup, 2022). The PI and another team member carried out this research.

To some extent, the infrastructure (securing that social, organisational, and technical infrastructure can support the sustainability of findings) is also considered in the PhD study (Bødker et al., 2022b). Socially, awareness and understanding of the young individuals' digital activities and communities from the PhD thesis can help put this phenomenon under the lens and shed light on the importance of this digital sphere in their social lives. Organizationally, the resource persons have the knowledge and insights (and tools to obtain insights) to support the young individuals in their digital lives. Technically, the available teaching material, tools (VTAs) and coping strategies have the potential for the resource to support the navigation and management of the digital sphere in collaboration with the young individuals, where, as emphasised in

Section 9.3, curiosity among resource persons is more crucial than technical skills. Thus, the argument is that understanding the study population and their needs, values and activities regarding their digital communities and arena is a vital contribution and basis for creating proper design solutions for and with the study population. Especially the digital aims identified in chapter 8 made designing interventions with the study population feasible (Kanstrup et al., 2021; Karadechev et al., 2021; Weber and Kanstrup, 2022).

# CHAPTER 10. CONCLUSION

*'In our own way, we are all weird; we are good weird' ~ P11*

This study sought to map and explain how young individuals living with cognitive disabilities use digital technology to maintain and develop relationships and communities. Empirically, the objectives were to identify and understand 1) the characteristics of digital technology use and value of the study population; 2) how digital technology forms and challenges the digital relationships of the study population; 3) how the study population manages digital relationships and communities; and 4) their ambitions in terms of their digital activities and communities. Methodologically, a fifth objective was to determine how to include the study population in researching their digital activities and communities.

The empirical findings show that young individuals living with cognitive disabilities participate in diverse communities of practice and use a multitude of technologies to develop and maintain meaningful digital relationships and communities. They negotiate which technologies are at the core of their lives. Notably, their digital use, relationships and aims are dynamic, but all of the participants value digital technology greatly and find it meaningful. The physical (digital devices), informational (applications), interactive (ease of use of the digital technology) and functional (participation in internal and external communities and personalised participation in digital communities) aspects all create a complex and comprehensive composition of an artefact ecology and communities of practice framework. The artefacts are connected in different ways, namely, via physical or informational technology or via the function of participation in diverse digital relationships and communities.

The study participants engage in internal digital relationships and communities of practice to maintain personal relationships in contextual layers via and around digital technology (movies, gaming, Makerspace, and the phone). Others participate in external digital relationships and communities to develop relationships and communities with individuals from contextual layers beyond their institutional sphere, in the peripheral participation or in contexts of international (but close) gaming platforms. Participants find these communities of practice meaningful as they foster togetherness, intimacy, fun, peer learning, joint enterprise, and recognition.

Most of the participants find it necessary to personalise and individualise their participation in digital relationships and communities due to the inherent challenges therein (digital harassment, digital separation, and digital disturbance). The study participants manage the challenges they experience in their digital relationships and

communities using problem-focused coping responses (togetherness and collaboration, blocking and confrontation) and emotion-focused coping responses (acceptance, avoidance, and caution). This illustrates active and independent behaviour, as well as the capability to manage digital relationships and communities. The study participants aim to acquire and develop their abilities to participate actively and independently in digital relationships and communities by producing digital content (particularly video material) and enhancing their gaming and social skills with peers and other important community members, thus demonstrating high ambition.

This PhD study contributes to existing research within the academic research fields of disability studies, Health Information Technology and Participatory Design, with an advanced framework for mapping and understanding the complex composition and value of participation in digital relationships and communities for young individuals living with cognitive disabilities. The core focus is on the social and interpersonal aspects of using and finding meaning in digital technologies by the study population to enable them to develop and not merely maintain relationships. In addition, the study advances knowledge about the study population's digital abilities, independence, activeness and learning possibilities in their digital lives. In highlighting the study participants' digital abilities, a main and original empirical contribution was the identification of the coping strategies employed by our study participants to manage the challenges in their digital relationships and communities. In addition, the explicit aims for digital activities and communities formulated by the study participants were a main and original empirical contribution. This study argues that individuals living with cognitive disabilities have both the right and the ability to experience and participate in meaningful interpersonal digital relationships and communities and experience the benefits that these can bring for social inclusion. Therefore, they should be treated as capable and independent human beings who can use their voices and participate actively in digital communities while also considering how to support them in dealing with their vulnerabilities in the digital sphere.

Notably, we learned that the possibility of including young individuals living with cognitive disabilities in research on their technology use and the meaning they accord to this comes with certain methodological and ethical challenges. The main methodological contribution of this study comprises the developed and advanced visual tangible artefacts, namely, Talking Mats and digital snapshots, as well as probing using digital artefacts and inspiration cards. The visual tangible artefacts can accommodate methodological and ethical challenges, as well as map, communicate and validate the findings with young individuals living with cognitive disabilities, and inspire reflections on future technology use and activities. Moreover, through these artefacts, the study population can be included in research on their digital technology use and the meaning they accord it in their everyday lives using traditional qualitative research methods. Using these tools and techniques made it possible to assign the participants an expert role and obtain perspectives and findings that would not have been possible to access otherwise. Other important elements to ensure a proper

inclusion of participants and presentation of their points of view were to consider the role of the researcher, the practice, the camera, ethical values, and norms, and to conduct a thorough data analysis.

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# APPENDICES

# Appendix A. Search protocol

1. Define your research subject and describe the specific focus of the performed search:

| |
|---|
| 1) How young people with cognitive disabilities use digital technology to form and maintain relations. Cognitive disability: ADHD, autisme, downs syndrom, developmental impairment, learning difficulties etc. (broad definition). Digital technologies: social media, on- offline games, gaming, video channels, developmental programmes, other communication tech (broad definition).<br><br>2) Data collection methods and design with people with cognitive disabilities. The methods of the PhD-project: anthropology, participatory design, action research user involvement, interview, observation, workshops, diaries. |

2. List the aspects that your subject contains and the search terms for each of the aspects:

| Aspect 1 | Aspect 2 | Aspect 3 | Aspect 4 | Aspect 5 |
|---|---|---|---|---|
| “Mentally disabled persons”* OR “Cognitive disability” OR “intellectual disability” OR “Cognition disorders”* OR<br><br>“neurocognitive disorders” OR ADHD OR Autism OR “Down Syndrome" OR "Learning Disability”*<br><br>“Mental disorder”* | ”Digital technology” OR ”social media” OR ”online games” OR ”offline games” OR Gaming OR ”video games” OR YouTube OR "Information Technology” OR “information and communication technology” | Social OR Relations OR Communities OR friends OR together | Challenges | Aims OR Goals OR Wishes OR Dreams |

| | | | | |
|---|---|---|---|---|
| "Neurodevelopmental" disorder"*<br><br>"Neurobehavioral manifestations"*<br><br>"Autistic disorder"* | | | | |

NB: AND between aspects! OR between terms.

Start by combining Aspect 1 and 2, afterwards Aspect 3 (aspect 3 the search limits further)

*MeSH term

3. Selection of relevant sources:

| **Source (databases, search engines, sources hand searched, persons/organizations contacted...)** | **Provider (which provider you accessed the source through)** | **Reason for selection of source (subject coverage, accessibility, key source…)** |
|---|---|---|
| Pubmed/Embase | Remember to add to box<br>Fritekst OG MeSH – combine search with OR | Health science. Has a "syranosauous" (MeSH term functionen). NB: Start by finding the proper terms i MeSH for the rest of the search |
| Proquest | Field: anywere but full text | Covering widely. Remember limitations in databases (it searches i 23 different databases – find the relevant ones) |
| Scopus/Web of Science | | Multidisciplinary |
| Bibliotek.dk / Google | | Danish litteratur |

| | | |
|---|---|---|
| ACM | ACM same thread snd method without parenteses. | Technology focus (leave aspect two blank) |
| IEEE | Command search (… OR) AND (… OR…) remember parenteses. | Technology focus (leave aspect two blank) |
| Den danske forskningsportal.dk | | |
| Open grey | | |

4. Define your inclusion and exclusion criteria (both formal characteristics

(e.g. study design, language, year and content-related considerations)

| | |
|---|---|
| **Inclusion criteria** | **All ages (Children, youth, adults)** |
| Exclusion criteria | |

5. The performed searches

| **Source** | **Search query (paste your exact query from the searched source to includes field codes in the search query)** | **Limitations (year, publication type, peer reviewed, …)** |
|---|---|---|
| PubMed | 1) Search ((“Mentally disabled persons”[Title/Abstract] OR “Cognitive disability”[Title/Abstract] OR “intellectual disability”[Title/Abstract] OR “Cognition disorders”[Title/Abstract] OR “neurocognitive disorders”[Title/Abstract] OR | |

| | | |
|---|---|---|
| | ADHD[Title/Abstract] OR Autism[Title/Abstract] OR “Down Syndrome"[Title/Abstract] OR "Learning Disability”[Title/Abstract])) AND (”Digital technology”[Title/Abstract] OR ”social media”[Title/Abstract] OR ”online games”[Title/Abstract] OR ”offline games”[Title/Abstract] OR Gaming[Title/Abstract] OR ”video games”[Title/Abstract] OR YouTube[Title/Abstract] OR "Information Technology”[Title/Abstract] OR “information[Title/Abstract] AND communication technology”[Title/Abstract])<br><br>2) Search ((((“Mentally disabled persons”[Title/Abstract] OR “Cognitive disability”[Title/Abstract] OR “intellectual disability”[Title/Abstract] OR “Cognition disorders”[Title/Abstract] OR “neurocognitive disorders”[Title/Abstract] OR ADHD[Title/Abstract] OR Autism[Title/Abstract] OR “Down Syndrome"[Title/Abstract] OR "Learning Disability”[Title/Abstract])) AND (”Digital technology”[Title/Abstract] OR ”social media”[Title/Abstract] OR ”online games”[Title/Abstract] OR ”offline games”[Title/Abstract] OR Gaming[Title/Abstract] OR ”video games”[Title/Abstract] OR YouTube[Title/Abstract] OR "Information Technology”[Title/Abstract] OR “information[Title/Abstract] AND communication technology”[Title/Abstract]))) AND (Social[Title/Abstract] OR Relations[Title/Abstract] OR Communities[Title/Abstract] OR friends[Title/Abstract] OR together[Title/Abstract]) | |
| IEEE | (("Mental disorders" OR "Down Syndrome" OR "Mentally disabled" OR "Learning Disability*" OR ADHD OR autism OR "cognitive disability*" OR "intellectual disability*") AND (social OR relations)) | |

| | | |
|---|---|---|
| | | |
| Proquest | noft("Mental disorders" OR "Down syndrome" OR "Mentally disabled" OR ("learning disability") OR ADHD OR autism OR "cognitive disability" OR "intellectual disability") AND noft("Digital technology" OR "social media") AND relation* | |
| ACM (digital liberary) | “Mentally disabled persons” OR “Cognitive disability” OR “intellectual disability” OR “Cognition disorders”<br><br>“neurocognitive disorders” OR ADHD OR Autism OR “Down Syndrome" OR "Learning Disability” **AND** Social OR Relations OR Communities OR friends OR together | |

Tilpas søgning til de enkelte databaser, men lav så ens søgning som muligt.

6. Search results

| Source | Number of results and number of relevant results in parentheses | Date of performed search |
|---|---|---|
| ACM (digital liberary) | 897 (first search).<br><br>876 (second search)<br><br>Focus on learning and autism | 28/2 2020 |
| IEEE | 6. | 1/3 2020 |

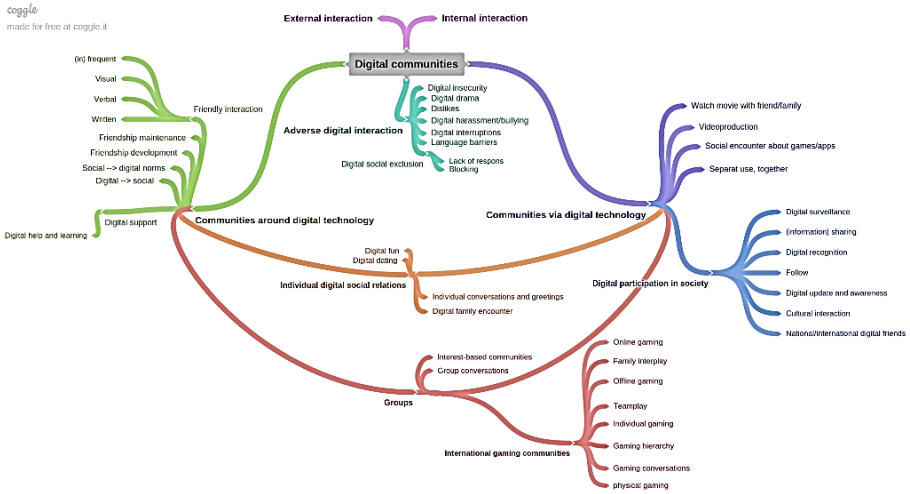
| | | |
|---|---|---|
| | Robots, learning and autism. | |
| PubMed | 246 (first search)<br><br>140 (second search)<br><br>Focus on autism and vaccinations + addiction (especially gaming) and ADHD. Many relevant articles. | 24/2 2020 |
| ProQuest | | |

8. Date of finalization of search protocol, persons involved and their organizational affiliation

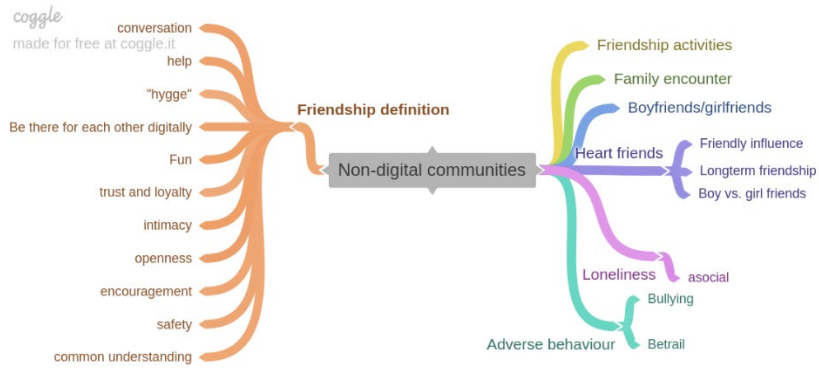
| |
|---|
| **March 2020, AAU** |

# Appendix B. Code trees

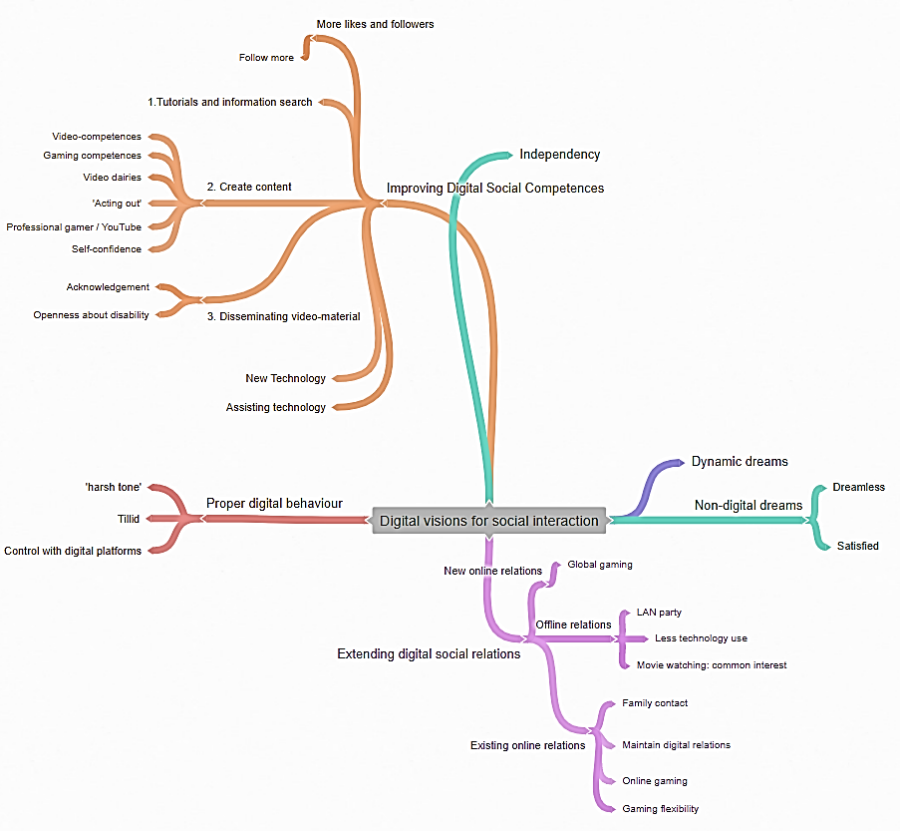
## Code tree 1: digital communities



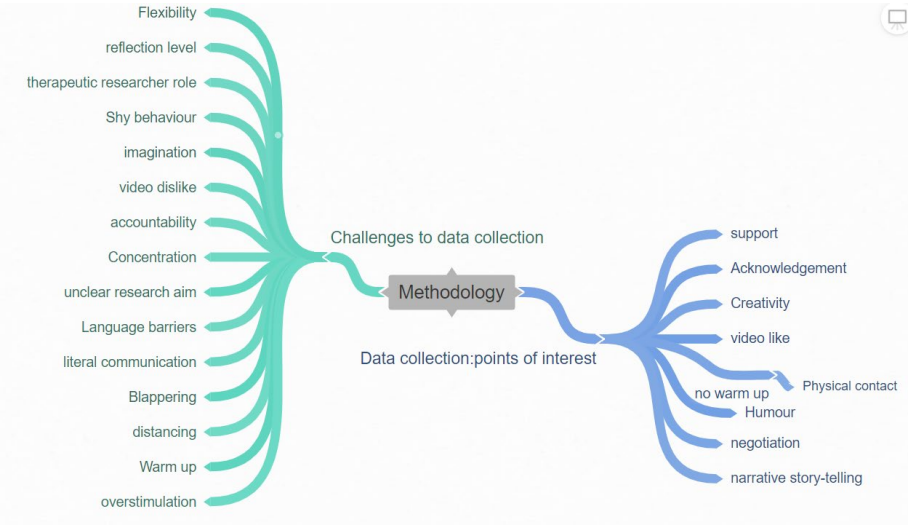

## Code tree 2: non-digital communities (friendship definitions)



## Code tree 3: digital aims (visions)



## Code tree 4: Methodology



# Appendix C. Informed consent form

## Samtykkeerklæring

I overensstemmelse med databeskyttelsesforordningens krav til gyldigt samtykke

Aalborg Universitet
Cvr. nr. 29102384
Frederik Bajers Vej 5
DK-9100 Aalborg

Aalborg Universitet (AAU) skal bruge dit samtykke til at behandle personoplysninger om dig i forbindelse med din deltagelse i projektet: Digitale fællesskaber for unge med kognitive handicap.

Det er frivilligt, om du ønsker at give dit samtykke til, at AAU behandler dine personoplysninger, men mangel på samtykke kan bevirke, at AAU ikke kan have din deltagelse i projektet.

Du kan til enhver tid ændre eller trække dit samtykke tilbage. Afhængig af hvilken brug af oplysningerne, du ønsker at trække tilbage, kan det medføre, at AAU ikke kan opfylde de aftaler, der er indgået med dig. Du vil blive oplyst om dette i de tilfælde, hvor du anmoder om at ændre eller trække dit samtykke tilbage. Samtykket kan ikke tilbagekaldes med tilbagevirkende kraft.

Ønsker du at ændre eller trække dit samtykke tilbage kontakt: Anne Marie Kanstrup, Institut for Planlægning ved Aalborg Universitet.

| AAU skal behandle dine personoplysninger til: forskning i digitale fællesskaber for unge med kognitive handicap | |
|---|---|
| AAU indsamler og behandler følgende personoplysninger: | Vi indsamler, opbevarer og analyserer og formidler data med projektets deltagere via video- og audio (dvs. billeder og lyd). Alle data opbevares aflåst og anvendes kun af projektets forskere. Alle data bruges til analyse. Alle data anonymiseres inden formidling i forskningspublikationer og -præsentationer. |
| *Udfyldes af den registrerede:*<br><br>Jeg giver samtykke til, at AAU må behandle mine oplysninger til brug for ovenstående formål<br>Sæt kryds ☐<br>Dato/navn: | |

AAU forventer, at behandlingen af dine personoplysninger vil ophøre *5 år efter projektets afslutning*. Alle data slettes herefter.

Ønsker du at klage over AAU's behandling af dine personoplysninger, kan du kontakte Datatilsynet, Borgergade 28, 5, 1300 København K, der er den danske tilsynsmyndighed på det databeskyttelsesretlige område.

AALBORG UNIVERSITET

# SUMMARY

Disability research within the domain of health information technology tends to focus on individuals living with cognitive disabilities as passive users of digital technology in need of protection from the digital sphere and support from assistive technologies due to the adaptive, communication and interaction challenges they experience. Moreover, the concentration is mainly on the digital challenges rather than managing and coping with these digital challenges. In addition, concentration on aims for digital participation is limited.

The PhD study aimed to investigate how young individuals living with cognitive disabilities use digital technology to maintain and develop relationships and communities. The PhD thesis maps and explains the complex digital communities, abilities, coping strategies and aims of the study population. Specifically, the PhD thesis maps and explains what characterises the digital relationships and communities of the study population, the technologies and strategies used to participate in and manage digital relationships and communities, and their learning possibilities in formulating aims for digital participation. Methodological, the contribution of the PhD thesis was to develop visual and tangible artefacts to include the study population in research about their digital activities and communities.

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